

Teen Guide

Dealing with Crohn's & Colitis



CROHN'S & COLITIS
FOUNDATION OF AMERICA



Dealing with Crohn's & Colitis

Introduction

You've just found out that you have inflammatory bowel disease—or "IBD" for short. You probably have never heard of this disease before. And now you have it. Actually, it isn't one disease at all, but rather a group of diseases that are clumped together under this one name. (But we'll talk more about that later.)



Maybe you had stomachaches on and off for a long time before doctors figured out what was wrong. Or you may have been losing weight for no particular reason. Perhaps you were sick for just a short while before they found out that you had IBD. For many teens, hearing an actual diagnosis comes as a relief. That may sound weird, but it's true. At last there's a name for what you have. And the good news is that something can be done about it.

Now that you know what it is, you need to know some other really important things:

- 1) Nothing you ate or did gave you IBD.
- 2) You didn't catch it from anyone else.
- 3) You certainly aren't alone. There are up to 1.4 million people in the U.S. who have IBD. And at least 140,000 of them are under the age of 18, like you.
- 4) IBD is a "chronic" disease, which means it won't go away. But that doesn't mean you can't have a long, fulfilling life.
- 5) Although IBD is a chronic illness, it doesn't mean that you'll be sick every day.
- 6) IBD comes and goes. Sometimes you'll feel pretty sick, but at other times you may not even remember that you have IBD because you feel so great.
- 7) Most people who live with IBD are healthy more often than they are sick.
- 8) Even though you'll have IBD for life, it doesn't have to *take over* your life.
- 9) Kids with IBD can be whatever they want to be and do whatever anyone else can do: go to school, date, go to college, have a career, get married, have kids, travel—you name it!
- 10) You CAN cope with IBD and we'll help you learn how to do it.

You'll have a *ton* of questions about your illness, many now and many more as time goes on. Although you'll be learning a lot about IBD—probably more than you ever wanted to know—you won't be able to take it all in right away. That's okay. No one expects you to absorb it all at once. But you'll be doing yourself a big favor if you learn everything you can about your IBD and how it affects your body.

Your life will be changed by IBD, but don't let it get the better of you. You've heard the expression, "Knowledge is power." Get to know the disease you're living with. Ask your doctor questions, go to sites on the Internet with reliable health information (such as ccfa.org and ucandcrohns.org), and pick up the medical jargon. Don't let fear of the unknown overwhelm you. The next step is to master the skills you'll need to take care of yourself. And, finally, learn how to cope with the disease and your feelings about it.

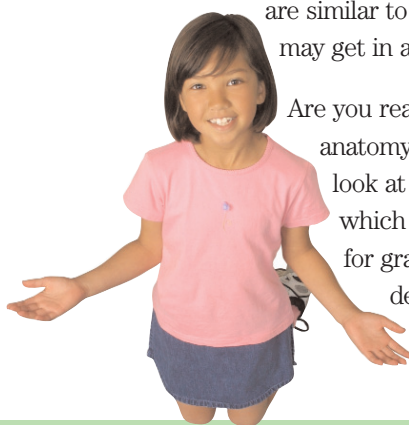
That's the purpose of this booklet:

- ▶ To give you the basics about IBD
- ▶ To show you the skills to manage it
- ▶ To help you cope with the disease... and with your feelings about it

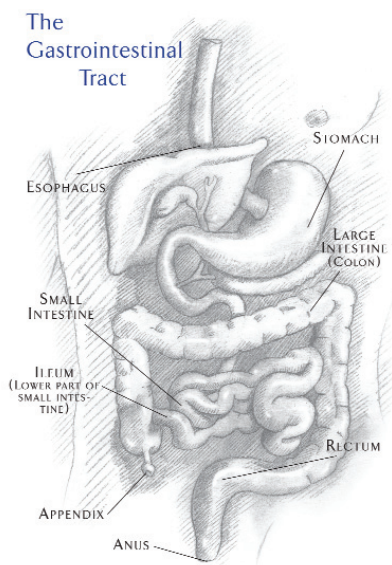
What is IBD?

