



**CROHN'S
& COLITIS**
FOUNDATION

Crohn's Disease & Ulcerative Colitis:

A Guide for Parents and
Pediatric Caregivers



What's Inside

| | |
|--|----|
| IBD: The basics | 2 |
| Signs and symptoms | 3 |
| Beyond the intestines..... | 3 |
| Causes of IBD | 4 |
| Diagnosis | 5 |
| Treatment | 8 |
| Prescription medication | 9 |
| Over-the-counter (OTC) medications | 12 |
| Medication changes and adherence..... | 13 |
| Nutritional support therapy | 14 |
| Surgery | 16 |
| Complementary medicine | 16 |
| Other considerations | 17 |
| Diet and nutrition..... | 17 |
| Vitamin and mineral supplementation..... | 18 |
| Vaccinations | 19 |
| Daily activities..... | 19 |
| School accommodations..... | 20 |
| Physical activities..... | 24 |
| Emotional health and social support | 25 |
| Transitioning to independence and adult care..... | 28 |
| Living your life | 29 |
| Hope for the future | 31 |
| Knowledge and support are power! | 32 |
| Glossary of terms | 36 |



You recently learned that your child has **Crohn's disease** or **ulcerative colitis**. As a parent or a caregiver of a child with **inflammatory bowel disease (IBD)**, you are now taking an important step: learning about these illnesses, how they're treated, and how you can help your child learn to live with their disease.

The purpose of this brochure is to start you on that educational path—to walk you through some key points about Crohn's disease and ulcerative colitis and what you may expect. The more you know, the better you'll be able to advocate for your child. Most importantly, you'll be armed with the knowledge and resources to be an active member of your child's healthcare team.

.....

The Crohn's & Colitis Foundation provides this information for educational purposes only, which is current as of the print date. We encourage you to review this educational material with your healthcare professional, as this information should not replace the recommendations and advice of your doctor. The Foundation does not provide medical or other healthcare opinions or services. The inclusion of another organization's resources or referral to another organization does not represent an endorsement of a particular individual, group, company, or product.

IBD: The basics

Doctors and scientists are working hard to find the causes and cures for Crohn's disease and ulcerative colitis. Despite the challenges of living with a **chronic** illness, your child can have a happy, productive life. While there are not yet cures for these diseases, appropriate treatment can control the chronic **inflammation** that is a hallmark of IBD. This can help achieve long-term treatment goals, including elimination of chronic **gastrointestinal (GI)** symptoms, restoration of growth, and improved quality of life.

Crohn's disease and ulcerative colitis are the two most common types of IBD. While these conditions produce similar symptoms and may be treated with similar therapies, they are not the same.

Crohn's disease may affect any part of the **GI tract**, from the mouth to the **anus**. Unlike ulcerative colitis, Crohn's can skip large segments of **bowel** before reappearing in others. The areas most often affected are the lower part of the **small intestine (ileum)** and the **large intestine (colon)**. In Crohn's patients, the inflammation does not stop at the mucosa (tissue lining) and may affect all layers of the bowel wall.

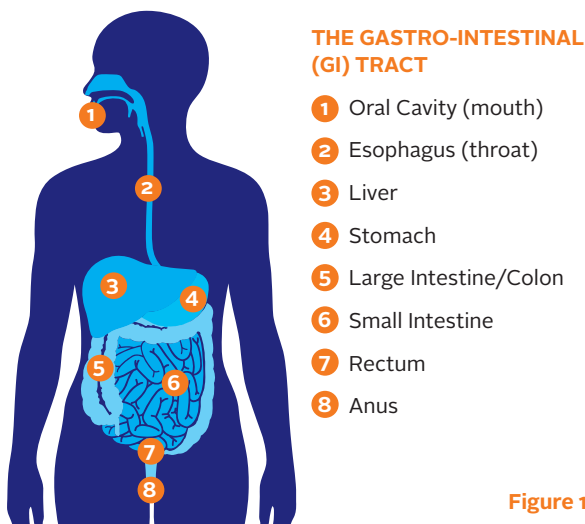



Figure 1



In ulcerative colitis, only the colon and **rectum** are affected, and 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.

Signs and symptoms

Despite the differences between Crohn's disease and ulcerative colitis, both cause similar symptoms. Patients may have one or more symptoms, including:


- persistent **diarrhea**
- abdominal pain and/or cramps
- urgent bowel movements
- intestinal bleeding
- fever
- weight loss

Beyond the intestines

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

In some people, extraintestinal manifestations may be the first signs of IBD, appearing even years before the bowel symptoms. In others,



they may occur right before a **flare-up** of the disease.

