



CROHN'S & COLITIS
FOUNDATION OF AMERICA

Crohn's Disease & Ulcerative Colitis:

A Guide for Parents



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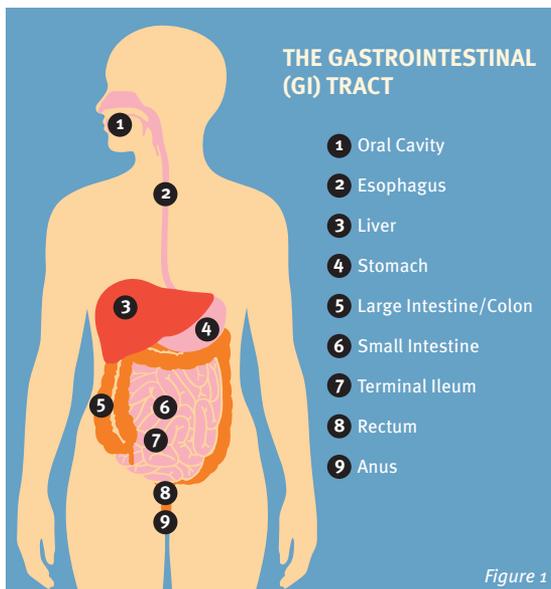
You recently learned that your child has Crohn's disease or ulcerative colitis. Now you're taking an important step: learning about these conditions, how they're treated, and how your child can learn to live with IBD.

The purpose of this brochure is to start you on that educational path—to inform you of some key points about Crohn's disease and ulcerative colitis, and what you may expect. You won't become an expert overnight, but gradually you'll learn more. And the more you know, the better you'll be able to become an advocate for your child. Most important: You'll be an active member of your child's healthcare team.

IBD: The basics

It is important to note, first and foremost, that inflammatory bowel diseases (IBD), specifically Crohn's disease and ulcerative colitis, are chronic but treatable conditions.

Doctors and scientists are working hard to find the causes of and the cure for IBD. Despite the challenges of living with a chronic disease, your child can have a normal, happy, productive life. While there is not yet a cure for these diseases, appropriate therapy can control the chronic inflammation that is a hallmark of IBD. This will help achieve long-term treatment goals, including elimination of chronic gastrointestinal symptoms, restoration of growth, and a normal quality of life.



Crohn's disease and ulcerative colitis are the two most common types of inflammatory bowel diseases. While these conditions produce similar symptoms and use similar therapies, they are not the same.

In ulcerative colitis, only the colon is affected; of the multiple layers of the intestinal wall, only the innermost lining of the colon, the *mucosa*, becomes inflamed. Ulcerative colitis also spreads *proximally*, meaning it starts from the rectum and can spread continuously to the rest of the large intestine (*colon*).

Crohn's disease, on the other hand, may affect any part of the gastrointestinal (GI) tract, from the lips to the anus. Unlike ulcerative colitis, Crohn's can skip large segments of bowel before reappearing in others. The areas most often affected, however, are the lower part of the small intestine (*ileum*) and the large intestine (*colon*). Also, in Crohn's patients, the inflammation does not stop at the *mucosa* (tissue lining) and may burrow through the entire thickness of the bowel wall.

Signs and symptoms

Despite the differences between Crohn's disease and ulcerative colitis, both cause similar symptoms when active—all brought on by chronic inflammation.

Patients may have one or more symptoms, including:

- persistent diarrhea
- abdominal pain and/or cramps

- fecal urgency
- intestinal bleeding
- fever
- weight loss

While these symptoms are the same in children and adults, children may be affected by a delay in growth and sexual maturation. In fact, a significant number of pediatric IBD patients are diagnosed after reporting growth delays. This primarily affects Crohn's patients because of the direct effects on bone growth and decreased absorption of nutrients. However, it can affect all pediatric IBD patients if abdominal pain or other symptoms result in reduced appetite.

It is important to understand that these symptoms can vary significantly from patient to patient and do not have to be persistent. Such symptoms are only present when IBD is active and can be eliminated by inducing and maintaining remission and avoiding *flare-ups* (active symptoms) of the disease. Symptoms may appear suddenly and severely and may seem to be triggered by stress or a viral or bacterial illness; they may also build slowly over time.

You can learn more about signs and symptoms through the following brochures offered online at www.cdfa.org:

- *Living with Crohn's Disease*
- *Living with Ulcerative Colitis*
- *Managing Flares and Other IBD Symptoms*

Beyond the intestines

In addition to having symptoms in the GI tract, some people may experience a variety of symptoms in other parts of the body associated with IBD.

Signs and symptoms of the disease may be evident in:

- eyes (redness, pain, and itchiness)
- mouth (sores)
- joints (swelling and pain)
- skin (tender bumps, painful ulcerations, and other sores/rashes)
- bones (osteoporosis)
- kidney (stones)
- liver (primary sclerosing cholangitis, hepatitis, and cirrhosis)—a rare development

All of these are known as *extraintestinal* manifestations of IBD because they occur outside of the intestine. In some people, these actually may be the first signs of Crohn's disease, appearing even years before the bowel symptoms. In others, they may occur right before a flare-up of the disease.

Who gets IBD?

Approximately 1.6 million Americans have either Crohn's disease or ulcerative colitis.

That number is almost evenly split between the two conditions. Here are some quick facts and figures:

- More than 1.6 million Americans have IBD.
- On average, people are more frequently diagnosed with Crohn's disease or ulcerative colitis between the ages of 15 and 35, although the disease can occur at any age.
- Males and females appear to be equally affected.
- While IBD can affect people from any ethnic background, Caucasians develop it more than other groups.



Causes of IBD

No one knows for sure what causes Crohn's disease or ulcerative colitis, but experts believe there may be several factors that work together to lead to the development of the diseases, including:

Genes—Studies have shown that 5% to 20% of affected individuals may have a first-degree relative (i.e., parent/child, sibling) with one of these diseases. Your genes clearly play a role, although no specific pattern of inheritance has yet been identified. This means that right now there is no way to predict which, if any, family members may develop IBD.

Environmental elements—Viruses, bacteria, and other factors have been studied with no conclusive results. Researchers are now focusing on microscopic elements.

Inappropriate immune reactions—Scientists continue to study whether a glitch in patients' immune systems—perhaps launched by an environmental prompt—may result in the body attacking itself.

While researchers continue to study possible causes, some have been ruled out, including tension, anxiety, personality traits, or dietary factors. Also, the diseases are not contagious.

Diagnosis

Your child's diagnosis of Crohn's disease or ulcerative colitis likely occurred following a few tests.

In addition to a thorough medical history and physical examination, children may undergo a combination of blood tests, barium x-rays, magnetic resonance imaging (MRI), and endoscopy of the upper and lower GI tract. In general, physicians will begin by prescribing the least invasive tests, progressing to more invasive testing until a diagnosis is obtained. This is especially true in pediatric patients.

- Blood tests are done to check for a low red blood cell count (*anemia*) or high white blood cell count (*inflammation*). Other blood tests may be performed to look for evidence of inflammation in the intestine and elsewhere. More recently, various antibody tests have been discovered that can show the altered GI immune process in some people with IBD.
- Barium x-rays and MRI include the *upper GI* and *small bowel series*, which helps to visualize areas of the intestines that are out of reach of *endoscopies* (see next bullet). (The lower GI series, or *barium enema*, has been replaced by colonoscopy.) During the small bowel series, your child swallows a chalky liquid containing barium or a similar material that coats the upper intestinal tract so it will show up on an x-ray or MRI. Areas of swelling, narrowing, or other signs of intestinal inflammation can be identified with these imaging techniques. X-rays, MRIs, and other imaging tests will be used wisely to limit your child's lifetime exposure to radiation.

- *Endoscopy* is a test that involves inserting a lighted viewing tube through either the mouth into the upper intestine (*upper endoscopy*) or through the anus into the colon (*colonoscopy*). The physician performing the exam can also remove tiny pieces of tissue (*biopsies*) from the intestines, which are later examined for microscopic signs of the diseases. During the endoscopy, your child's doctor may also insert a video capsule, which takes pictures of the inside of the small intestine. These pictures can show areas of soreness, ulceration, or bleeding that may not be detectable by other methods. Generally, these tests are performed on children who are sedated. A new form of endoscopy, called the pill endoscopy, does not involve anesthesia. Instead, a patient swallows a small pill-shaped camera, which takes pictures as it travels through the intestines; the images are captured on a device worn by the child. The camera pill is excreted in the child's stool.

Crohn's disease and ulcerative colitis may look like other conditions. One example of this is *irritable bowel syndrome*, or IBS. IBS shares many symptoms of IBD, including abdominal pain and diarrhea. However, IBS is a functional bowel disorder, meaning the muscles of the intestines react improperly, either moving the bowel contents too quickly or too slowly. IBS does not involve inflammation, however. Because there are no physical signs of IBS, it is usually diagnosed after ruling out other conditions, including Crohn's and colitis.

In some individuals, it is difficult to determine whether their IBD is Crohn's disease or ulcerative colitis—even after extensive testing. Very rarely, people are given the diagnosis of “indefinite colitis.” Such uncertainty is more common in the youngest patients—those under five years old at the time of diagnosis.

For in-depth information on diagnostic tests, please see the *Diagnosing and Managing IBD* brochure available at www.cffa.org.

Treatment

Because Crohn's disease and ulcerative colitis are considered *chronic*, meaning that they can flare up after an initial remission, the goal of treatment is to achieve and maintain remission.

Treatments can include medication, surgery, or nutritional therapies.

Prescription medication

While there is no medical cure for IBD, there are a number of drug therapies that can help your child. It is important to understand that just as the disease impacts each patient differently, medication regimens change from person to person, sometimes from flare to flare. For example, one individual may have few symptoms and may respond well to mild drug therapy during one flare but may require different, stronger medication during a more severe or prolonged flare.

The three main goals of treatment for IBD are:

- Achieving remission (remission is defined as the absence or decrease of symptoms)
- Maintaining remission
- Improving quality of life

These goals may be achieved with a combination of over-the-counter and prescription medication, nutritional support therapy, and/or surgery, depending on each individual case.

Broadly speaking, five different categories of treatments are used in IBD, both for children and adults. These treatments include:

Aminosalicylates: These include aspirin-like compounds that contain 5-aminosalicylic acid (5-ASA) and are used to treat mild-to-moderate disease or to maintain remission. These drugs, which can be given either orally or rectally, reduce inflammation in the intestine, similar to the way aspirin works against inflammation in other parts of the body such as the joints (arthritis). Possible side effects of aminosalicylates may include diarrhea, headaches, and nausea.

Corticosteroids: These medications affect the body's ability to launch and maintain an inflammatory process. In addition, they work to suppress the immune system. Corticosteroids are used for children with moderate-to-severe IBD. Administered orally, rectally, or intravenously (through a vein), steroids are effective for short-term control of flare-ups but are not recommended to maintain remission in children due to undesirable long-term side effects, including stunted growth. Some side effects of corticosteroids include weight gain, insomnia, mood swings, osteoporosis, scalp hair loss or facial hair growth, acne, appearance of stretch marks, and increased susceptibility of infection and bruising.

Immunomodulators: This class of medication reduces the activity of the body's immune system so that it cannot cause ongoing inflammation. Usually given orally, immunomodulators are used in the majority of children with IBD, especially when aminosalicylates and corticosteroids haven't been effective or have been only partially effective. They may be useful in reducing or eliminating dependency on corticosteroids and are frequently used to maintain remission. Immunomodulators may cause nausea, a decrease in white and red blood cell counts, and inflammation of the pancreas (*pancreatitis*) or liver (*hepatitis*). There is an increased susceptibility to infection related to the use of these medications.



Also, there is a small increase in the absolute risk of developing certain cancers, such as non-melanoma skin cancers and lymphoma. However, the benefits of long-term remission should be weighed against these risks.

Antibiotics: Certain antibiotics may be used when infections, such as abscesses, occur in IBD.

Biologic therapies: The newest class of therapies to be used in IBD are proteins that selectively target key cells in the inflammatory cycle, thus short-circuiting the process. These therapies are used to control moderate-to-severe disease and to maintain remission. These medications are administered by injection or intravenous infusion on a schedule that varies from weekly to every few months, depending on the individual and the medication.

Over-the-counter (OTC) medication

Prescription medications reduce intestinal inflammation and form the core of IBD treatment. Even so, these important prescription medications may not eliminate all of your child's symptoms. Naturally, you may want your child to take over-the-counter medications in an effort

to make him or her feel better. Before doing so, speak with your child's doctor, or other health-care professional. Sometimes your child's symptoms can indicate a worsening of the inflammation that may require a change in prescription IBD medication or other course of treatment.

As with all medications, you should know the risks and benefits of these medications and discuss any concerns with your child's doctor. For more information about medications and their side effects, download the brochure *Understanding IBD Medications and Side Effects* at www.ccfa.org.

Medication changes and adherence

With the right treatment, your child should expect to achieve a life without symptoms. You should have an open dialogue with your child's doctor or provider and inform them if your child is still experiencing IBD symptoms while on treatment. During these discussions you should feel comfortable asking the doctor about other available treatment options.

Even the best medications in the world won't help if you forget to take them. Adherence means that your child is following the medical advice of the physician with regards to:

- Taking prescribed medication in the proper dose at the proper time
- Taking the recommended vitamins and supplements
- Ensuring that feedings are done on schedule, if necessary

Even with the best intentions, it is easy to forget taking medication. To help your child remember, suggest the following:

- Utilize CCFA's GI Buddy interactive disease management tool: available online or as a

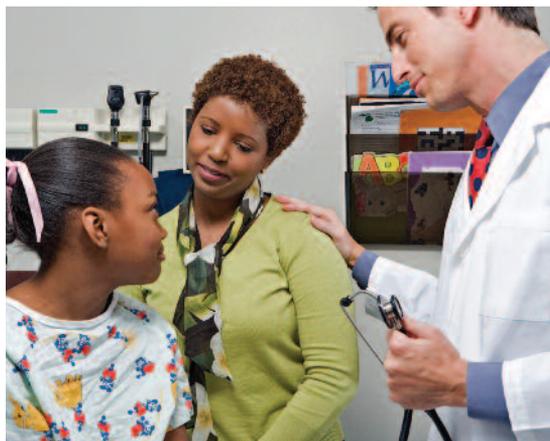
mobile app for iPhone® and Android™ (www.cdfa.org/gibuddy). Not only can you keep track of your child's symptoms, treatment, foods, and lifestyle factors, but also customize a daily treatment reminder and store notes for your next doctor's appointment.

- Place medications in locations where your child will be during that time of the day. For example, a medication that has to be taken in the morning and at night might be best stored in plain sight in the same bathroom where the child brushes his or her teeth.
- Load a multi-dose pillbox with medications each week so missed doses can easily be seen.

However, even with complete adherence, it is still possible to experience symptoms. When this happens, your child's physician should be notified so that the need for a change can be assessed. It is not unusual for a child to be prescribed different medications in response to an increase or decrease in symptoms or in response to an evidence-based change in a standard of care.

Nutritional support therapy

Optimal nutrition is a goal for well-being and development in all children, but in those with IBD, this may be difficult to achieve without intervention. Nutrition therapy may be as simple as regular visits with a nutritionist to ensure dietary goals are being met. The nutritionist may prescribe foods and liquid supplements that are higher in calories and protein. Because IBD, especially Crohn's disease, may improve with nutritional support, it may be necessary to deliver a nutrient-rich liquid formula directly into the stomach or small bowel. Known as *enteral nutrition*, this type of feeding is given overnight through a tube, most commonly from the nose to the stomach. This is called a *nasogastric (NG) tube*. This method ensures that patients receive nutrition while sleeping. In the morning,



they remove the tube and go to work or school and generally pursue their normal activities. In this way, patients receive all the nutrition they need and are free to eat normally—or not—throughout the day.

Enteral feedings can be taken by mouth or *gastrostomy tube (G-tube)*. A *gastrostomy* is a surgically created opening through the abdominal wall, leading directly into the stomach. The feeding tube is passed through this opening. The feedings are most commonly given overnight, but they can also be given intermittently throughout the day. Some patients prefer this approach because it avoids the discomfort of passing a tube down through the nose.

Total parenteral nutrition (TPN) is delivered through a catheter placed into a large blood vessel, usually one in the chest. Although it bypasses the intestine and thereby allows the bowel to rest, parenteral nutrition may create more complications than enteral nutrition. It is also more expensive than the other methods of nutritional support and requires more specialized training to use. TPN, however, is rarely used in pediatrics.

To find more information on nutritional support therapy, be sure to download the *Diet, Nutrition, and Inflammatory Bowel Disease* brochure at www.cdfa.org.

Surgery

No parent ever wants to have their child undergo surgery. In the treatment of IBD, all medical efforts are aimed at preserving the intestines, especially in children.

But there are circumstances when surgery is the best option or the only alternative. In fact, many Crohn's patients and a significant percentage of ulcerative colitis patients will reach a point where surgery is the best intervention.

The reasons for surgery include:

- unsuccessful medical control of the disease
- life-threatening colon conditions known as fulminant colitis and toxic megacolon
- fistulas and abscesses that are uncontrolled or not healed by medication
- strictures and obstructions, especially those caused by scar tissue
- perforation of the intestines
- colorectal cancer or risk of it

In ulcerative colitis, the condition is cured with the surgical removal of the colon and the lining of the remainder of the rectum, which is not the case in Crohn's disease. Even with the removal of the colon, some patients may experience extra-intestinal complications (symptoms outside the colon). There is no cure for Crohn's and the disease may reoccur at the site of the surgery. However, the patients usually feel much better after the diseased segment of intestines is removed and may be able to reduce their medications as a result. It is also important to note that newer, minimally invasive surgical techniques help patients to heal faster, allowing them to return to their normal activities more quickly.

To learn more about these surgeries, please download the brochure *Surgery for Crohn's Disease and Ulcerative Colitis* at www.cdfa.org.

Complementary & alternative medicine

Complementary and alternative medicine, or CAM, describes products or practices that are not part of evidence-based standards of care that are usually followed by doctors when they plan the treatment of a condition. While traditional, standard treatments are well researched for safety and efficacy, complementary and alternative treatments may not be. Therefore, if you are interested in exploring a complementary and alternative therapy for your child, bring it to the attention of your child's health-care provider.

To learn more about CAM, check out the fact sheet on *Complementary and Alternative Medicine* at www.cdfa.org.

Lifestyle modifications

With IBD, there may be some adjustments you need to help your child make, including altering his or her diet as necessary or preparing them for daily activities.

Diet and nutrition

Two things you should remain vigilant about are your child's weight and growth rates. Since weight loss is a symptom of a flare-up, any loss in weight should be reported to your child's physician. Similarly, growth may slow or cease during periods of disease activity. If your child's

growth seems to slow considerably (wears the same size clothing for more than a year, seems smaller than other children of the same age, etc.), bring this to the attention of the child's doctor.

Because IBD affects the digestive system, diet and nutrition are impacted in a variety of ways. Attention must be paid to avoiding foods that worsen or trigger disease symptoms. It is also important to help children learn how to make healthy food choices, replace nutritional deficiencies, and maintain a well-balanced nutrient-rich diet.

There is no evidence to suggest that any particular food or diet causes, prevents, or cures IBD. There is no one special IBD diet. Dietary recommendations are generally aimed at easing symptoms during flares and ensuring an overall adequate intake and absorption of nutrients, vitamins, and minerals.

Every child needs good nutrition to help him or her grow and develop. While most children with IBD require relatively little or no change in diet, there may be times when modifying the diet can be helpful, particularly when their disease is active. An altered diet may be recommended during different times by your child's physician.

To learn more about diet and nutrition, review *Diet, Nutrition, and Inflammatory Bowel Disease* at www.cdfa.org.

Vitamin and mineral supplementation

Some children with IBD may become deficient in certain vitamins and minerals (including vitamins D, B12, and C; folic acid; iron; calcium; zinc; and magnesium), and they may need to supplement their diet to make up for the deficiencies.

Vitamin D is essential for good bone formation and for processing calcium. It is recommended that children and adolescents with IBD be screened and monitored for vitamin deficiency. The recommended daily allowance for vitamin

D depends on age and ranges from 400–600 international units (IU) per day.

Vitamin B12 is absorbed in the ileum. Children and adolescents with Crohn's disease that affects the ileum and those who have had surgery to remove 20 inches or more of the ileum may have vitamin B12 deficiency because they are unable to absorb enough of this vitamin from their diet. A blood test can measure the amount of vitamin B12 in the blood. A monthly injection or weekly nasal spray of vitamin B12 may be required for individuals who are deficient.

Folic acid absorption may be affected by some drugs used to treat IBD, such as sulfasalazine and methotrexate. Patients who take these medications may require a folic acid supplement.

Calcium supplements are recommended for patients taking corticosteroid medication, those not getting enough calcium in their diet, and those who have reduced bone mineral density.

Your child's healthcare provider can determine if a deficiency is present and if supplements are needed.

Vaccinations

Your child should continue to see a pediatrician to help monitor their physical development and make sure they are up to date with vaccinations, including annual flu vaccines. Make sure this physician is fully informed about your child's medications, as children on immunosuppressive or biologic therapies should not receive live virus vaccines.

Daily activities

Now that your child has a disease that causes a greater reliance on the bathroom, you should plan for more bathroom breaks in any scheduled activities. You may also want to encourage your child to review bathroom locations in malls, playgrounds, movie theaters, or other regularly used areas outside of your home. Doing so can help your child feel more in control of their condition.

Some states have created laws that allow access to “employee only” restrooms in businesses open to the public. Call your local CCFA chapter to see if your state has passed the **Restroom Access Act**. If so, make sure your child has the required physician’s note describing your child’s need for immediate bathroom access any time he or she ventures out. During times of flare-ups, it may also help to pack a spare change of clothing and some moist wipes in a backpack for your child to carry.

School

Because children spend most of their waking hours in school, adults who tend to your child at school should be told about your child’s illness for several reasons, including:

- IBD may lead to frequent absences or hospitalizations, make-up work, and other educational needs.
- Children with IBD may have a greater reliance on bathrooms and thus need open bathroom passes or access.
- Certain medications may need to be taken during the school day.

Requesting a meeting with administrators and teachers to discuss the illness and your child’s needs is a proactive way of dealing with potential future issues caused by IBD. Download and share a copy of the brochure *A Guide for Teachers and Other School Personnel* with your child’s teacher (www.ccfa.org).

While informing the administrators and teachers about your child’s needs is necessary, your child may feel embarrassed about letting others know. Because it may be important to him or her, let your child decide with whom and when to share that information with others.

Access other related resources that may be helpful to your child at www.ccfa.org:

- *A Guide for Kids and Teenagers*
- *Pete Learns All About Crohn’s and Colitis* comic book
- *IBD & Me Activity Book* (for kids ages 8-12)

School accommodations

If your child is falling behind in school, or requires special accommodations to maintain their academic performance, he or she may benefit from a 504 plan or an individualized education program (IEP). Two federal laws, Section 504 of the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act, provide protection for public school students with disabilities. Although both laws apply to students with disabilities, not all students with disabilities qualify for the protections of both laws. Each law has specific eligibility requirements and guidelines for services.

- **504 Plan:** This comes from Section 504 of the Rehabilitation Act of 1973. This act requires recipients of federal education funding to provide children with disabilities appropriate educational services designed to meet the individual needs of such students, to the same extent as the needs of students without disabilities are met. A 504 plan spells out the modifications and accommodations that will be needed for these students to have an opportunity to perform at the same level as their peers, and might include such things as blood sugar monitoring, an extra set of textbooks, or home instruction. A Section 504 plan involves an evaluation of the child’s disability as well as his or her academic abilities and specific provisions to help the child reach his or her academic potential.

- **Individuals with Disabilities Education Act (IDEA):** First passed as the Education for all Handicapped Children Act in 1974 and most recently amended in 2004, the act governs how states and agencies provide certain educational services to children with disabilities, including children with health impairments like IBD. For students with disabilities who require specialized instruction, IDEA controls the procedural requirements. The IDEA process is more involved than that required under Section 504. One of the provisions of the act requires schools that receive public funding to create an IEP for each child covered by the plan, ensuring that the unique needs of the child are met in the least restrictive environment. The “individualized” part of IEP means that the plan has to be tailored specifically to your child’s special needs. IDEA covers children with disabilities from birth to age 21.

Informal (verbal arrangement with a teacher) and formal accommodations (items covered under a 504 plan or IEP) for a child may help them reach and maintain their academic potential. Accommodations should be requested as soon as possible, preferably in the beginning of the school year, so that there is time to make necessary arrangements and formalize plans. Remember: Even if your child is perfectly healthy at the start of a school year, they may need accommodations during the year. It is always best to plan ahead! Some potential accommodations include, but are not limited to:

- **Unlimited bathroom pass:** Students with active disease symptoms may need to use the bathroom many times per day—often urgently in order to avoid fecal incontinence. Student and teacher should work out an appropriate bathroom signal to help avoid drawing attention to the student’s frequent bathroom breaks.
- **“Stop the clock” testing:** When taking an exam, the student may need to take a break due to pain or bowel urgency. Their test time

will be extended by the amount of time that the student is away from the exam.

- **Ability to hydrate:** Frequent bowel movements and medication contribute to loss of fluids. Students should be allowed to carry and drink fluids throughout the day.
- **Supply bag:** Student will be permitted to eat small snacks and carry candy (to treat dry mouth), wet wipes, and other supplies throughout the day and use as needed.
- **Tests and project limits:** Medications and active disease symptoms may contribute to sleep deprivation and fatigue. As a result, the number of tests and projects can be limited to one to two per day. Test and project deadlines can also be extended without penalty.
- **Rest period:** School nurse will provide a location as needed for students to lie down, or a private place to change clothes.
- **School absence:** After a specified number of days absent from school, the student will receive in-home or hospital tutoring.
- **Alternate seating:** To accommodate easy access to classroom exits, the student’s seat may be changed.
- **Medications:** The student, parent, and nurse will meet to discuss and establish a medication schedule.
- **Tutoring and support:** If the student is absent for more than “x” days from school, he/she will have an opportunity to make up or get assistance with assignments. Students will be allowed to have an extra set of books at home.
- **Extra-curricular programs:** The student will be allowed to participate in programs and events without penalty due to absenteeism.



■ **Physical education class:** The student should be allowed to self-monitor his/her energy level to determine if he or she can participate in physical activities. The physical education teacher will notify their parents if there is ongoing non-participation in gym class.

To learn more about school accommodations, please contact CCFA's Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center) by email at info@ccfa.org, phone at (888) 694-8872, or online chat at www.ccfa.org.

Physical activities

Young people with IBD should be as active as possible. Outside of the physical benefits, including building stronger muscles and bones, these activities provide an outlet for stress and can help build confidence.

Generally, there is no reason not to participate in sports, dance, or other physical activities, even if the disease is flaring up. But some modifications may be necessary if strenuous activities cause fatigue or aggravate abdominal pain, arthritis, or other symptoms. You and your child should also be vigilant about maintaining proper hydration.

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 advisable.

Emotional health and social support

The diagnosis of a chronic illness can be a tough blow for anyone, but for children, it can be especially hard to bear.

Still developing a sense of themselves both emotionally and physically, young people now must face an extra hurdle of chronic illness, which can pose a threat to a child's sense of well-being and security.

As a result, children with IBD may become:

- anxious
- depressed
- clingy
- dependent
- agitated

It is important to remember that these reactions are a response to their disease, and not its cause.

Children with IBD may be more prone to subtle emotional problems, which may not always be reflected in school performance, but may require them to exert more effort/energy to keep up with academic and social demands. As a result, the

child may get fatigued more quickly, feel less efficient, and become overwhelmed, leading them to withdraw from school and friends. These symptoms will require careful monitoring from parents, teachers, and students to minimize the potential for undue distress.

The emotional support provided by healthcare professionals can go a long way toward reassuring your child. At times, a counselor or child psychologist may be helpful in enabling your child to regain the self-confidence that is sometimes affected by chronic illness. If it takes much more work for your child to get good grades, keep up with friends, enjoy things they used to, the child may benefit from educational and/or psychological interventions.

Children can also find peer support and education through a number of avenues, including:

- **Camp Oasis**—A CCFA-sponsored summer camp for children with Crohn’s disease or ulcerative colitis. Learn more at www.ccfa.org/kidsteens/camp.
- **CCFA Support Groups**—The best help, advice, and understanding will come from interacting with people who know what you or your child is going through from personal experience. Find support groups in your area by contacting your local CCFA chapter.
- **Just Like Me**—An online resource for teens with IBD containing age-appropriate disease information and resources (www.justlikemeibd.org)
- **Campus Connection**—A website for college students that provides resources for living and coping with IBD, as well as an opportunity to connect with others from campuses around the country (www.ccfa.org/campus-connection).

Stress is impossible to avoid in life. Since stressful situations can precipitate a flare-up in

some individuals, it might be helpful to teach your child techniques for coping with or relieving stress. By using these techniques, your child can stay calm, maintain perspective, and avoid anxiety. Encourage your child to try several different approaches and stick with ones that work for him or her. These can include:

- relaxation and breathing exercises
- practicing yoga or tai chi
- cognitive behavioral therapy
- meditation
- books, recordings, guided imagery, etc.

Realize that others in the family may also be suffering emotionally from the diagnosis. If there are other children in the family, they need to understand their sibling’s condition and the impact it’s likely to have on their lives. It’s important to reassure them that you still love them and want to be as involved in their lives as you’ve always been, although you may have to devote more time to the child who is ill.

You, your child, and the rest of the family may find comfort and support by participating in educational, social, and fundraising activities sponsored by your CCFA chapter. Annual walks, Camp Oasis, educational seminars, and fundraising events build a sense of community among those diagnosed with the disease and those who love them. To find out what is happening in your chapter, go to www.ccfa.org/chapters.

Transitioning to independence and adult care

Depending on your child’s age and level of maturity, he/she may need more or less support with self-management related to his/her IBD. However, the earlier you help teach your child how to manage IBD, the easier it will be for them to transition to independence as an adolescent and young adult.

In order to achieve independence, self-management plans can be used to teach your child to complete tasks on their own by taking an active role in planning, organizing, and monitoring his/her own behavior with the ultimate goal of self-reliance. Self-management strategies can be used to improve academic performance, productivity, and medication adherence, and to decrease negative feelings. The critical elements of self-management include setting goals, monitoring behavior, and evaluating progress.

Building behavior, cognitive, organizational, problem-solving, follow-through, and other skills and self-management strategies will require that parents and healthcare providers work together to specifically teach the child—from understanding their condition and knowing their medications, to making their own appointments and more general self-advocacy.

Below are some examples for IBD-related self-management tasks appropriate for different developmental stages:

- 10–13 years: Knows about IBD, is able to name current medications, doses, and side effects, knows how and when to take meds, understands and is able to talk about impact of IBD on school/life, can articulate feelings, and starts becoming more aware of own learning style
- 14–16 years: Able to identify medical team, knows medical history, procedures and tests, school and community supports, understands risk of treatment non-adherence, drugs, and alcohol
- 17–19 years: Knows how to get IBD information, makes own appointments, contacts providers, refills prescriptions, knows insurance coverage, plans for medical, educational, and social supports needed in college

- 20–23 years: Contacts and visits adult GI provider, and manages medical, psychological, and work/college needs with high degree of independence

Living life

It may be difficult and stressful for your child to accept that he or she has Crohn's disease or ulcerative colitis.

As time goes on, this will not always be the case. In the meantime, try not to hide your child's condition from family, friends, and co-workers. Discuss it with them and let them help and support you and your family. You'll learn that there are numerous strategies that can make living with IBD easier.

Coping techniques for dealing with the disease may take many forms. For example, attacks of diarrhea or abdominal pain may make your child fearful of being in public places. But that isn't necessary. All it takes is some practical advanced planning. You may want to help your child incorporate some of the following steps into his or her plans:

- Find out where the restrooms are in restaurants, public parks, theaters, and on public transportation.
- Carry extra underclothing and toilet paper or moist wipes when traveling. When venturing farther away or for longer periods of time, speak with your child's doctor first. Travel plans should include a long-term supply of medication, its generic name in case your child runs out or loses it, and the names of doctors in the area he or she will be visiting.

- Encourage your child to go about his or her daily life as normally as possible, pursuing activities as they did before their diagnosis. There's no reason for your child to sit out on things that he or she has always enjoyed or has dreamed of doing one day.
- Help your child learn coping strategies from friends and other supportive individuals. Your local CCFA chapter offers support groups as well as informational meetings. It helps your child and you to share what you know with others, too.
- Develop a support network of family and friends to help you and your child manage the disease. Bring a family member or friend to your child's doctor's appointment for support.
- Join CCFA's free online community at www.ccfacommunity.org to get the support you need through participation in discussion boards, personal stories, chat rooms, and much more.
- Make sure your child follows his or her doctor's instructions about taking medication. Even when he or she is feeling perfectly well, your child should continue to take their medication.
- Maintain a positive outlook. That's the basic—and best—prescription!

While Crohn's disease and ulcerative colitis are serious chronic diseases, *they will not affect the life span of your child*. There's no doubt that living with IBD is challenging—your child will have to take medication and, occasionally, make other adjustments. It's important to remember that most people with Crohn's disease and ulcerative colitis are able to lead rich and productive lives. Remember, too, that taking maintenance medication can help your child to maintain remission of disease activity and symptoms, allowing them to experience normal growth and development.

Hope for the future

Investigators all over the world are devoted to research to find the causes and cure for Crohn's disease and ulcerative colitis.

That's good news when it comes to the development of new therapies for these diseases. It is a very exciting time in the development of new therapies. With many experimental treatments for IBD in clinical trials, experts predict that a wave of new therapies for IBD is on the way.

With an ever-increasing number of clinical trials, there is an even greater need for patient participation to see if these experimental therapies work. To locate clinical trials in your area, go to CCFA's Web site at www.ccfca.org/trials/ or call **888.MY.GUT.PAIN** (888-694-8872).

Your child can also take part in finding a cure through CCFA Partners: Kids & Teens Program. This program is designed to improve the quality of life for those with IBD through research and education. To learn more about CCFA Partners: Kids & Teens Program, visit www.ccfapartners.org.

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