As we said, IBD is a general term given to a number of different illnesses that produce inflammation inside the digestive tract. The inflammation causes pain, swelling, redness, and heat. That's why you have diarrhea, stomach cramps, and other symptoms. Diarrhea is the most common sign of IBD, with frequent visits to the bathroom—up to 20 or more times a day. Sometimes, in addition to inflammation, ulcers form inside the intestines. Ulcers are sores in the lining of the intestines that may cause bleeding and pain. They are similar to the "cold sores" that you may get in and around your mouth.

Are you ready for a mini lesson in anatomy? Let's take a quick look at the digestive system, which most people just take for granted. Your body depends on this system to take in food and absorb



its nutrients so that the body can function. That's what keeps you healthy and helps you grow. Running all the way from your mouth to your rectum, the digestive system represents a lot of "real estate" in your body. In fact, the whole collection of organs linked together measures about 30 feet from one end to the other. But when it comes to IBD, the most important organs are the small and large intestines. You can see what they look like in the illustration below.



Types of IBD

IBD includes a number of different illnesses, but the two major ones are Crohn's disease and ulcerative colitis.

What is Crohn's disease?

Crohn's disease may occur in any part of the large intestine (also called the colon). In fact, it can happen anywhere in the entire digestive system. However, it most commonly develops right where the small and large intestine meet. That's at the *ileum*, the lower part of the small intestine.

Sometimes Crohn's disease of the ileum is referred to as *ileitis*. When Crohn's affects the colon, it may be called *Crohn's colitis*. If it involves both the ileum and the colon, the disease may be referred to as *ileocolitis*.

Crohn's disease affects all the layers of the intestinal wall—causing inflammation and swelling as well as ulcers. In turn, this irritation may lead to bleeding. It also prevents the intestine from absorbing nutrients from food.

If you have Crohn's disease, you may experience any or all of the following symptoms:

- ▶ Diarrhea (sometimes bloody)
- ▶ Stomach cramps or pain
- ▶ Weight loss
- ▶ Fever
- ▶ Dehydration

All of those symptoms may leave you feeling pretty wiped out. In addition to fatigue, you also may not have much of an appetite. And the diarrhea, cramping, and pain may become worse when you eat because of the increased intestinal activity—so you really may not feel like eating.

But Crohn's disease is not the same for everyone. Symptoms vary from person to person. Some people may have a lot of discomfort and frequent diarrhea. Others may have only occasional diarrhea and very little pain. Sometimes the inflammation and ulcers can penetrate through the walls of the intestine, forming an *abscess* (a collection of pus). An abnormal connection with other parts of the intestine or other organs also may form. This is called a *fistula*.



What is ulcerative colitis?

Ulcerative colitis affects just the large intestine and rectum. That's where inflammation and ulcers develop. The inflammation prevents water from being reabsorbed into the bloodstream. The result is diarrhea.

If you have ulcerative colitis, you may have:

- ▶ Diarrhea (frequently bloody)
- ▶ Stomach pain and cramping
- ▶ Urgent need to go to the bathroom

Inflammation and ulceration cause bleeding, which is why there is often blood mixed in with the diarrhea. You also may experience nausea, fatigue, weight loss, and loss of appetite. As with Crohn's disease, symptoms vary—largely depending on the part of the large intestine that is involved. Unlike Crohn's disease, which has clear (disease-free) sections of the colon (also called “skipped” sections), ulcerative colitis moves in a continuous way along the colon—with no skipped areas.

Ulcerative colitis that involves only the rectum is called *proctitis*. If the disease affects the left side of the colon, it is referred to as *left-sided colitis*. If it involves the entire colon, it is called *pancolitis*.

