



Crohn's Disease and Ulcerative Colitis:  
A Parent's Guide



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.

When a child has a chronic illness, everyone in the family is affected. Naturally, as a parent, you want your child to get the best care available. If you have other children, they need to understand their sibling's condition and the impact it can have on their lives. It's important to reassure them that you love them and want to hear about their hopes and concerns, even though you may have to devote more time to the child who is ill. Finally, you'll want to share information with friends, neighbors, and school personnel. We hope you'll take advantage of the other brochures in this series ("A Guide for Children and Teenagers," "A Teacher's Guide"), as well as the many CCFA materials and programs that have helped thousands of families cope with Crohn's disease and ulcerative colitis.

## WHAT ARE CROHN'S DISEASE AND ULCERATIVE COLITIS?

Crohn's disease and ulcerative colitis are the two most common types of chronic inflammatory bowel disease (IBD). In both diseases, the inner surface of the intestine appears raw and eroded, similar to traumatized skin. The inflammation of Crohn's disease usually extends through the full thickness of the intestinal wall. The lower part of the small intestine (ileum) and the large intestine (colon) are most often affected. However, Crohn's disease may affect any part of the gastrointestinal (GI) tract, from the mouth to the skin around the anus.

In ulcerative colitis, the inside lining of the colon is inflamed. Unlike Crohn's disease, however, ulcerative colitis is confined to the colon. All or just a part of the large intestine may be involved. Occasionally, only the rectum is inflamed. The bowel injury of ulcerative colitis is present only on the inner lining of the colon, and it does not extend through the full thickness of the intestinal wall.

## WHAT ARE TYPICAL SYMPTOMS OF ULCERATIVE COLITIS AND CROHN'S DISEASE?

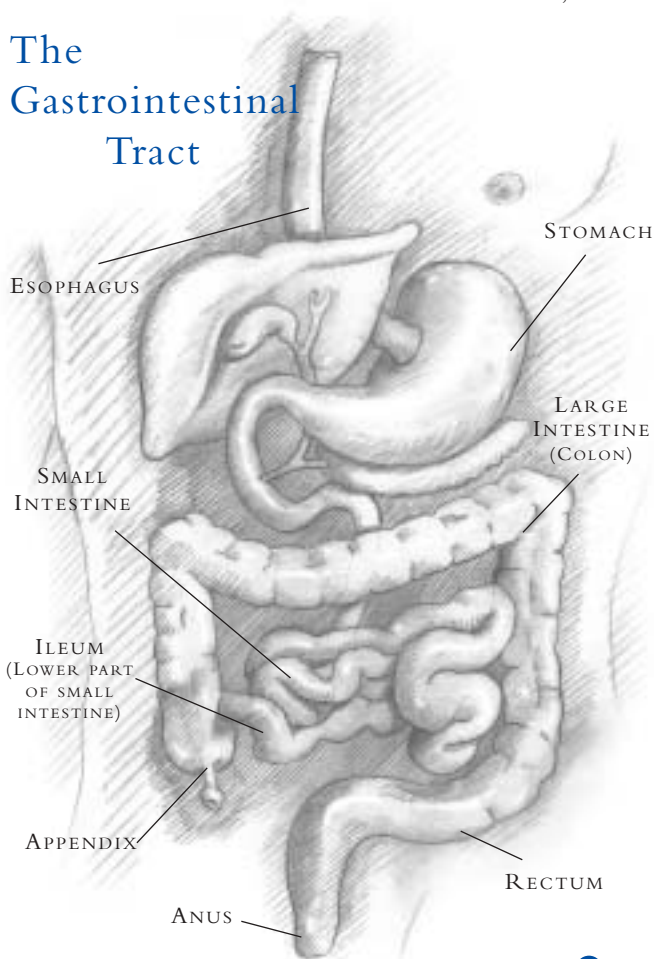
Despite the differences between Crohn's disease and ulcerative colitis, both forms of IBD cause similar symptoms in young people. Symptoms occur because intestine affected by IBD does not work well. Because the small intestine is where food is actually digested and absorbed into the body, inflammation in the small intestine results in malabsorption—that is, loss of nutrients into the stools. These malabsorbed nutrients tend to carry extra water with them, making stools loose. The main function of the large intestine is to reabsorb, or recycle, water that is added to food when it is higher in the GI tract during digestion. When the large intestine is inflamed, it is unable to reabsorb this water adequately, again resulting in loose stools. Thus, both Crohn's disease and ulcerative colitis can cause diarrhea. Inflammation also may cause abdominal pain, decreased appetite, and weight loss. Symptoms may appear gradually, or develop very

suddenly. Occasionally, severe symptoms appear to be “set off” during a mild illness, such as the flu. In retrospect, some patients realize that symptoms had been present for a long time.