While most symptoms are the same in children and adults, children may additionally be affected by a delay in growth and **puberty**. In fact, a significant number of pediatric IBD patients are diagnosed after reporting growth delays. This primarily affects Crohn's patients because of 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 symptoms can vary significantly from patient to patient. Because Crohn's disease and ulcerative colitis are chronic diseases, patients will go through periods where the disease flares up and causes symptoms. In between flares, people may experience no distress at all. These symptom-free periods (known as **remission**) can span months or even years, although symptoms typically do return at some point.

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

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

Causes of IBD

No one knows for sure what causes Crohn's disease or ulcerative colitis. Most experts believe there may be several factors that contribute to the development of these diseases, including:

- **Genetics**—Researchers have discovered that IBD tends to run in families. In fact, data from recent studies demonstrate that the risk for developing IBD is between 1.5 and 28 percent


for first-degree relatives (i.e., parents, children, siblings) of a patient with IBD.¹ More than 200 genes have now been associated with IBD, though their exact role is still under investigation. It's likely that a person inherits one or more genes that make him or her more susceptible to Crohn's disease. These genes then lead to an abnormal immune response to some environmental triggers. Scientists have not yet identified specific triggers but the bacteria in the intestine, part of our **microbiome**, are a leading candidate.

- **Environmental elements**—Environmental factors likely play a role. In a genetically susceptible individual, whatever the trigger is, it prompts the person's **immune system** to “turn on” and launch an attack in the GI tract. That is when the inflammation begins.
- **Inappropriate immune response**—Scientists continue to study whether defective signaling in a patient's immune system may result in an individual's immune system attacking their own GI tract.

Though there is a lot that we don't fully understand about IBD, existing data has helped us to resolve some early concerns. We now know that there is no data to support the idea that tension, anxiety, or personality traits *cause* IBD. In addition, we know that these diseases are not contagious (like a cold or flu).

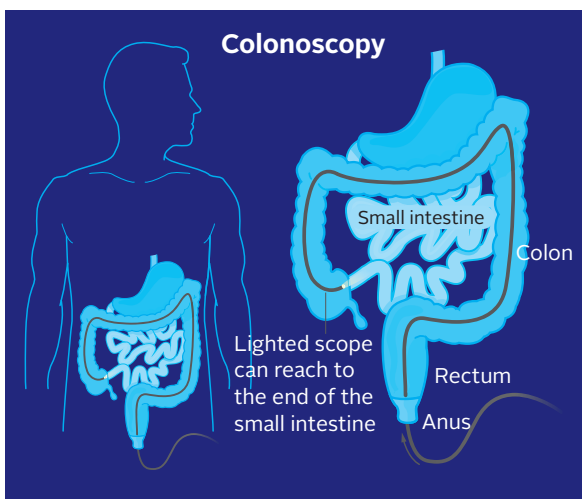
Diagnosis

Your child was diagnosed with Crohn's disease or ulcerative colitis after completing an extended evaluation that likely included obtaining a thorough medical history; completion of a physical examination; laboratory studies, including blood testing; radiology studies; and an **endoscopic** evaluation of the upper and lower GI tract.



Physicians generally begin by prescribing the least invasive tests, and may progress to more thorough testing until a diagnosis is obtained. Tests include:


- **Stool tests** to exclude infection or detect inflammation (fecal calprotectin or lactoferrin).
- **Blood tests** to check for a low red blood cell count (anemia) or high white blood cell count (suggestive of infection or inflammation). Blood tests may also detect the presence of abnormal antibodies and/or nutritional and vitamin deficiencies.
- **Radiology studies** to determine the extent of disease. Barium x-rays, CT scans, and MRI studies visualize areas of the small intestine that are out of reach of standard endoscopes (see next bullet). During a barium small bowel series, or CT scan, your child swallows a chalky liquid containing barium (or a similar material that coats the upper intestinal tract). Areas of swelling, narrowing, or other signs of intestinal inflammation can be identified with these imaging techniques. MRI studies typically use clear liquid contrast instead of barium. MRI studies provide great information without the need for radiation. However, this study requires patients to lie still for 45-60 minutes, and this can be difficult for some children. The goal will always be to limit your child's lifetime exposure to diagnostic radiation.
- **Endoscopy** is a test that involves inserting a lighted viewing tube/telescope 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 can later be examined microscopically to assess for signs of allergy, infection, or inflammation. Another type of endoscopy, called wireless capsule or 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 then excreted in the child's stool. As with all tests and procedures, there are rare risks involved that should be discussed with your child's doctor.