Beyond the intestines

You also may have some symptoms that have nothing to do with the digestive tract. Both Crohn's disease and ulcerative colitis may cause problems in other parts of the body, far removed from the intestines. Here are some of them:

- ▶ **Arthritis.** Joints (usually the knees and ankles) can be swollen, painful, and stiff. Arthritis affects about 30% of people with Crohn's and 5% of those with ulcerative colitis. Medications can help, but the problems usually go away when the intestinal inflammation is controlled.
- ▶ **Mouth ulcers.** These are like canker sores. They usually develop during periods of active inflammation in the intestine. The sores go away once the inflammation is treated.
- ▶ **Fever.** Fever is an indicator of inflammation, so it's common to have a fever during a flare-up of symptoms. However, fever can be present weeks or months before other symptoms appear. When the intestinal inflammation is treated, the fever disappears.
- ▶ **Eye symptoms.** Eyes may become inflamed—with redness, soreness, and sensitivity to light. These symptoms usually appear right before a flare of disease and go away once the intestinal symptoms are treated.
- ▶ **Skin symptoms.** People may develop rashes or painful, reddish bumps on their legs. Treatment of the intestinal symptoms cures the skin symptoms.

Who gets IBD?

People of any age, from infants to older adults, may develop IBD. But it occurs most often in young people between the ages of 15 and 35. Approximately 30,000 new cases are discovered each year in the U.S.

IBD is not contagious. No one else gave it to you, like the flu or a cold. And you can't pass it on to anyone else either.



What causes IBD?

So where does it come from and why did you get it? At this point, the exact cause or causes are still unknown—although researchers have a lot of good clues. IBD appears to be hereditary, at least in part—passed from one generation to the next through genes. In fact, about 20% of people with IBD have a relative with the disease.

But it looks like other things are involved, too. For instance, experts think people who develop IBD may have some sort of defect in their immune system. The immune system is a complex assortment of cells and proteins that protects the body from harmful bacteria, viruses, and other microscopic organisms. You may have had some unknown virus or bacteria that triggered your immune system, causing it to “switch” on. But then it didn’t turn off. That seems to be a problem in people with IBD. The immune system *overworks*. Instead of defending you against invading substances, it turns against you—attacking your intestines.

How does IBD affect growth?

When kids get IBD, they develop the same kinds of symptoms that adults do. But there is one important difference. Adults have already reached their full growth, so if their bodies don’t get all the necessary nutrients, they may lose weight, but otherwise they will still look pretty much the same.

When kids have IBD, they tend to eat less because of pain and cramping. In addition, food isn’t absorbed well, so important nutrients are lost. Moreover, some medications that are needed to quiet down the inflammation also may

interfere with normal growth. What all that means is that teens may stay at pretty much the same height on the growth chart for a while. In addition to being smaller than others, they may look a lot younger, too. Kids who are 14 may look like they are only nine years old. That can be pretty difficult, sometimes even tougher to bear than the stomach cramps and other symptoms that go along with IBD.

On top of everything else, IBD tends to strike exactly during the years of rapid growth spurts. In fact, some kids may grow four or more inches in just one year! As their friends are getting taller, that makes the slower growth in teens with IBD even more noticeable. The good news is that kids with IBD do catch up at some point, although they may not grow as fast as their friends. With the proper nutrients and medications, teenagers with IBD eventually do reach their expected adult height. Your doctor will work with you to make sure your growth is a top priority. In the meantime, don’t let the fact that you may look different from your friends keep you from mixing in. Almost all teenagers have something they don’t like about their own appearance.

Along with the delay in growth is a possible delay in puberty. That’s the time when your body begins to develop and change as you move from child to adult. When your friends are going through sexual development, you may not. Not everyone experiences a delay in sexual development to the same degree, though.



What about testing for IBD?

Infections and a bunch of other conditions may look like IBD, so it's important for your doctor to make sure it isn't something else. When you first became sick, your doctor examined you and asked about your symptoms and whether you had ever had these kinds of symptoms before. He or she also may have asked about your family's medical history. That's because IBD often runs in families.



After that, the doctor probably took some blood to send to the lab. Blood tests can tell if there are any signs of inflammation in the body or if some sort of infection is present. They also can show if you have anemia (a low red blood cell count). The next step usually is to give a stool sample. This is another way to see if there is any intestinal bleeding.