In Crohn’s disease, abdominal pain and diarrhea are often the earliest signs. Obvious rectal bleeding is a little less common than in ulcerative colitis. Lack of appetite, weight loss, and poor height growth also are common. Other signs of Crohn’s disease include sores in the anal area, extra folds of skin around the anal opening, and anal fistulas, which are tiny openings or pores from which pus-like fluid can seep.

Most young people with ulcerative colitis develop loose bloody stools. Crampy abdominal pain is common, as is the persistent urge to have a bowel movement. Symptoms vary; some young people with ulcerative colitis have little or no diarrhea,

## The Gastrointestinal Tract



just rectal bleeding with an occasional cramp. Diarrhea may develop slowly or begin suddenly. Some children may awaken from sleep with the urge to move their bowels.

Both Crohn's disease and ulcerative colitis may have symptoms outside the GI tract. These may include rashes, mouth sores, joint pain and swelling, or, rarely, liver disease and other less common symptoms.

## HOW COMMON IS IBD?

It is estimated that there may be as many as 1,000,000 Americans with IBD. Males and females appear to be equally affected. Though Crohn's disease and ulcerative colitis afflict people of all ages, they are primarily diseases of younger persons. Adolescents and young adults between the ages of 15 and 35 are the most susceptible. There may be 100,000 children under the age of 18 who suffer from IBD.

## ARE ULCERATIVE COLITIS AND "SPASTIC COLON" THE SAME DISEASE?

No. "Spastic colon" is a term used to describe a disorder called irritable bowel syndrome, or IBS. A child with this disorder may have diarrhea and pain that simulates IBD. Irritable bowel syndrome, however, does not cause bowel inflammation and bears no relationship to Crohn's disease or ulcerative colitis.

## WHAT CAUSES IBD?

Researchers do not know what causes these diseases. At one time, it was widely thought that tension, anxiety, or diet actually caused Crohn's disease and ulcerative colitis. Now it is known that these diseases are not caused by emotional stress or food, nor are they contagious. Research has shown that the immune system within the intestinal wall is not working properly in a person with IBD. Normally, the intestinal immune system protects the GI tract against foreign substances, including food by-products and microorganisms, such as bacteria. People with IBD may have an overactive immune system, which fails to shut off properly after being

“turned on” by a disease-producing microorganism. In this situation, the intestinal wall itself can be damaged by the immune system, sometimes slightly or sometimes severely.

## WHAT TESTS ARE USED TO DIAGNOSE IBD?

There is no single test to identify Crohn’s disease or ulcerative colitis. In addition to a thorough medical history and physical examination, persons undergo blood tests, barium x-rays, and endoscopy of the upper and lower GI tract. Blood tests are done to check for a low red cell count (anemia) or high white cell count (inflammation). Other blood tests may be done to look for evidence of inflammation in the intestine and elsewhere, including the erythrocyte sedimentation rate (ESR or sed rate) and C-reactive protein (CRP). Additional blood tests check for nutritional imbalances of IBD and for evidence of side effects of medication.

Barium x-rays include the “upper GI and small-bowel series” and “lower GI series,” or “barium enema.” During the upper GI series, barium is swallowed to allow the upper intestinal tract to be seen by x-ray. Similarly, during a barium enema, barium is passed into the rectum to allow the large intestine to be seen on x-ray. Areas of swelling, narrowing, or other signs of intestinal inflammation are identified. The upper GI series is done on an empty stomach, which usually means an overnight fast and skipping breakfast. Before a barium enema is done, a clear liquid diet and laxatives are often given for one to two days to clean out the large intestine.

Endoscopy is a test that involves inserting a lighted viewing tube through either the mouth into the upper intestine (upper endoscopy) or the anus into the colon (colonoscopy). Like an upper GI x-ray series, upper endoscopy is done on an empty stomach. Unlike the upper x-ray, upper endoscopy is done on a person who is sedated in some way—either asleep under general anesthesia, or under medication given through an intravenous (IV) line to create “twilight sleep.” Colonoscopy is done in much the same way as upper endoscopy. A clear liquid diet and laxatives are given for one to two

days before colonoscopy in order to be able to see the inside lining of the large intestine. In addition to looking for inflammation from IBD, the doctor can obtain tiny pieces of tissue, termed biopsies, during upper endoscopy and colonoscopy. Biopsies are viewed under a microscope to see abnormalities not clearly visible to the naked eye.