Patients with Crohn's disease and ulcerative colitis can present with symptoms observed in other common GI conditions, including irritable bowel syndrome (IBS). Like IBD, patients with IBS may experience symptoms including abdominal pain and diarrhea. However, it is believed that IBS does not involve inflammation of the lining of the small and large intestine. Instead, IBS is thought of as a functional bowel disorder in which the muscles of the intestines react improperly, either moving the bowel contents too quickly or too slowly.

In some individuals, it can be difficult to determine whether the symptoms and inflammation observed in patients with IBD are the result of Crohn's disease or ulcerative colitis, even after extensive testing. In these cases, some patients are given a diagnosis of "indeterminate colitis."



Disease overlap is more common in the youngest patients (those under six years old at the time of diagnosis).

Very early onset IBD (VEO-IBD) is defined as IBD that occurs in children less than six years of age. Within this group of patients is a subset with infantile IBD, which is IBD that develops in children less than two years of age. Children with VEO-IBD often have severe symptoms that do not respond to standard treatments. Many children with VEO-IBD have a strong family history of IBD. Some also have underlying immunodeficiencies, which can impact therapy. Researchers are working to identify causes and treatment options for VEO-IBD to improve quality of life for patients.

For further information about diagnosing Crohn's disease and ulcerative colitis, please read our brochure "Diagnosing and Monitoring IBD", available at www.crohnscolitisfoundation.org.

Treatment

Because Crohn's disease and ulcerative colitis are chronic, meaning that they are lasting inflammatory diseases that will present with increasing and decreasing symptoms, the goal of treatment is to relieve a patient's symptoms to improve overall quality of life, achieve and maintain clinical remission, and to prevent complications of the disease.


There is no "one size fits all" treatment for IBD. Because each person with IBD is different, the treatment used to control their illness is unique. Doctors typically work to customize an individual's treatment plan, based on the type and severity of symptoms. There are effective treatments available that may help control your child's IBD.

Prescription medication

It is important to understand that just as the disease impacts each patient differently, there may be a need to change medication regimens over the course of an individual patient's disease. For example, a patient may have few symptoms and may respond well to low-dose drug therapy during one flare, but may require different, and stronger, medications during a more severe or prolonged flare.

There are different categories of treatments used in the management of patients with IBD. These include:

- **Aminosalicylates:** These aspirin-like compounds contain 5-aminosalicylic acid (5-ASA) and are used to treat mild-to-moderate active disease or to maintain disease remission. These drugs can be given either orally or rectally. They reduce inflammation in the intestine, similar to the manner in which aspirin works against inflammation in other parts of the body such as the joints (arthritis). Aminosalicylates do not suppress the immune system. Possible side effects of aminosalicylate therapy include diarrhea, headaches, and nausea.
- **Corticosteroids:** Potent anti-inflammatories, these medications work to keep a patient's immune system in check. Corticosteroids are used for children with moderate-to-severe IBD. Administered orally, rectally, or intravenously, steroids are effective for short-term management of flare-ups, helping to bring the disease under control. However, they are not recommended for longer-term treatment to maintain remission in children due to their potential unwanted side effects—particularly at higher doses and longer duration—including, weight gain, sleep problems, mood swings, cognitive and memory changes, osteoporosis, scalp hair loss or facial hair growth, acne, stretch marks, increased susceptibility of infection and bruising, and stunted growth.



To minimize the chance of osteoporosis, adequate calcium and vitamin D intake is essential. Once remission is achieved, corticosteroid dosage is tapered gradually. When patients are tapered off of corticosteroids, a strict schedule should be followed in order to minimize side effects that can occur if patients are weaned off too quickly.

- **Immunomodulators:** This class of medications modifies the body's immune system so that it cannot contribute to ongoing inflammation. The approach to use of immunomodulators as a treatment in children can vary. Usually given orally, immunomodulators may often be prescribed as a combination therapy with biologics. They may also be used when aminosalicylates and corticosteroids haven't been effective, or only partially effective. This medication class can be useful in reducing or eliminating dependency on corticosteroids, and maintaining remission. All patients on immunomodulators need to be monitored closely for side effects, such as nausea, a decrease in white and red blood cell counts, as well as inflammation of the pancreas (pancreatitis) or liver (hepatitis). There is an increased susceptibility to infection, and particularly less common infections, in patients being treated with these medications. Also, there is a small but increased risk of developing certain cancers, including nonmelanoma skin cancers and lymphoma.
- **Antibiotics:** Antibiotics may be used when infections—such as an **abscess** (pocket of pus)—occur. They treat Crohn's disease, **perianal** Crohn's disease, and ulcerative colitis. They are also used to treat **pouchitis**, which is an inflammation of the ileal pouch (also known as a j-pouch, a surgically constructed internal pouch for those who have had their large intestine removed), and for prevention of recurrent Crohn's disease after surgery.

- **Biologic therapies:** Biologic therapies are commonly used in the treatment of pediatric IBD. Biologics are protein-based therapies made from living organisms, either human or animal. These medications are antibodies that stop certain proteins in the body from causing inflammation. These therapies are used to control moderate-to-severe disease and to maintain clinical remission. Biologics are typically administered by injection or intravenous infusion on a schedule that varies from weekly to every few months, depending on the individual and the medication. There are also biologic medications known as biosimilars. Biosimilars are designed to be structurally similar and near identical copies of other already approved biologic therapies, also known as the originator drugs. Biosimilars have the same effectiveness and safety profile as the originator drug. Some biologic agents are particularly useful for one form of IBD, and others can be used in patients with either Crohn's disease or ulcerative colitis.
- **Janus kinase inhibitors (JAK Inhibitors):** These medications, currently available as tablets, are broken down in the gastrointestinal tract after ingestion and are directly absorbed into the bloodstream via the intestinal wall. Due to the small size of these chemically active substances, they can be transported through the bloodstream to nearly any site in the body, including the immune system. Unlike some of the other tablet-based agents like thiopurines and methotrexate, these agents work more quickly and can induce and maintain remission. Tofacitinib is the first JAK inhibitor approved to treat ulcerative colitis.
- **Off-Label:** Sometimes doctors will prescribe medications that the Food and Drug Administration (FDA) has not specifically approved for the treatment of Crohn's or ulcerative colitis, or may not be specifically approved in children. Nonetheless, these medications have been shown to be very effective in

reducing symptoms. Prescribing medications for other than FDA-approved conditions is known as “off-label” use. Your healthcare provider may have to obtain prior approval from insurance companies before prescribing a medication for off-label use. Your health care team might need to make a special appeal in order for an insurance company to pay for an off-label medication.

Over-the-counter (OTC) medications

Prescription medications reduce intestinal inflammation and form the core of IBD treatment. As such, prescription medications may not eliminate all of your child’s symptoms. You may want your child to take over-the-counter medications in an effort to make them feel better. Before doing so, please speak with your child’s doctor, or other healthcare 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 and discuss any concerns with your child’s doctor.

There are many therapies currently under investigation. For a current up-to-date list of all FDA-approved medications for IBD, please visit the Foundation’s online IBD Medication guide: www.ibdmedicationguide.org.



Additional information is available in our Understanding IBD Medications and Side Effects brochure.

Medication changes and adherence

Your child's Crohn's disease or ulcerative colitis can be controlled with the right treatment. You should have an open dialogue with your child's healthcare provider and inform them if your child is still experiencing IBD symptoms while in treatment. During these discussions, you should feel comfortable asking the doctor about other available treatment options.

Keep in mind that medications are most effective when they are taken as prescribed by your child's doctor.

Adherence means that your child is following the medical advice of the physician with regard to:

- Taking prescribed medication, vitamins, and supplements in the proper doses and at the proper times
- Returning for scheduled medical appointments

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

- Check out the applications available on your mobile device that can help to track symptoms, diet, and fitness goals. Many of these apps have the option to add notes alongside entries, which can help track and manage your symptoms or triggers. You can also go off-line and track various aspects of your disease in a daily journal.
- 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 their teeth.

- Load a multi-dose pillbox with medications each week so missed doses can easily be seen.

It is still possible to experience symptoms even with complete adherence. Your child's physician should be notified if this happens, so that they can consider whether or not this should trigger a change in therapy (agent, dose, or dosing interval). 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 necessary to ensure optimal growth and development in all children. However, this may be difficult to achieve without intervention. In some cases, patients benefit from regular visits with a nutritionist to ensure that dietary goals are being met. In cases in which children with IBD are manifesting poor weight gain or linear growth (getting taller), the nutritionist may prescribe specific foods and liquid supplements that are higher in calories and protein.

Intestinal inflammation in patients with IBD, and particularly those with Crohn's disease, may improve with nutritional support. This may require the delivery of a nutrient-rich liquid formula directly into the stomach or small bowel (known as **enteral nutrition**). This type of nutritional support is typically given overnight and delivered through a nasogastric (NG) tube. This method ensures that patients receive adequate nutrition over the course of the day with the least amount of effort and stress (both for the patient and the parents). In the morning, the NG tube is removed, and the patient can go to school and pursue their usual activities.

If it is anticipated that enteral feedings will be required over a more prolonged period, and the

Parenteral and Enteral Nutrition

PARENTERAL NUTRITION

Feeding intravenously, bypassing the usual process of eating and digestion.

A Feeding through the central vein

B Feeding through peripheral veins

ENTERAL NUTRITION

Liquid supplemental nutrition is either taken by mouth or is given via a feeding tube.

Nasal or oral feeding tube terminates at, either:

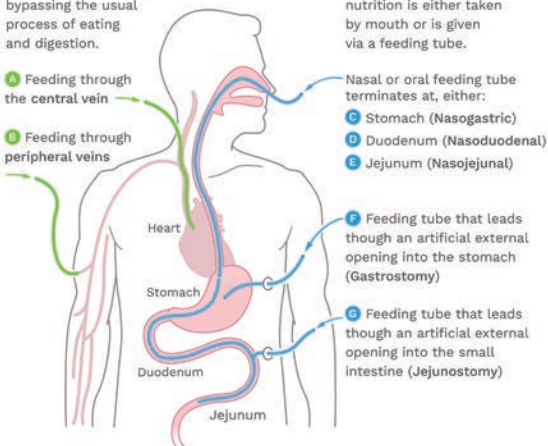
C Stomach (Nasogastric)

D Duodenum (Nasoduodenal)

E Jejunum (Nasojejunal)

F Feeding tube that leads through an artificial external opening into the stomach (Gastrostomy)

G Feeding tube that leads through an artificial external opening into the small intestine (Jejunostomy)



idea of placing an NG tube every night causes increasing inconvenience or discomfort, patients can undergo placement of a gastrostomy tube (G-tube). A gastrostomy is a surgically created opening through the abdominal wall, leading directly into the stomach. A feeding tube can be passed through this opening. Feedings can be delivered overnight through the gastrostomy. However, because there is no need to insert a tube, patients with IBD can also receive enteral nutrition intermittently throughout the day.

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

To find more information on nutritional support therapy, download the Diet, Nutrition, and Inflammatory Bowel Disease brochure.

Surgery

In the treatment of IBD, all medical efforts are aimed at sustaining the health of the intestines, especially in children. However, some patients may reach a point where surgery is the best option, or may be necessary.

In Crohn's disease, surgery may involve removal of the diseased area of the bowel (called a resection), but the disease may reoccur at the site of the surgery or other area along the gastrointestinal tract.

In ulcerative colitis, surgery may be recommended to remove all or part of the colon, which may also involve removal of the rectum. After surgery, some patients may experience extraintestinal complications (symptoms outside the colon).

While in some situations patients and their loved ones are able to decide whether surgery is the right choice for them, there may also be urgent situations that require more immediate surgery. As with all procedures there may be risks involved, new diet recommendations, or other changes to daily activities that your child may need to adjust to.

To learn more about the different types of surgeries, download the [Surgery for Crohn's Disease and Ulcerative Colitis](#) brochure.

Complementary medicine

Some people living with Crohn's disease and ulcerative colitis look toward complementary medicine, also known as complementary and alternative medicine (CAM) to use together with conventional therapies to help ease their symptoms. Complementary therapies may work in a variety of ways. They may help control symptoms and ease pain, enhance feelings of well-being and quality of life, and possibly boost the immune system. If you are interested in ex-

ploring a complementary therapy for your child, discuss it with your child's healthcare provider.

To learn more about complementary medicine, check out the Complementary and Alternative Medicine fact sheet at www.crohnscolitisfoundation.org.

Other considerations


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

Diet and nutrition

Paying attention to diet may help reduce symptoms, replace lost nutrients, and promote healing. 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 (they wear 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 your child's doctor.

Because IBD affects the digestive system, diet and nutrition are impacted in a variety of ways. There is no evidence to suggest that any particular food or diet causes, prevents, or cures IBD. There is no single diet or eating plan that will work for everyone with IBD. 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, address nutritional deficiencies, and maintain a well-balanced, nutrient-rich diet.

Every child needs good nutrition to help them grow and develop. While many 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 the Diet, Nutrition, and Inflammatory Bowel Disease brochure, videos, and more at www.crohnscolitisfoundation.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 his or her 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.

To learn more about healthcare maintenance for your child, download our healthcare maintenance discussion guide.

Daily activities

Now that your child has a disease that causes a greater reliance on the bathroom and other symptoms that may impact function, you should plan for more 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 visited 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. Contact your local Crohn's & Colitis Foundation chapter to see if your state has passed the Restroom Access Act. If so, make sure your child has the required documentation describing their 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.

Find a Crohn's & Colitis Chapter and get more information about the Restroom Access Act at www.crohnscolitisfoundation.org/chapters.

School accommodations

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 Guide for Teachers and Other School Personnel brochure with your child's school.

While informing school 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 them, let your child decide with whom and when to share that information.


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

- *A Guide for Kids and Teenagers*
- *Pete Learns All About Crohn's and Colitis comic book*
- *IBD & Me Activity Book*



If your child is falling behind in school, or requires special accommodations to maintain academic performance, a 504 Accommodations Plan or an Individualized Education Program (IEP) can help. 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 Accommodations Plan:** Also known as the “504 Plan,” this law 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




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 full 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 an 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 an IEP) for a child may help them reach and maintain their academic potential. Accommodations should be requested as soon as possible, preferably before the school year begins, 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.



The 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. 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 or 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 their energy level to determine if they can participate in physical activities. The physical education teacher will notify the student's parents if there is ongoing non-participation in gym class.

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

Physical activities

Young people with IBD should be as active as possible. Outside of the physical benefits that include 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. 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.






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 difficult for anyone, but for children, it can be especially challenging to process and accept. Still developing 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
- Frustrated
- Stressed
- 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, they may get fatigued more quickly, feel less efficient, and become overwhelmed, leading them to withdraw from school and friends. These symptoms require careful monitoring from parents, teachers, and students to minimize the potential for undue distress.

At times, a counselor or child psychologist may be helpful in enabling your child to regain the self-confidence that is sometimes impacted by chronic illness. If it takes much more work for your child to get good grades, keep up with friends, or enjoy things they used to, your 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**—This Crohn’s & Colitis Foundation-sponsored summer camp for children with Crohn’s disease or ulcerative colitis. Learn more at www.crohnscolitisfoundation.org.
- **Support**—Support groups can be especially helpful. 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 Foundation chapter.
- **Justlikemeibd.org**—A website for teens.
- **Campus Connection**—Your child can find tips for adjusting to their new environment in college and can connect to our online community through Facebook with other students who also are affected by IBD at www.crohnscolitisfoundation.org.



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 the diagnosis may also have an emotional impact on others in the family. If there are other children in the family, they need to understand their sibling's condition and how it may impact 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.

Your family may find comfort and support by participating in educational, social, and fund-raising activities sponsored by your Crohn's & Colitis Foundation chapter. Annual walks, Camp Oasis, educational seminars, and fund-raising 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.crohnscolitisfoundation.org.

Transitioning to independence and adult care

Depending on your child's age and level of maturity, they may need more or less support with self-management of IBD. However, the earlier you help your child learn how to manage and take ownership of their IBD, the easier it will be for them to transition to independence as a young adult.

In order to achieve independence, self-management plans can be used to teach your child to complete tasks on his or her own by taking an active role in planning, organizing, and monitoring their own behavior. Self-management strategies can be used to improve academic performance, productivity, and medication adherence, and to decrease negative feelings. The key components 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 requires that parents and healthcare providers work together to teach the child—from understanding his or her condition and knowing medications, to making his or her own appointments and more general self-advocacy.

Some important skills your child should start working toward building include:

- Describing their disease
- Naming their medication, doses, and side effects
- Taking medications independently
- Understanding risk of treatment non-adherence

- Knowing why medical tests are done
- Understanding the impact that drugs and alcohol can have on their body
- Voicing needs at school
- Asking questions and talking directly to doctors during appointments, without parents' help
- Knowing their medical team and how to reach them
- Knowing their health insurance information


Every child is unique and learns these skills at their own pace. Encourage your child to practice these skills as early as possible, and to ask for help and support when needed.

Children and teens can visit www.ibdskillsquiz.org to take a short quiz on managing IBD.

Living your life

It may be difficult and stressful for your child to accept that they have 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 people close to you. Discuss it with them and help them understand what kind of support you need.





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 as needed.
- 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 that will be visited.
- Encourage your child to go about daily life as normally as possible, pursuing activities as they did before diagnosis. There's no reason for your child to sit out on things that they have always enjoyed, or have dreamed of doing one day.
- Help your child learn coping strategies from friends and other supportive individuals. Your local Crohn's & Colitis Foundation chapter offers support groups, as well as informational meetings. This can allow you and your child to help others by sharing what you know, 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 the Crohn's & Colitis Foundation's free online community www.crohnscolitiscommunity.org to get the support you need through participation in discussion boards, personal stories, chat rooms, and much more.
- Make sure your child follows the doctor's instructions about taking medication. Even when your child 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, it's important to remember that most people with Crohn's disease and ulcerative colitis can lead rich and productive lives. There's no doubt that living with IBD is challenging—your child will have to take medication and, occasionally, make other adjustments. 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, visit the Crohn's & Colitis Foundation's clinical trials community website at www.crohnscolitisfoundation.org.

Your child can also take part in finding a cure through the Crohn's & Colitis Foundation's IBD 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 the program, visit cgibd.med.unc.edu/ccfapartners/index.php.

Knowledge and support are power!

Find the answers you need to help control your child's Crohn's disease by joining the Crohn's & Colitis Foundation:

- **Local Education and Support Programs**
To find programs, support groups and events in your area, go online to www.crohnscolitisfoundation.org to find your local chapter.
- **Power of Two**
The Foundation's Power of Two peer-to-peer support program allows patients seeking guidance on a specific issue to speak with a peer from within the IBD community who has traveled a similar path or has had a similar experience. To find out more, contact powerof2@crohnscolitisfoundation.org.
- **Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center)**
The IBD Help Center is a free service designed to provide you with disease-specific information, guidance and support. Our Information Specialists can be reached by calling 888-MY-GUT-PAIN (888-694-8872) Monday through

Friday, 9 a.m. to 5 p.m. Eastern Time, or by emailing info@crohnscolitisfoundation.org.

- **Crohn's & Colitis Community**

The Foundation hosts a free website where you can get the support you need. You'll participate in discussion boards, share or read personal stories, and much more. The Crohn's & Colitis Community is waiting for people just like you. Join today at www.crohnscolitiscommunity.org.

- **I'll Be Determined**

I'll Be Determined is an interactive patient journey website where you can learn more about Crohn's disease and ulcerative colitis. We offer tools and resources, the perspectives of IBD patients and experts, and a chance to connect with people like you www.ibdetermined.org.



- **Camp Oasis**

The Crohn's & Colitis Foundation Camp Oasis is a co-ed residential camp program. Its mission is to enrich the lives of children with IBD by providing a safe and supportive camp community. For more information, visit www.crohnscolitisfoundation.org or contact the IBD Help Center.

• **Membership**

By joining the Crohn's & Colitis Foundation, you'll get:

- Under the Microscope, our newsletter with research updates
- News, educational programs and supportive services from your local chapter
- An "I can't wait" card (provides help with public restroom access)
- To contribute to research to find a cure for these challenging diseases

The Crohn's & Colitis Foundation sponsors specific major events to increase awareness and raise funds to find a cure for Crohn's disease and ulcerative colitis. Below are just some of these events. Contact your local chapter or visit www.crohnscolitisfoundation.org to find an event nearest you.



• **spin4 crohn's & colitis cures**

Use your #power2cure in an exciting new way to connect with the IBD community— participate in a high-energy spin4 crohn's & colitis cures event near you! With inspirational instructors and fun playlists to keep you motivated, these indoor cycling relays are truly a #partyonabike. Teams of up to four

people each ride for a 30-minute session, and every teammate receives plenty of swag! The events generate awareness of Crohn's disease and ulcerative colitis, and raise funds to support groundbreaking IBD research and patient services. Learn more at www.spin4.org.

- **Take Steps for Crohn's & Colitis**

Take Steps for Crohn's & Colitis is the Crohn's & Colitis Foundation's national walk program. Take Steps enables patients and families to raise money for crucial research and to build awareness about Crohn's disease and ulcerative colitis. Visit www.cctakesteps.org for more information.



- **Team Challenge**

Team Challenge is the Foundation's endurance training and fundraising program. With options including running, walking, triathlon, cycling, and hiking, there are unlimited ways to challenge yourself while raising vital funds to cure these diseases. Each of our training programs are created by expert coaches to suit all experience levels, and you'll be joined by a supportive community of teammates who share the common goal of ending Crohn's and colitis. For more information on our destination events, or to participate in your own event through our Race In Orange program, visit www.ccteamchallenge.org.

Glossary of terms

Abscess: A collection of pus from infection.

Aminosalicylates: Medications that include compounds containing 5-aminosalicylic acid (5-ASA).

Antibiotics: Drugs that may be used when infections occur.

Anus: Opening at the end of the rectum that allows solid waste to be eliminated.

Biologic therapies: Antibodies that bind with specific proteins to block inflammation.

Bowel: Another name for the intestine. The small bowel and the large bowel are the small intestine and large intestine, respectively.

Chronic: Long-lasting or long-term.

Colitis: Inflammation of the large intestine (the colon).

Colon: The large intestine.

Complementary & Alternative Medicine (CAM): A group of diverse medical and health-care systems, practices, and products that are not generally considered part of conventional medicine.²

Corticosteroids: These medications affect the body's ability to begin and maintain an inflammatory process.

Crohn's disease: A chronic inflammatory bowel disease that primarily involves the small and large intestine, but can affect other parts of the digestive tract as well. Named for Dr. Burrill Crohn, the American gastroenterologist who first described the disease in 1932.

Diarrhea: Passage of excessively frequent or excessively liquid stools.

Endoscopy: Visual inspection of the internal organs using a tubular camera scope.

Enteral nutrition: Form of nutrition that is delivered through a feeding tube that is inserted directly into the stomach or small intestine.

Extraintestinal manifestations: Complications that occur outside of the intestine.


Fissure: A crack in the skin, usually in the area of the anus in Crohn's disease.

Fistula: An abnormal connection occurring between two loops of intestine or between the intestine and another nearby structure (such as the bladder, vagina, or skin).

Flare or flare-up: Bouts or attacks of inflammation with associated symptoms.

Gastroenterologist: A doctor who specializes in problems of the gastrointestinal tract.





Gastrointestinal (GI) tract: Referring collectively to the esophagus, stomach, and small and large intestines.

Genes: Microscopic building blocks of life that transfer specific characteristics from one generation to the next.

GI tract: Short for gastrointestinal tract.

Ileum: The last section of the small intestine.

Immune system: The body's natural defense system that fights against disease.

Immunomodulators: This class of medications basically overrides the body's immune system so that it cannot cause ongoing inflammation.

Inflammation: A response to tissue injury that causes redness, swelling, and pain.

Inflammatory bowel disease (IBD):

A term referring to a group of disorders—including Crohn's disease (inflammation in the gastrointestinal tract) and ulcerative colitis (inflammation in the colon).

Intestine: The long, tube-like organ in the abdomen that completes the process of digestion. It consists of the small and large intestines.

Large intestine: Also known as the colon. Its primary function is to absorb water and get rid of solid waste.

Microbiome: The human microbiome is a community of micro-organisms, like bacteria, viruses, fungi and archaea, that live on the human body, especially inside the gastrointestinal tract. Scientists hypothesize that when the microbiome composition is disturbed, as may be the case in IBD, serious health problems can arise as a result.

Oral: By mouth.

Osteoporosis: A disease in which the bones become porous and prone to fracture.

Perianal: Situated in or affecting the area around the anus.

Pouchitis: Inflammation of the ileal pouch.

Puberty: Period during which adolescents become sexually mature.

Rectal: Having to do with the rectum.

Rectum: Lowest portion of the colon.

Remission: Periods in which symptoms disappear or decrease and good health returns.

Resection: Surgical removal of a diseased portion of intestine. Reattachment of the two ends of healthy bowel is called anastomosis.

Small intestine: Connects to the stomach and large intestine; absorbs nutrients.

Ulcer: A sore on the skin or in the lining of the GI tract.

Ulceration: The process of ulcer formation.

Ulcerative colitis: A disease that causes inflammation of the large intestine (the colon).

References

1. Loftus EV JR., Schoenfeld P & Sandborn WJ (2002) The epidemiology and natural history of Crohn's disease in population-based patient cohorts from North America: a systematic review. *Aliment. Pharmacol. Ther.* 16(1):51-60.
2. <https://nccih.nih.gov/health/intergrative-health>. Accessed 04/29/19.

About the Crohn's & Colitis Foundation

Established in 1967, the Crohn's & Colitis Foundation is a non-profit, volunteer-driven organization dedicated to finding the cures for Crohn's disease and ulcerative colitis, and improving the quality of life of children and adults affected by these diseases.

Since our founding, the Foundation has remained at the forefront of research in Crohn's disease and ulcerative colitis. Today, we fund cutting-edge studies at major medical institutions, nurture investigators at the early stages of their careers, and finance underdeveloped areas of research.

In addition, the Crohn's & Colitis Foundation provides a comprehensive series of education programs, printed and online resources, support services and advocacy programs to members of the IBD community, including patients and caregivers.

We can help! Contact us at:

888-MY-GUT-PAIN

(888-694-8872)

info@crohnscolitisfoundation.org

www.crohnscolitisfoundation.org

Credits:

Reviewers:

This resource was reviewed by the Pediatric Affairs Committee.

Jullie Cundiff

Christine Mrakotsky, PhD

Dylan DeLay

Paul A. Rufo, MD, MMSc

Contributors:

Jill Sklar

Design & Layout:

Rubicon Design Associates

This resource is supported through the Crohn's & Colitis Foundation's annual giving program and donors.



733 Third Avenue
Suite 510
New York, NY 10017
800-932-2423

www.crohnscolitisfoundation.org

The Crohn's & Colitis Foundation is a nonprofit organization that relies on the generosity of private contributions to advance its mission to cure Crohn's disease and ulcerative colitis and to improve the quality of life of children and adults affected by these diseases.