In addition to your regular doctor, you also may see a gastroenterologist—a doctor who specializes in diseases of the digestive tract, like IBD. The gastroenterologist may perform a test called a *colonoscopy*, which is simply a way to look at the inside of your colon to see if there is any bleeding, ulcers, or inflammation inside the walls of the colon. To do that, a long thin tube called an *endoscope* is inserted through the anus. The endoscope is actually a special kind of video camera, and it is attached to a TV monitor. During the procedure, the doctor may remove a tiny piece of tissue from the intestinal wall. This is called a biopsy. It is sent off to a lab so that it can be examined more closely. You will be given a mild sedative so that you won't feel any pain or discomfort during the procedure.

The gastroenterologist also may do another kind of procedure with an endoscope. This time it is inserted through the mouth and down the esophagus (the tube that connects your mouth with your stomach). This test is called an *upper endoscopy*, and the purpose is to have a look inside the esophagus, stomach, and upper small intestine to see if there is any bleeding, ulcers, or inflammation in any of those organs.

Another test is called a *barium study*, a *barium X-ray*, or an *upper GI series*. For this procedure, you have to drink a thick, chalky solution called barium. A series of X-rays is taken as the barium moves through your system. Everyone is different, and the timing varies. The barium shows up white on the X-rays—giving the doctor a good look at your intestines.

Once you have been diagnosed with IBD for sure, the testing doesn't stop. You will need to have blood tests done regularly to see if you're getting all the proper nutrients that you need from the food that you eat. The doctor also uses blood tests to check how well the medications are doing their job. Other tests will be repeated periodically so that your doctor can see how your disease is progressing. Make sure that your doctor explains what tests are necessary and what they involve. Getting a "heads-up" on what these tests are can prepare you and make you feel less nervous about them.



How is IBD treated?

Because Crohn's disease and ulcerative colitis are chronic illnesses, they tend to require long-term treatment. The type of medication depends on how severe

your disease is, the part of the intestines affected, and whether you have any complications. In general, though, the purpose of all medical treatment for IBD is to control the inflammation.

A number of different medications are used to treat IBD. None of these will *cure* the condition, but they may keep it under control. When your disease is under control, your symptoms disappear. This period is called *remission*. This disease-free time may last months or sometimes years.

There are two key goals when it comes to treating people with IBD:

1) To bring the active disease under control (into remission)

2) To keep the disease in remission.

When the disease becomes active again and you have another flare-up, this is called a *relapse*. Both Crohn's disease and ulcerative colitis are marked by periods of remissions and relapses.

Because IBD varies so much from person to person, your treatment program will be tailored especially for you. Your treatment will depend on the areas of your intestine that are affected by the disease. Certain drugs reach certain places in your intestine, and that's why your doctor has chosen them. The tests that your doctor has ordered help identify those places so that treatment can be as effective and targeted as possible. It may take a while to figure out exactly which drug or combinations of drugs works best for you. As you get better, your doctor may change the medications or adjust the dosage of the ones you're already taking.



There are six types of drugs that are commonly used to treat IBD. Some of these *bring* your disease under control; others *keep* your disease under control. Sometimes the same drugs are used for both purposes. The six categories of drugs are:

- ▶ **Aminosalicylates:** These drugs, which are related to aspirin, are the most frequently used medications for IBD. They are generally given to people with mild-to-moderate ulcerative colitis or Crohn's disease to control the inflammation. They include mesalamine, balsalazide, olsalazine, and sulfasalazine.
- ▶ **Corticosteroids:** These are the second most commonly used group of medications for IBD. They are fast-acting, which is why they're very useful during flare-ups of disease. In addition to reducing inflammation, corticosteroids also reduce the activity of your immune system. Prednisone and methylprednisolone are the most commonly used drugs in this group. (By the way, don't confuse these drugs with anabolic steroids, which are used—and frequently abused—by athletes and body builders.)
- ▶ **Antibiotics:** These drugs help maintain a balance between all the bacteria, both the good kind and the bad, that live inside your intestines. The two most commonly prescribed antibiotics are metronidazole and ciprofloxacin. They are mainly given to treat active cases of Crohn's disease.
- ▶ **Immunomodulators:** This class of drugs includes 6-MP (also called 6-mercaptopurine), azathioprine, and methotrexate. 6-MP and azathioprine are the most widely used. As their name implies, immunomodulators regulate your immune system. They are used for long-term maintenance.