Physicians who perform endoscopies on children usually have preferences as to what specific laxatives are given and how children are sedated. These matters should be discussed with your doctor if you have questions or concerns. The type of x-ray or endoscopy that needs to be done to identify IBD depends in part on the symptoms and whether Crohn's disease or ulcerative colitis is suspected. IBD is often difficult to diagnose because of these illnesses' tendency to mimic other conditions. Thus, correct diagnosis of Crohn's disease and ulcerative colitis may take some time. Research is underway to develop blood tests that can distinguish Crohn's disease from ulcerative colitis.

In some patients, it is difficult to determine whether their IBD is Crohn's disease or ulcerative colitis, even after extensive tests. For those patients, their physician may use additional blood tests to help distinguish between the two forms of IBD. Very rarely, these patients are given the diagnosis of indeterminate colitis.

## IS IBD INHERITED?

We know that Crohn's disease and ulcerative colitis tend to run in families. Studies have shown that up to 15 to 20 percent of patients may have a close relative with one of these diseases. There does not seem to be any clear-cut pattern to family inheritance. Researchers are currently working to identify genes that influence the tendency to develop IBD.

## DO CHILDREN EVER OUTGROW THESE ILLNESSES?

No. Crohn's disease and ulcerative colitis are considered chronic diseases that persist throughout life. However, many children and adults enjoy long periods of time when they are free of symptoms (remissions). Some have only mild symptoms, and

many respond well to drug therapy, whether the initial symptoms were mild or severe. Occasionally, a child with ulcerative colitis may become so ill that surgical removal of the entire large intestine, including the rectum, is necessary. This provides a permanent cure for ulcerative colitis. Surgery for Crohn's disease is not considered a cure. The latter usually involves removal (resection) of a particular region or regions of irreversibly diseased intestine. Although this surgery is not a cure, it can provide the child with many disease-free years, with reduced need for drug therapy. (See below, "What is the role of surgery in treating IBD?")

## WHAT MEDICATIONS ARE USED TO TREAT IBD?

Often, the same drugs are used for the treatment of either Crohn's disease or ulcerative colitis. Several types of drugs are used. The first types are those drugs containing 5-aminosalicylic acid (5-ASA), also called mesalamine. The best known of this type is sulfasalazine (brand name Azulfidine®). Drugs containing mesalamine reduce inflammation in the intestine, similar to the way aspirin works for inflammation in other parts of the body, such as the joints (arthritis). Mesalamine-containing agents, which include Azulfidine®, Dipentum®, Asacol®, Canasa®, Colazal®, Pentasa®, and Rowasa®, are often given when symptoms are relatively mild or moderate. They are also sometimes given directly into the rectum in the form of an enema, suppository, or foam.

The second type of drug used to treat IBD is corticosteroids. These are often given when symptoms are more severe or at the time of diagnosis to induce a remission. Corticosteroids are taken by mouth or, in some cases, administered intravenously. Prednisone is a commonly prescribed corticosteroid that is taken by mouth. Prednisone and similar drugs such as budesonide (Entocort™ EC) are like cortisone, a hormone made by the adrenal glands. They have powerful anti-inflammatory effects. Prednisone, however, is at least five times stronger than natural body cortisone. It is often given at the onset of IBD and during periodic flare-ups of symptoms. Corticosteroids are also available for rectal use in the form of enema, suppository, or foam.

Rectal corticosteroids are useful particularly when disease involves the lower part of the large intestine.

The third class of drugs for IBD is the immunosuppressives or immunomodulators. Drugs of this type directly inhibit the immune system, which triggers the intestinal damage of IBD. Immunosuppressives include azathioprine (Imuran<sup>®</sup>), 6-mercaptopurine (6-MP, Purinethol<sup>®</sup>), cyclosporine, and methotrexate. Generally, immunosuppressives are given when disease is severe and persistent. Their major benefit may be in reducing or eliminating dependence on corticosteroids. However, it may take six weeks to six months for some of them to start working.

Additional drugs useful for IBD are antibiotics. The most commonly used is metronidazole (Flagyl<sup>®</sup>). Metronidazole has been helpful in treating perianal complications of Crohn's disease (complications that occur in the area of the anus, such as fistulas). Antibiotics also may be important when there is extension of intestinal inflammation into the abdomen. In particular, abscesses (pockets of fluid containing many bacteria) may accumulate outside the intestinal wall. This is more likely to occur in Crohn's disease than in ulcerative colitis.