- ▶ **Cyclosporine and tacrolimus:** These drugs are called immunosuppressants. They also affect the immune system, but they are not the same as immunomodulators. Cyclosporine and tacrolimus are used for severe cases of ulcerative colitis that have not responded to corticosteroids.
- ▶ **Infliximab:** This drug is in a class by itself. It is an antibody that reduces inflammation. It is most effective for people whose IBD has not improved with other medications, and for those with fistulas. Infliximab is given intravenously (through a vein) every eight weeks.

Here's the scoop on "meds" for IBD: It's no fun to have to take pills all the time, and it can be hard to remember your meds, especially when you are at school or hanging out with your friends. On top of that, all of these drugs can have side effects. At times, some of the side effects may seem about as bad as, or even worse than, the disease itself. Some may give you headaches or make you feel like throwing up. Some—like prednisone and other steroids—may make your face swell, giving you a "moon-like" appearance. (Hint: Cutting back on salt and salty foods goes a long way toward reducing the puffiness.) Steroids also can make you feel moody or restless. And they may give you pimples, as if you needed anything more to do that! The good news is that once you stop taking these medications, all these side effects go away. Your doctor will talk to you about what you may expect from your meds and how to deal with it.

But—and this is a big "but"—it's really important that you *stay on the medications that your doctor has given you*. You'll be tempted to ditch them, but don't!

- ▶ Keep taking them even when you're feeling perfectly well.
- ▶ Keep taking them even when it's a royal pain to carry pills around and swallow them at regular intervals.
- ▶ Remember, those meds are what's keeping you healthy and your IBD under control.



Will you need surgery?

Medications are the treatment of choice for IBD, but sometimes they no longer work and the answer is surgery. No one particularly likes the idea of an operation, but occasionally surgery is necessary to control symptoms that medication can no longer control.

If you have IBD, you may need to have part of your intestine removed. During the operation, the surgeon will take out the inflamed part of the intestine and then sew the two healthy ends of the intestine back together. This is called a *resection*. In fact, you may need several operations over time to remove diseased sections of the intestine.

Sometimes surgery is needed just to remove a blockage or obstruction in the intestine, which may be caused by severe inflammation and scarring. Ulcerations also may cause severe bleeding. If the bleeding doesn't stop, then surgery may be necessary to remove the ulcerated section of the intestine. New surgical techniques can accomplish these things much more easily, with smaller incisions and shorter recovery time. Usually people feel a lot better after the operation.

Talk to your doctor about surgery if you have any questions. To learn more, you can also call CCFA or visit our Web site at www.ccfa.org.

What's the role of nutrition?

First, let's set the record straight: Nothing that you ate caused Crohn's disease or ulcerative colitis. But now that you have one of these disorders, you may need to pay a little more attention to what you're eating than you did before. Making some changes in your diet—particularly during flare-ups—may help reduce your symptoms as well as replace lost nutrients.

Whatever you put in your mouth will affect your intestines in some way. When your disease is more active, you may have to watch what you eat more closely. Various foods won't cause flare-ups of disease, but they may make flare-ups worse. Similarly, some foods may help you feel better during disease flares. Some people do better after cutting down on dairy foods and foods high in fiber (like raw fruits and vegetables). Other people improve after reducing their intake of foods high in fat or sugar. Again, everyone's disease is different. The foods that make you feel worse (or better) may not be the same foods that make someone else feel worse or better. It's basically a question of trial and error. Keeping a food diary will help you track what foods makes your symptoms better or worse. Once you see which foods make you feel sick, stay away from them. Your doctor will probably bring in a dietitian or nutritionist—someone who specializes in figuring out the best eating plans—to create one that works best for you.

Of course, you should eat a healthy diet with the fruits, vegetables, fish, and lean meats that work for you. With your dietitian's help and by

knowing your own body, you'll find it easy to figure out what you can have when you're eating out with friends, so you'll feel that you're part of the crowd. If you and your friends go somewhere that has *absolutely nothing* that you can or should eat, depending on how you're feeling at the time, then just order something to drink instead.

When you have diarrhea, you lose a lot of fluids. For that reason, it's important to drink a lot to make up for the fluids you've lost. You also lose a lot of nutrients, which you need in order to grow. In addition, you may have lost a lot of weight and now need to put some of it back on. Your doctor or dietitian may recommend some special drinks or shakes that can provide extra nutrition. These are called "supplementary" foods. In addition to calories, these offer vitamins and minerals as well. Because they're liquids, they don't need to make the intestines work to absorb them. That allows the intestines some "time out."

Sometimes you may simply feel too sick to eat. Your stomach hurts and you have diarrhea. Even the special drinks are too much. At times like these, you may need to get nourishment in other ways. One is by having a soft, thin tube passed through your nose and into your stomach. The tube is called a nasogastric (or NG) tube. That allows liquid food containing thousands of nutrient-rich calories to nourish you and help you grow, even while you're asleep. You can even learn how to insert the tube yourself. This may go on for several months. But sometimes you may have to go into the hospital to get food through an intravenous (IV) line. This kind of feeding is called *total parenteral nutrition*, or TPN. Not everyone needs these kinds of liquid diets, though.



What's the role of stress?

Years ago, it was thought that IBD was caused by stress. But people no longer believe that is correct. What does seem to be true, though, is that stress and other emotional factors can make IBD worse and cause symptoms to flare up. This is true of just about any chronic illness.

Most teenagers are surrounded by stress. You've got exams to prepare for and papers to write. You might have missed some school, too, and you're worried about what those absences might mean—both academically and socially. These are all sources of emotional stress, but on top of that, you have physical stress. Your illness takes a toll on your body. It may have caused a lack of sleep. The combination of these “stressors” is tough, and you need to “de-stress” yourself as much as possible:

- ▶ Try to manage stress in a positive way.
- ▶ Some people find that learning breathing and relaxation exercises can help.
- ▶ Regular exercise is a great stress buster, too, if you're up to it.
- ▶ Pursue a hobby or find some other kind of outlet that you enjoy.
- ▶ A strong support network (composed of family, friends, health care professionals, and teachers) can help you reduce stress.
- ▶ Find a “middle ground” for yourself: Keep on top of your IBD but don't let it rule your life.
- ▶ It's your choice: You can either dwell on how IBD is ruining your life or keep doing the things you want to do.



Taking charge of your IBD

A lot is going on during this stage of your life. Above all, this is a period of transition. You're not a little kid any more, but you're not quite an adult yet either. It's important for you to be independent—to think and act for yourself.

Taking responsibility for your own health care is one way that you can establish your independence. It's difficult for anyone to have a chronic illness like IBD, but for a teenager it can be really tough. So much is happening to you anyway, and now this! But since you'll have IBD for life, you have to learn how to manage it. You may be on your own soon and off to college, and your parents won't be going with you. The resources at college (and beyond) will be different from what you're used to, so the sooner you learn how to identify those resources that can assist you, the better.

One thing that's really important is to form a good working relationship with your doctor. That's the person who's going to help you get well and stay well. You two need to become partners in your own health care. It may be a pain to follow all the instructions your doctor gives you, but if that's what it takes to stay healthy, just do it.

- ▶ Keep track of your symptoms so that your doctor can chart your progress.
- ▶ Take your medications according to the schedule you and your doctor have set up.
- ▶ Be responsible for making medical appointments and talking to your doctor.

It's important to remember that IBD affects the whole family, not just you. Your parents will always be concerned about you, and now that you have an ongoing illness, they may become

even more overprotective than usual. That's normal, and it's a good idea to acknowledge their concern. Assure them that you're on the case. If they see how well you're doing—sticking to a healthy diet and taking all your medications as prescribed—they'll ease up and stop hovering over you quite so much. That doesn't mean they don't love you anymore. It just means that they trust you to keep on top of your IBD. But do let your parents know if you're having a lot of stomach pain or if your symptoms are getting worse. Also inform them if the medicine you're taking seems to be making you worse instead of better. Above all, tell your parents if you're feeling kind of shaky and just need to talk.