The fifth form of therapy for IBD is dietary. Strictly speaking, altering the diet is not a drug therapy, but it may have the same practical effect as taking medicine. Dietary therapy for IBD may include consumption of a predigested (elemental) formula by mouth or through a feeding tube. Dietary therapy may also involve not eating altogether but, rather, receiving nutrition through an intravenous line. Another term for full intravenous feeding is total parenteral nutrition (TPN). Special diets and TPN are sometimes used, particularly in people with Crohn's disease, when drug therapies have been ineffective or have been associated with too many side effects.

A new class of drugs, called biologic modifiers, has recently been introduced, particularly for

use in Crohn's disease. These include anti-tumor necrosis factor, or anti-TNF (infliximab, known as Remicade™); interleukin-10; and other inhibitors of inflammation. Clinical research has shown that blocking TNF production in patients induces remission and may help to heal fistulas in Crohn's disease more rapidly. As of this writing, Remicade is the only biologic agent that the FDA has approved for the treatment of IBD; others are under study.

## WHAT ARE THE MOST COMMON SIDE EFFECTS OF MEDICINES USED FOR IBD?

All medications can have some side effects, and medications for IBD are no exception. Sulfasalazine occasionally causes nausea, headaches, anemia or other blood disorders, skin rashes, or diarrhea. Some of these side effects can be reduced when the drug is given first in small doses, then increased steadily to a recommended daily dose. Physicians watch for the occurrence of these side effects and decide whether the drug should be continued, reduced, or replaced with some other preparation.

Corticosteroids, such as prednisone, may cause rounding of the face (facial “mooning”), acne, increased appetite and weight gain, and may interfere with growth. They may cause bones to lose their calcium and become more susceptible to fracture. Additional side effects include development of diabetes and high blood pressure. Patients on prolonged corticosteroid therapy should see an eye doctor regularly because these drugs can cause cataracts and glaucoma. Prednisone also can interfere with the body's ability to fight infection. If your child develops an infection, especially chicken pox, you should notify his or her physician.

Side effects of prednisone decrease when the dose is reduced and usually disappear altogether when prednisone is discontinued. High blood pressure usually can be prevented by a low-salt diet. In most cases, prednisone and

similar corticosteroids such as budesonide (Entocort™ EC), which may have fewer side effects, can be administered safely with close supervision. Serious side effects are not as threatening as they may sound. Prednisone remains an extremely valuable drug in the treatment of IBD.

Another important effect of prednisone is that it puts the adrenal glands “to sleep.” These glands can sense if there is cortisone or prednisone in the blood stream. When prednisone is taken every day, the adrenal glands will respond by shutting down. Once shut down, it takes a while for the adrenal glands to start making cortisone again. The longer prednisone is taken, the longer it takes for the adrenal glands to begin producing cortisone. That is why prednisone therapy is reduced gradually. Prednisone should not be stopped without your child’s physician’s knowledge. During periods of stress, such as infections, surgery, dental work, and accidents, temporary increases in prednisone therapy may be necessary. You should notify your child’s doctor if any of these periods of bodily stress occur.

Long-term side effects of many other drugs for IBD are less well known, because they have not been used for as long as corticosteroids and mesalamine-containing agents. Azathioprine and 6-mercaptopurine may cause nausea, a decrease in the white and red blood cell count, and irritation of the pancreas (pancreatitis) and liver (hepatitis). Metronidazole may cause nausea and abdominal discomfort, a metallic taste in the mouth, tingling in the hands and feet, and may also darken the urine. All of these agents have been known to cause tumors in laboratory animals, but at dosages much higher than those used in people with IBD.

Therapy for IBD is in a constant state of change. New forms of drugs are being introduced and tested all the time. In fact, you and your child with IBD may someday be invited to participate in a clinical trial—a research study that evaluates one of these agents.

## WHAT IS THE ROLE OF SURGERY IN TREATING IBD?

Surgery becomes necessary in Crohn’s disease when medication no longer controls symptoms,

or when there is an intestinal obstruction or other complication that can't be controlled by medication. In most cases, an irreversibly diseased segment of bowel is removed, and the two ends of healthy bowel are joined together. This is called resection and anastomosis. While this surgery may allow many symptom-free years, it is not considered a cure for Crohn's disease, because the disease may return at or near the site of anastomosis.

For ulcerative colitis, surgical removal of the entire colon and rectum (proctocolectomy) is a permanent cure. During proctocolectomy, an artificial opening is created on the front of the abdomen. The remaining small intestine is attached to this opening. This is called an ileostomy. The ileostomy drains liquid waste into a small bag attached to the skin with a special adhesive. Either during the same operation or at a later surgery, the lowest part of remaining small intestine is reattached to the anal opening. The attachment is called an ileoanal anastomosis. Once the ileoanal anastomosis has healed, the abdominal wall ileostomy is closed, and evacuation of feces then occurs in the normal way, through the anus. This operation is rarely used in Crohn's disease because of the possibility of the disease returning in the bowel just inside the anal opening, the "ileal pouch."

For a detailed discussion of these procedures, please request CCFA's brochure on surgery.

## WHAT IS THE ROLE OF DIET AND NUTRITION IN IBD?

Good nutrition is essential in any disease, but especially in illnesses like IBD, where reduced appetite, digestive problems, and diarrhea are typical. Restoring proper nutrition is a vital part of the overall treatment program. A few specific comments apply. Salt intake should be limited during corticosteroid therapy, because salt worsens fluid retention. Occasionally, the ileum is severely inflamed, making its internal passageway quite narrow. In this situation, a low-fiber diet can be useful, and "chunky" high-fiber products, such as popcorn, must be avoided. A few children get cramps and diarrhea when they consume dairy products because of an inability to digest milk

sugar (lactose intolerance). A registered dietitian can plan a low-fiber, low-sodium, or low-lactose diet when necessary. In practice, relatively little or no dietary modification is necessary for most people with IBD.

Diet also plays a role in keeping “healthy” bacteria in the gastrointestinal tract. In some cases, your child’s doctor or dietitian may recommend increasing foods which promote an environment for these good types of bacteria.

Certain vitamins and minerals, for example, vitamin B-12, folic acid, vitamin C, iron, calcium, zinc, and magnesium, are sometimes deficient in children with IBD. Your child’s doctor can identify and correct these deficiencies with supplements when necessary. Most researchers, however, feel that simply providing adequate calories by encouraging children or teenagers to eat almost anything they desire is the first priority and is likely to prevent other problems.

For children who have trouble eating, nutritionally complete liquid diets are available. These can be used by themselves or along with regular food to increase caloric intake. The decision to use one of these preparations should be made in consultation with your child’s physician.

Another way to provide extra calories is the use of continuous liquid diet infusion at night. While the child is asleep, the formula is pumped through a narrow tube that has been passed through the nose into the stomach. This is usually done at home for several months.

## CAN LIVING WITH A CHRONIC DISEASE LIKE IBD CAUSE EMOTIONAL PROBLEMS?

It can. Different persons cope with chronic physical problems in different ways. Some people seem to have little emotional reaction. Others experience emotional distress when they develop a medically incurable disorder, whether it is IBD or another condition, such as diabetes or asthma. This is because a chronic disease poses a threat to a person’s well-being and feeling of security. Signs of anxiety, insecurity, and dependence may develop.

These reactions are a response to the disease and not its cause.

Most children experience some anxiety in response to their illness. The emotional support provided by healthcare professionals is frequently satisfactory. At times a counselor or child psychologist may be helpful, enabling the child to regain the self-confidence that is sometimes affected by chronic illness. When there are indications of more severe emotional disturbances, such as an inability or unwillingness to attend school, social isolation, or other signs of inability to cope, consultation with an experienced psychologist, psychiatrist, or psychiatric social worker may be useful.

## DO CHILDREN OR THEIR FAMILIES EVER EXPERIENCE FEELINGS OF GUILT THAT THEY HAVE BROUGHT THE ILLNESS UPON THEMSELVES BECAUSE OF THINGS THEY DID OR DIDN'T DO?

Yes. It is natural for people to feel this way, but there is no scientific basis that IBD is caused by psychological factors or other causes within the family's control. Therefore, there is no reason for an affected child or any member of the family to feel guilty about causing the disease.

## ARE THERE THINGS I DO AS A PARENT THAT CAN MAKE THE SITUATION WORSE? WHAT CAN I DO TO PREVENT THAT?

There is nothing that you have done as a parent to cause your child's illness. Chronic illness in a child, however, can cause parents to become overly protective. This is only natural. As soon as your child is old enough, it is a good idea to foster independence by encouraging him or her to take responsibility for some medical routines, such as taking medications and calling the doctor when necessary. The illness can become a source of tension between parent and child, coming at an age when independence is a major issue. In particular, parents may become alarmed when their child loses weight or eats poorly. Children and adolescents need to voice their fears about changes in their

bodies brought on by illness and treatment. You and your child should openly discuss these concerns with your physician.