A lot of teenagers say that having IBD has made them grow up a lot faster than they normally would. You're facing a set of challenges (medications, diet, activities) that most teenagers don't have to face. In exchange, you'll become a stronger and a more compassionate person, better able to understand other people who are undergoing similar challenges in life. So there are positive as well as negative sides to your illness. If nothing else, IBD certainly broadens your perspective.

Can you live a normal life in spite of IBD?

The answer is “yes!” There will be ups and downs, for sure. When you're in the middle of a flare-up and your symptoms are pretty bad, life really isn't playing fair. Let's face it, having IBD is not only distressing and inconvenient but it also can be painful.



You can feel sick a lot of the time or really tired or both. You may have to have an operation or go to the hospital for some other reason. But periods like these don't last forever, and in between those times you'll probably feel fine.

Coping with IBD

Bad timing. You may feel that IBD is hitting you at absolutely the WORST possible time in your life. You're involved in school and in extracurricular activities. You want to play sports, hang out with your friends, and date. Now this illness is messing it all up. Just when all you really want to do is to fit in and be like everyone else, IBD is making you stand out like a sore thumb. It's making you miss out on a lot of the things that you want to do and that your friends are doing.

IBD can affect your body image, sense of self-esteem, and lifestyle. The symptoms you have can come out of nowhere. They also are exhausting, uncomfortable, and may be embarrassing.

Practical matters. The frequent diarrhea that goes along with IBD may make you feel as if your life centers around the bathroom. And speaking of bathrooms, make sure you always know where to find one (in school, at the movies, restaurants, at the mall, and while traveling). Also:

- ▶ Carry travel sizes of wet wipes.
- ▶ Keep soft tissues on hand in case there's no toilet paper or you want something softer.
- ▶ Have an extra pair of underwear on hand as well as a plastic bag for the old pair.
- ▶ Find out where the least-used bathrooms are so you'll have more privacy.

Sharing the news. Even when you are in school, it's tough to be cool when you have to run to the bathroom all the time. Sometimes it seems like everyone knows what's happening, and your privacy, which is super important to you, seems to be almost nonexistent. But you can find ways to be "discreet" about taking care of your needs.

This isn't an easy illness to hide. The truth of the matter is that you really don't want to hide it because that just makes it worse. You don't have to advertise it or put a sign around your neck, but it is a good idea to tell your circle of friends what's going on. This will make you feel less alone with your disease. It also will make your friends feel closer to you because you have shared something very personal with them. You might want to ask your doctor or nurse about the best way to explain IBD to others. Some people suggest that you explain the inflammation of IBD as "having sunburn inside the intestines."

Certainly your school nurse needs to know and the same goes for your teachers, because there will be times when you'll be absent and will need to make up classwork or exams. If teachers know about your IBD, they'll just let you go to the bathroom without asking every time.

Talking it out. You may feel depressed and isolated and embarrassed by the symptoms. On top of that, you may have a poor body image if you're particularly short or thin or have a puffy face because of the steroids. You may feel pretty vulnerable and like your body has sort of let you down. These feelings may keep you from participating in a lot of activities. Talking to your friends, family, and doctor can help you release some of these feelings and help others understand what you're going through.

Talking about your illness and how it makes you feel may be embarrassing or difficult at first

because you don't normally talk about bowel movements—especially at school. But it will get easier. And talking about it will clear up a lot of misinformation. Some other kids might not have believed that you were ill, particularly when you were looking pretty good. (It's really odd that sometimes you can feel so lousy and still look fine.) They might have thought you were just being lazy when you complained of fatigue. Some might have thought you had anorexia when you lost a lot of weight. Once they learn the truth, you'll feel like a big weight has been taken off your chest. You'll find that people—the people that matter to you—will listen and understand. They'll be there with you when you're feeling great and they'll be there, too, when you're feeling crummy.