## HOW CAN I TELL IF MY CHILD IS NOT GROWING PROPERLY?

Growth failure may occur in children with Crohn's disease when disease onset occurs before puberty. Signs of growth failure include a lower-than-expected increase in height and weight. A child may notice that he or she is shorter than other children in the same class are. Moreover, parents may notice that the size of a child's shoe, glove, or coat remains the same for a long period of time.

Your child's doctor can plot his or her growth curve on a growth chart. This should be done at six- to 12-month intervals. The chart will plot the rate at which your child is growing, compared with the average growth rate of other children across the country. This is a simple technique, and your child's doctor may show you how to keep track of your child's growth rate at home using these same charts. An alert parent is often the first to spot these changes in a child's development. Other signs of failure to grow are delayed bone development (which can be measured using x-rays) and an onset of puberty that appears delayed compared to the usual family pattern.

## WHAT ABOUT THE ONSET OF PUBERTY? WILL MY CHILD BE NORMAL?

Even though puberty may be delayed by several years because of IBD, most teenagers do reach maturity and function normally. Some continue to grow in height into their 20s, after the onset of puberty and long after their peers have stopped growing. Many reach their "normal" height in this way.

## HOW MUCH INFORMATION SHOULD I GIVE MY CHILD ABOUT THE ILLNESS?

Your child or teenager will probably indicate to you just how much information about the disease he or she wants to know. Parents should encourage

children to ask questions and discuss concerns with their healthcare providers. The physician can manage the illness better when he or she has a working dialogue with the child. Some children feel much more in control when they know the facts. One young teenager told her mother that she was able to face surgery without feeling panicky, because her mother had spoken frankly about the illness and about what was going to happen during surgery.

## HOW DO CHILDREN COPE WITH IBD?

Encourage children or adolescents to find practical ways of dealing with the illness in school. They can learn where the nearest bathrooms are, visit the school nurse's office when needed, and carry extra underclothing. When school attendance is a particular problem, testing may be necessary to determine whether the disease is flaring or if perhaps depression or other emotional problems are responsible.

## SHOULD MY CHILD'S FRIENDS AND TEACHERS BE TOLD ABOUT THE ILLNESS?

Your child should decide whether to tell anyone about the disease. The disease may seem difficult to explain, and children can often be cruel about such things. Therefore, your child may choose not to tell friends about the problem in the beginning. As young patients develop a better understanding of their disease, however, this may change. You should respect their wishes whenever possible. However, if there are hospitalizations or frequent absences from school, teachers or school administrators should be told matter-of-factly about the child's illness. CCFA's brochure, "Crohn's Disease and Ulcerative Colitis: A Teacher's Guide," can be helpful. Such explanations can make life easier when a child needs to make frequent trips to the bathroom or has to be out of school for long periods. The school nurse can be helpful in dealing with bathroom and gym issues.

Educational needs must be addressed, and tutoring arranged if necessary. Your school system should be willing to work with you to ensure the child's continuing education. Keeping the lines of

communication open between you and your child's medical team and school is key to avoiding major difficulties.

## SHOULD A CHILD WITH IBD PARTICIPATE IN SPORTS?

Young people with IBD should be as active as possible. There is generally no reason not to participate in sports if the disease is under control. Some limitation may be necessary if strenuous sports cause fatigue or aggravate abdominal pain, arthritis, or other symptoms. Furthermore, prolonged high-dose steroid therapy may make bones more susceptible to fracture during contact sports, such as football and wrestling. In these instances, a modified exercise program may be the answer.

## IS IT POSSIBLE TO LEAD A NORMAL LIFE WITH IBD?

This is perhaps the most important question to be asked. While Crohn's disease and ulcerative colitis are serious chronic diseases, they are not considered to be fatal illnesses. Most people with IBD continue to lead active and productive lives, even though they often need to take medications regularly and may occasionally have to be hospitalized. Sometimes, the disease "flares" or exacerbates, requiring temporary increases in drug therapy or the use of additional medication. Nonetheless, between these "flares," many people feel fully well and are relatively free of symptoms.

Though there is no medical cure for Crohn's disease or ulcerative colitis, research and educational programs funded by CCFA have improved the health and quality of life of people with IBD. Through CCFA's continuing research efforts, much more will be learned and a cure will be found.



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