Social questions. Don't define yourself as someone with IBD. You're more, much more, than just "the girl who has IBD" or "the boy who has IBD." The best way to deal with your illness is to accept it, rather than to deny that it exists. Make a commitment to do what you have to do to stay well and stick with it.

Can you date if you have IBD? Sure, you can! Having a chronic illness doesn't mean that you can't have a social life. Tell your date that your condition means that you may have to go to the bathroom a lot. If you feel like going into more detail, that's up to you.

It's also good to talk to other teens who have IBD. You'll see that you're not alone in this. You'll learn how others cope with their illness and what strategies they've figured out that make them feel better and make their lives easier. You also might want to join a support group in your area or participate in an Internet chat site on IBD. It helps to hear that someone else is going through the same things that you're experiencing.

Sports. You were active in sports before you knew you had IBD, but what about now? The answer is that when you're feeling well and your disease is in remission, you can do pretty much anything you feel like doing. It's a good idea to get your doctor's OK on that first.

Sounds like a plan

Living with a chronic illness can be a lot of work at times, but that doesn't mean that IBD has to rule you. Here are some things you can do to keep it from taking over your life:

- ▶ Get enough rest, even if you're not having any symptoms.
- ▶ Stay with the foods that have worked well for you and avoid those that make you worse.
- ▶ Keep taking the medications that your doctor has prescribed, even when you're feeling well.
- ▶ See your doctor regularly, even when you have no symptoms.

Sticking with a system that works is the best way to make sure that your IBD doesn't interfere with what you want to do in life. And, although it may be difficult at times, try to keep a sense of humor. Laughter is the best medicine. It will help you get through more than you think possible.



Hope for the future

The good thing about IBD is that, all over the world, researchers are working on finding a cure. Over the past 10 years, huge advances have been made. There's plenty of reason for hope. New options in treatment are being developed all the time. By the time you reach adulthood, it's quite possible that a cure for IBD will have been found. In the meantime, the most important thing you can do is take good care of yourself.

For more information

Crohn's & Colitis Foundation of America (CCFA)

**386 Park Avenue South, 17th Floor
New York, NY 10016
(800) 932-2423**

www.ccfa.org

This is the place to go for the most up-to-date information about Crohn's disease and ulcerative colitis. You can also get local chapter news and learn about CCFA's Camp Oasis, our camps for kids and teens with IBD, support groups and other programs in your area.

www.ucandcrohns.org

This teen site is sponsored by CCFA and the Starlight Starbright Children's Foundation. It was designed especially for you! Here, you'll find coping tips, videos, stories about other teens, and much more.



PLEASE CHECK ONE:

- ☐ Individual \$30
- ☐ Family \$60
- ☐ Supporting \$100
- ☐ Contributing \$250
- ☐ Patron \$500
- ☐ Benefactor \$1,000

I am a: ☐ New Member ☐ Renewing Member

I do not want to be a member, but want to support CCFA's programs. Enclosed is my donation of \$_____.

Name: _____

Address:

City: _____ State: _____ Zip: _____

Home #:

Email address:

Optional & Confidential (For CCFA use only):

CCFA does not sell, lend or exchange its member information with anyone. All information is kept strictly confidential.

Employer/

Business Name:

Address: _____

City: _____ State: _____ Zip: _____

Work #: _____

Email:

- ☐ Crohn's patient ☐ Colitis patient
- ☐ My child has Crohn's
- ☐ My child has colitis ☐ Other

METHOD OF PAYMENT

- ☐ Check enclosed (Please make your check payable to CCFA)
☐ Credit card (Please include the following information):
☐ Visa/Mastercard ☐ American Express ☐ Discover

Account #:

Expiration Date:

Signature: _____

NOTES

[illegible]



800.932.2423

www.ccfa.org

National Headquarters
386 Park Avenue South
17th Floor
New York, NY 10016-8804

The printing of this brochure was made
possible by an unrestricted grant from: