



IBD Wellness Guide





This manual is designed for families living with Inflammatory Bowel Disease (IBD). Information about IBD is important, and patient education is a mainstay of CHOC's Gastroenterology division. We are dedicated to helping every parent and child to fully understand this condition and its management.

Use this manual to help organize and become prepared with assisting your child's care.

Items you may want to add to this manual:

- Dividers with pockets to store lab slips, lab results and check-out instructions
- Lined paper to write down questions and/or symptoms for future clinic visits
- Other possible pocket folders for:
 - Take Steps information (Crohn's and Colitis Walk)
 - Camp Oasis
 - Future appointment notes
 - 504 Plan for school
 - Support group handouts and pamphlets
 - Miscellaneous

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Meet Your CHOC IBD

- **My IBD Doctor:** The doctor works with me, my family and my other doctors to create a treatment plan that is right for me.
- **My IBD Psychologist (PhD):** The mental health provider understands the connection between IBD and the emotional health of children and adolescents and is skilled in discovering and treating anxiety, depression, pain and stress. The psychologist focuses on improving health behaviors and coping with IBD.
- **My IBD Dietitian:** The registered dietitian's goal is to help patients and families understand the role nutrition can play in IBD and to be a resource to help patients achieve their nutritional goals so they can grow and thrive.
- **My Clinical Social Worker:** The clinical social worker supports the child and their family by providing counseling and community referrals, including collaboration with school staff. The social worker assists with barriers to treatment, such as medical costs and transportation.
- **My IBD Nurse Coordinator:** The nurse coordinator provides education regarding IBD and supports complex patient care.
- **My IBD Program Coordinator:** The coordinator facilitates quality and research efforts including ImproveCareNow (ICN), a national quality organization for pediatric IBD.

Office Locations *

CHOC
1201 W. La Veta Avenue, Orange, CA 92868

CHOC at Mission Hospital
26691 Plaza, Suite 130, Mission Viejo, CA 92691

CHOC Corona
854 Magnolia Avenue, Suite 101, Corona, CA 92879

CHOC Fountain Valley
11100 Warner Avenue, Suite 368, Fountain Valley, CA 92708

CHOC Newport Beach
500 Superior Avenue, Suite 140, Newport Beach, CA 92663

CHOC PIH
15725 E. Whittier Blvd, Suite 300, Whittier, CA 90603

Thompson Autism Center at CHOC
170 S. Main St., Orange, CA 92868

**Gastroenterology
Office Number:
714-509-4099**

**Appointment Line:
1-888-770-2462**

**CHOC physicians have access to medical records at all CHOC locations.*

What to Expect from Your IBD Team

Our mission is to partner with you and your family to discuss a wide range of treatment options to help you achieve good health and return to doing all the things you did before your IBD symptoms began.

Clinic visit schedule and what to expect:

Appointment	What to Expect
First visit (newly diagnosed or existing diagnosis new to CHOC)	Discuss diagnosis of IBD, how it affects the body, available therapies
Second visit: 1 to 2 months after first visit	Evaluate response to therapies
Third and future visits: 2 to 4 months after second visit, then every 3 months or as determined by the doctor	Assess current health state Adjust therapy as needed General care and check-ups

It is important to keep follow-up visits, even when you are doing well.

New research shows that early detection of changes in and intervention for IBD help promote intestinal healing and healthier outcomes. The severity of your IBD does not always match your symptoms.

At each visit, we will:

- Discuss how you are doing and how current therapies are working
- Discuss blood/stool tests, imaging, scopes and specialist consultations
- Ask questions about symptoms such as abdominal pain, stooling, appetite, energy level and overall well-being
- Ask what you are concerned about
- Answer your questions and make a plan

Ask your doctor to connect you to a psychologist to help with stress, anxiety and depression, and to find ways to help improve health behaviors to improve lifestyle adjustments with IBD; the dietitian if you have questions about diet; the social worker to assist you with barriers to treatment or school accommodations; or the IBD nurse with insurance questions or finding resources to help kids learn about self-care.

Telehealth: Ask your doctor if telehealth appointments are right for you

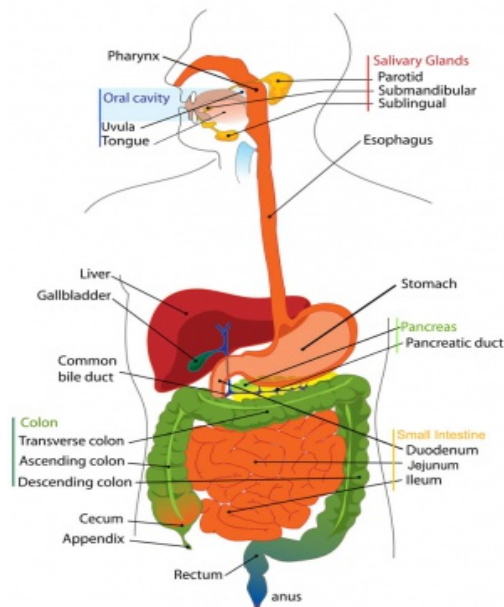
About my Medical Condition

I was diagnosed with:

I was diagnosed on this date:

My IBD is located:

Mark the area where the inflammation is:



My previous testing:

My previous treatments and therapies:

Notes:

The CHOC IBD Program is a participant of



ImproveCareNow has created a national Inflammatory Bowel Disease (IBD) community in which clinicians, researchers, parents and patients are empowered to collaborate to improve the care of the IBD patient population. This collaboration will help achieve healthier, happier children and adolescents affected by IBD all while learning how to care for our loved ones.

Since 2007, the percentage of patients in remission at ImprovedCareNow clinics has increased from about 55% to 80% without new medications!

How Does This Collaborative Work and How Does This Improve Patient Care?

By sharing data and working together to get better, ImproveCareNow centers collect information about patients during clinic visits. Information from all these centers is studied so that we can understand the best way to treat children with IBD.

This kind of health network means we all work together – care providers, researchers, patients and families – using scientific data to drive improvements for kids with Crohn’s disease and ulcerative colitis. We use the collected data and quality improvement tools to find gaps in care and close the gaps. Pre-visit planning meetings and tools are used to ensure that you get what you need when you come to a clinic visit. The result will be more reliable, proactive and individualized pediatric IBD care.

How Can You Help?

Your participation plays a critical role. To share your child’s information, we will need your consent. The information about your child’s name is declassified. This means that your child’s identity is kept anonymous.

What do I have to do if I decide to consent?

There are not any additional tasks that you have to do. We ask that you keep your regular appointments as recommended by your gastroenterologists, keep up with the lab work and other tests ordered and be compliant with medications and treatments.

Who can sign the consent?

For patients under the age of 18, a parent or legal guardian will have to sign the consent. If the patient is 18 years old or older and can make their own legal decisions, then the patient can sign on their own behalf.

The CHOC IBD Program is a participant of



How do I sign up?

Signing up is easy! Let your gastroenterologist provider know that you are interested in participating with ICN. They will ask you for your email address and your zip code. Your email address will be used for ICN to send a secured link to you.

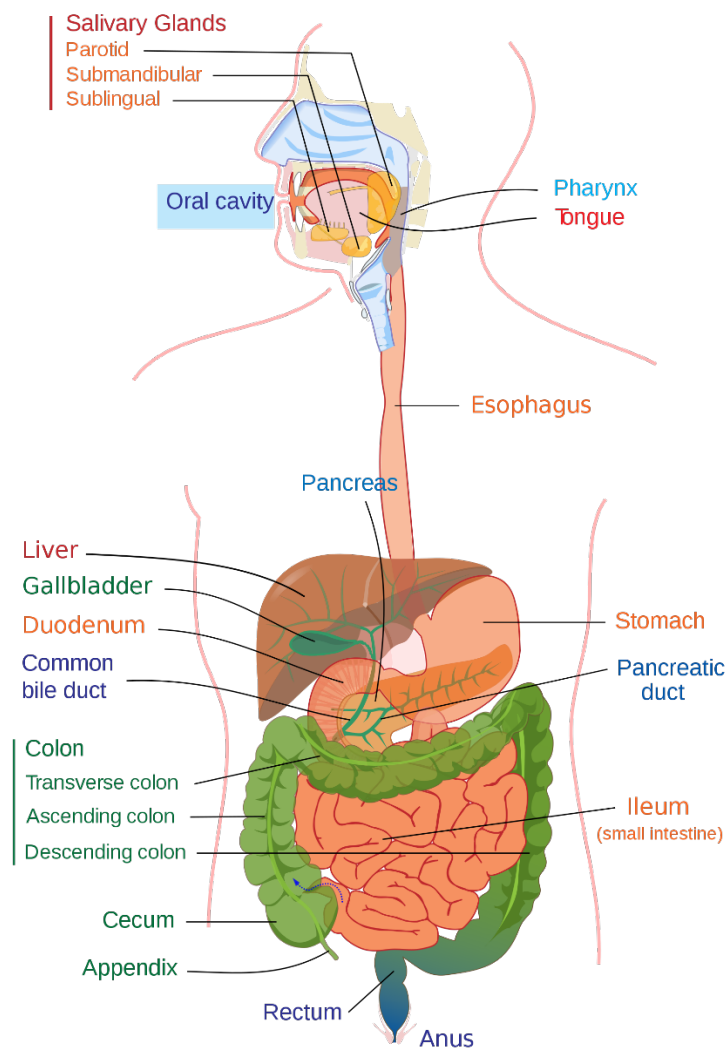
If I have agreed to receive the e-consent, what's next?

If you have agreed to participate and receive the electronic consent (e-consent), your provider will notify the IBD Program Coordinator so that they can send an email out to you to complete the consent. The email will come from "Help Desk" (helpdesk@improvecarenow.org). Click the secure link provided in the email. This link will redirect you to a secure website, where you will use your zip code as a password. Please note that the link can expire within a 10-14 days if the consent is not completed. If your link does not work or expires, please contact the IBD Program Coordinator at (714) 509-4099 for further assistance.

Inflammatory Bowel Disease (IBD) Overview

Inflammatory bowel disease (IBD) is a chronic condition caused by inflammation in the gastrointestinal tract. In IBD, the immune system overreacts and leads to injury of the intestines. There are two main types of IBD: Crohn's disease and ulcerative colitis. Crohn's disease involves the gastrointestinal tract anywhere from mouth to anus. Ulcerative colitis involves inflammation limited to the large intestine (colon).

It is estimated that over 1 million Americans are diagnosed with IBD. IBD occurs in both children and adults. According to the Crohn's and Colitis Foundation, there may be 80,000 children in the United States who are diagnosed with IBD.



Gastrointestinal tract

Crohn's Disease

Crohn's disease is an inflammatory bowel disease with inflammation that may penetrate through the entire thickness of the intestine and can affect any area of the gastrointestinal tract, from the mouth to the anus. It most commonly affects the small intestine but often also affects the colon. Some patients may also get sores or openings around the anus. It is a chronic condition that may come back at various times throughout a person's lifetime.



Crohn's disease affects any area of the gastrointestinal tract

What causes Crohn's disease?

No one knows for sure what causes Crohn's disease or why it shows up when it does. We do know that people who have a family member with IBD are more likely to develop Crohn's disease. One theory suggests that something, perhaps a virus or bacteria, affects the body's immune system and triggers an inflammatory reaction in the intestinal wall. There is evidence that patients with this disease have abnormalities of the immune system. It is not known, however, whether the immune problems are a cause or a result of the disease.

Why is Crohn's disease a concern?

The disease can be disabling when a patient is very ill. There may be remissions when symptoms go away for months or even years. However, symptoms may return if the disease is not properly monitored and treated. The CHOC IBD Program follows patients throughout their childhood and into early adulthood to help manage symptoms of Crohn's disease and develop a treatment plan that adapts as the child grows and his or her needs changes.

What are the symptoms of Crohn's disease?

The following are the most common symptoms for Crohn's disease; however, each child may experience symptoms differently. Symptoms may include:

- Abdominal pain, often in the lower right area
- Diarrhea, sometimes bloody
- Rectal bleeding
- Decreased appetite
- Decreased energy
- Fever
- Weight loss
- Failure to grow
- Rash
- Joint pain
- Canker sore in the mouth
- Persistent fissure, sore or opening in the skin in or around the anus

Crohn's disease may develop very slowly in some people with mild symptoms that may exist for years before diagnosis. After diagnosis, some people may have long periods of remission when they are free of symptoms, sometimes lasting for years. It may be difficult to predict when a remission may occur or when symptoms will flare. It is important to get care from a doctor experienced in diagnosing and caring for IBD.

Treatment Options for Crohn's Disease

Currently, there is no cure for Crohn's disease; however, there are things that can be done to help control Crohn's disease. At CHOC, customized treatment plans are developed based on each patient's medical, physical, social and emotional wellness.

The goals of treatment may include:

- Correcting nutritional deficiencies
- Controlling inflammation
- Supporting optimal growth and weight gain
- Reducing symptoms so your child can live a life of all-around wellness

Specific treatment is determined by your child's doctor based on the following:

- The child's age, overall health and medical history
- The extent and location of the Crohn's disease
- The child's tolerance for specific medications or therapies
- The family's option or preference

Treatment may include:

- **Medication therapy:** Your child's gastroenterologist may recommend one or a combination of medications that will help the intestine heal. The classes of medications available include aminosalicylates antibiotics, corticosteroids, immunomodulators, and biologic therapies.
- **Diet and vitamin supplements:** See Diet and Nutrition Section.
- **Psychology wellness care:** Having IBD can be difficult at times. Lifestyle and dietary adjustments can decrease IBD flares and support remission. However, these adjustments may be more challenging for others to accept or to change. Dealing with pain, anxiety and other emotions through the course of this condition can strain a social lifestyle. Good mental maintenance can help balance these emotions. At CHOC, we have a team of pediatric psychologists whose expertise help CHOC patients and their families cope with physical, emotional, and lifestyle changes associated with lifetime medical conditions.
- **Integrative medicine:** When dealing with IBD, other means of personal care should be considered. Patients may benefit from integrative medicine techniques such as acupuncture and guided imagery. Additional approaches can be discussed on a case to case basis.
- **Mindfulness-based stress reduction (MBSR):** MBSR is a blend of meditation, body awareness, yoga, and other therapeutic strategies. Mindfulness training and integrative medicine can have a significant therapeutic effect for those experiencing stress, anxiety, depression, chronic pain, and other health conditions including IBD.

- **Hospitalization:** Children with Crohn's disease are sometimes sick enough to need hospitalization to correct anemia and malnutrition and to stop diarrhea, vomiting, and loss of blood, fluids, and mineral salts. Patients may need a special diet, feeding through a vein, medications, and in rare cases, surgery.
- **Surgery:** Crohn's disease may be helped by surgery but is not likely to be cured by surgery. Inflammation tends to return to the areas of the intestine next to the area that has been removed. Any surgical intervention in Crohn's disease must be approached with caution. However, surgery may help relieve chronic symptoms of active disease that do not respond to medical therapy or to correct complications, such as intestinal blockage, perforation, abscess, fistula or bleeding.

* **Note:** These strategies are not a cure for serious medical conditions and should not be used as a substitute for medical treatment.

Types of surgery include:

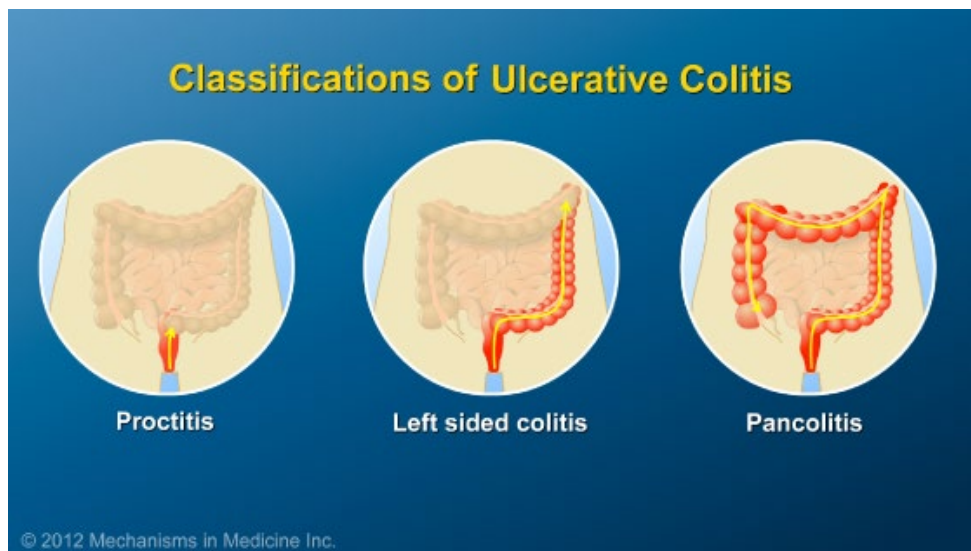
- Drainage of abscesses.
- Removal of section of bowel due to blockage, stricture or fistula. This type of surgery may result in shortened bowel that requires additional nutrition support.
- Some people must have part of their intestines removed and an opening for the stool to exit the body is created. This surgery to create the new opening is called ostomy creation and the new opening is called a stoma. This is usually not a permanent fix in children and adolescents.

The type of ostomy performed depends on how much and which part of the intestines is removed and may include:

- **Ileostomy:** The colon and rectum are removed and the bottom part of the small intestine (ileum) is attached to the stoma.
- **Colostomy:** Part of the colon is removed and bypassed, and a portion of the colon is brought up to the surface of the skin to create the stoma. Sometimes, a temporary colostomy may be performed when part of the colon has been removed and the rest of the colon needs to heal.
- **Ileoanal reservoir surgery (J-pouch, among other terms):** This is an alternative to a permanent ileostomy and uses part of the small intestine to create a pouch near the rectum to hold stool for evacuation later. The muscle of the rectum is left in place, so the stool in the pouch does not leak out of the anus. People who have this surgery can control their bowel movements. This surgery is more common in ulcerative colitis patients but may also be needed in Crohn's disease patients.

Ulcerative Colitis

Ulcerative colitis is a type of inflammatory bowel disease in which the inner lining of the large intestine (colon or bowel) and rectum become inflamed. The remainder of the intestinal tract is not involved. Abscess and fistula formation seen in Crohn's disease are not seen in ulcerative colitis. Although children and older people sometimes develop ulcerative colitis, it most often starts between the ages 15 and 30. It affects males and females equally and appears to be more common in families that have a member with IBD.



What causes ulcerative colitis?

No one knows for sure what causes ulcerative colitis or why it appears when it does. We do know that people who have family members with IBD are more likely to develop ulcerative colitis. One theory suggests that something, perhaps a virus or bacteria, affects the body's immune system and triggers an inflammatory reaction in the intestinal wall. It is likely that multiple factors combine to cause this disease.

Why is ulcerative colitis a concern?

Ulcerative colitis is a chronic illness that requires long-term medical care. The disease can be disabling when a patient is very ill. There may be remissions when symptoms go away for months or even years. However, symptoms may return, also known as a flare. For those patients whose colitis is significant, the lifetime risk of colon cancer is greater than normal, and it is important to see a doctor regularly so that they may monitor the patient's overall health.

Surgery to remove the colon may be necessary to cure the disease and minimize the risk of colon cancer. The CHOC IBD Program follows patients throughout their childhood and into early adulthood to help manage symptoms of ulcerative colitis and develop a treatment plan that adapts as the child grows and their needs change.



What are the symptoms of ulcerative colitis?

The following are the most common symptoms of ulcerative colitis; however, each child may experience symptoms differently. Symptoms may include:

- Abdominal pain
- Bloody diarrhea
- Urgency to pass stool
- Fatigue
- Weight loss
- Loss in appetite
- Rectal bleeding
- Fever

Treatment Options for Ulcerative Colitis

At CHOC, treatment plans are developed based on each patient's unique medical, physical and social and emotional needs.

The goals of treatment may include:

- Correcting nutritional deficiencies
- Controlling inflammation
- Supporting optimal growth and weight gain
- Reducing symptoms so your child can live a life of all-around wellness

Specific treatment is determined by your child's doctor based on the following:

- The child's age, overall health and medical history
- The symptoms and extent of the child's ulcerative colitis
- The child's tolerance for specific medications, procedures or therapies
- The family's option or preference

Treatment may include:

- **Medication therapy:** Your child's gastroenterologist may recommend one or a combination of medications that will help the large intestine heal. The classes of medications available include aminosaliclates antibiotics, corticosteroids, immunomodulators and biologic therapies.
- **Diet and vitamin supplements:** See Diet and Nutrition Section.
- **Psychology Wellness Care:** Having IBD can be difficult at times. Lifestyle and dietary adjustments can decrease IBD flares and support remission. However, these adjustments may be more challenging for others to accept or to change. Dealing with pain, anxiety and other emotions through the course of this condition can strain a social lifestyle. Good mental maintenance can help balance these emotions. At CHOC, we have a team of pediatric psychologists whose expertise helps CHOC patients and their families cope with physical, emotional and lifestyle changes associated with lifetime medical conditions.
- *** Integrative medicine and Mindfulness Based Stress reduction:** When dealing with IBD, other means of personal care should be considered. Patients may benefit from integrative medicine techniques such as acupuncture and guided imagery. Additional approaches can be discussed on a case-to-case basis. Mindfulness Based Stress Reduction (MBSR) is a blend of meditation, body awareness, yoga and other therapeutic strategies. Mindfulness training and integrative medicine can have a significant therapeutic effect for those experiencing stress, anxiety, depression, chronic pain and other health conditions alongside IBD.

- **Hospitalization:** Children with ulcerative colitis are sometimes sick enough to need hospitalization to correct malnutrition and to stop diarrhea and the loss of blood, fluids and mineral salts. Patients may need a special diet, feeding through a vein, medications and, in some cases, surgery.
- **Surgery:** Most children with ulcerative colitis do not need surgery. However, about 25 to 40 percent of children with ulcerative colitis eventually require surgery for removal of the colon because of bleeding, chronic debilitating illness, perforation of the colon or risk of cancer. Sometimes, removing the colon is suggested when medical treatment fails or the side effects of medications threaten the patient's health.

* **Note:** These strategies are not a cure for serious medical conditions and should not be used as a substitute for medical treatment.

Types of surgery include:

- **Proctocolectomy with ileostomy:** The most common surgery is the proctocolectomy (removal of the entire colon and rectum) with ileostomy (creation of a small opening in the abdominal wall where the tip of the lower small intestine, the ileum, is brought to the skin's surface to allow drainage of stool). This may not be a permanent fix for children and adolescences.
- **Ileoanal reservoir surgery (J-pouch, among other terms):** This is an alternative to a permanent ileostomy and uses part of the small intestine to create a pouch near the rectum to hold stool for evacuation at a later time. The muscle of the rectum is left in place, so the stool in the pouch does not leak out of the anus. People who have this surgery can control their bowel movements.



Diagnosics and Tests

Children and adolescents who have experienced chronic abdominal pain, diarrhea, fever, weight loss, growth failure and anemia may be examined for signs of IBD. Frequency of testing is at the doctor's discretion depending on a patient's status. The following are the types of tests that may be ordered:

Blood tests

These tests help doctors look for anemia or chronic inflammation. They also show any changes in the child's protein, vitamin and mineral levels. Sometimes blood tests can help distinguish between ulcerative colitis and Crohn's disease.

Stool tests

These tests look for evidence of blood loss or inflammation in the stool, or an infection by a parasite or bacteria causing the symptoms.

Esophagogastroduodenoscopy (EGD or upper gastrointestinal endoscopy)

A procedure in which a flexible scope is inserted through the mouth so that the child's doctor can see abnormal growths, narrowing, inflamed tissues, ulcers and bleeding sites in the lining of the throat, esophagus, stomach and the beginning of the small intestine. During an endoscopy, doctors can also treat areas that are bleeding and take very tiny biopsies of tissues they would like to test. Note that sedation is required for this procedure.

Colonoscopy

A procedure in which a flexible scope inserted through the anus allows the doctor to see abnormal growths, narrowing, inflamed tissues, ulcers, polyps and bleeding sites in the lining of the large intestine and the final portion of the small intestine (distal terminal ileum). During a colonoscopy, the doctor can treat areas that are bleeding, remove polyps and take very tiny biopsies of tissues they would like to test. Note that sedation is required for this procedure. Frequency of colonoscopies is at the provider's discretion depending on the patient's status.

Push endoscopy (push-pull enteroscopy or double balloon enteroscopy)

A procedure that allows the doctor to see the small intestine that cannot be reached with traditional esophagogastroduodenoscopy. It is performed similarly to an EGD. Biopsies can be taken during this study. Note that sedation is required for this procedure.

Video Capsule Endoscopy

A procedure that lets doctors see the parts of the small intestine that cannot be reached with traditional esophagogastroduodenoscopy. A video capsule is swallowed or placed in the intestine using an endoscope and passes through the intestine taking many pictures that can be compiled into a video. Biopsies cannot be taken during this study.

Biopsy

Tiny, painless samples of tissue taken from the lining of the intestine for examination under a microscope in a laboratory. The samples are used to find abnormalities that cannot be seen with the naked eye and help determine more information about a patient's disease. Taking a biopsy sample does not mean that the physician suspects a diagnosis of cancer.

Upper Gastrointestinal series (UGI, upper GI, barium swallow)

An X-ray that creates images of the organs of the upper part of the digestive system: the esophagus, stomach and duodenum (the first section of the small intestine). A fluid called barium (a chalky liquid) is swallowed and coats the inside of the intestine so that it will show up on the X-ray. This test is used to look at the anatomy and movement of the intestine. It does not show abnormalities in the lining of the intestine as well as endoscopy. Sedation is not used for this test.

Upper Gastrointestinal series with small bowel follow through (UGI w SBFT)

A test that creates images of the organs of the upper part of the digestive system, including the entire small intestine (not just the first section). A fluid called barium (a chalky liquid) is swallowed and coats the inside of the intestine so that it will show up on the X-ray. This test is used to look at the anatomy and movement of the intestine. It does not show abnormalities in the lining of the intestine as well as endoscopy. Sedation is not used for this test.

Computer Tomography Enterography (CT of abdomen and pelvis, CTE)

An X-ray of the intestine that gives a three-dimensional view of the belly, including the intestine and structures surrounding the intestine. This test uses oral and IV contrast and usually does not require sedation.

Magnetic Resonance Enterography (MRI of abdomen and pelvis, MRE)

An imaging test of the intestine that gives a three-dimensional view of the belly, including the intestine and structures surrounding the intestine. This test uses oral and IV contrast and may require sedation, depending upon the age of the patient.

Barium enema

An X-ray test that examines the organs of the lower part of the digestive system: the terminal ileum, colon and anus. Barium or another form of contrast is given through the anus as a controlled enema. This test is used to evaluate the anatomy and movement of the intestine. It may not show abnormalities in the lining of the intestine as clearly as a colonoscopy does. Sedation is not used for this test.

Medications Guidelines

1. Taking medications every day can be difficult for both children and adults. However, continuing to take medications as prescribed, even when symptoms are not present, is the best way to prevent symptoms from coming back, as well as protect against the long-term risk of colon cancer, stricture and fistula formation and even growth failure.
2. Because many IBD medications can reduce the body's ability to fight infections, your IBD doctor will check your immunization status before prescribing the medication. This includes checking for tuberculosis on a yearly basis. It's important to keep up with routine immunization schedule, excluding live vaccines, which are not recommended for IBD patients on many IBD medication. Regular blood tests to monitor biologic level may be required.
3. Be sure to alert us of all allergies.
4. Your child will need to take medications as prescribed by the doctor. Do not change the dose of medication or stop using the medication unless told to do so by a member of the IBD team. When you need more medication, please call your pharmacy for a refill. They will contact us to get approvals for refills. Call at least two weeks before you need the medication to give us time to process the request.
5. Maintain a list of ALL medications (prescribed and over the counter), as well as vitamin and herbal supplements your child is taking. Be sure to alert the provider of any changes in your medication therapy since your last visit.
6. If your child misses a dose of medication, it is important to take it as soon as possible after the missed dose. If it is almost time for the next dose, your child should skip it and take the next regular scheduled dose. DO NOT take a double dose. Contact your GI doctor or the IBD team for advice about missing a medication dose.
 - a. For medications that are three times a day: take at breakfast, after school and bedtime.
 - b. For medications that are four times a day: take at breakfast, lunch, supper and bedtime.
7. Many over-the-counter and prescription pain relievers contain aspirin or non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Advil®, Motrin®, Aleve®, Anaprox®, Naprosyn®, Daypro®, etc) have been shown to cause ulcerations or irritation in the intestine and could cause more IBD symptoms. These products should be avoided unless ordered by your child's doctor. Products such as Tylenol® containing acetaminophen are fine to use.
8. Unless a doctor documents an infection, avoid taking antibiotics. Some antibiotics can cause IBD to flare.

Common IBD Medications



5-ASAs - Pentasa, Lialda, Apriso, Colazal, Delzicol, Asacol HD, Sulfasalazine, Canasa, Rowasa

These drugs are anti-inflammatory medications, chemically related to aspirin. Similar to aspirin, they help start healing, reducing inflammation and decrease discomfort. They may be given orally or rectally. These are 5-ASAs that are released at different parts of the bowel, which allow treatment where the disease is located. Rare side effects of these medications include allergic reactions, pancreatitis and kidney injury. If you are taking these medications, you should wear sunscreen when outside to reduce the risk of skin rash and sunburns.

Corticosteroids - Prednisone, Orapred, Methylprednisolone, Hydrocortisone, Entocort, Cortifoam

These are drugs that usually bring a rapid “remission,” controlling most symptoms within a short period of time. There are possible side effects which may increase and become more serious the longer the medication is taken. Our goal is that these medications be taken for short periods of time. A sudden stop in steroids can also bring on dangerous side effects, so always follow the schedule your doctor prescribes. Entocort, a corticosteroid, has a local effect and is released slowly in the last section of the small bowel and the first section of the large bowel. Lower incidence of side effects are associated with Entocort. Side effects of corticosteroids can include weight gain, hunger, high blood pressure, high blood sugar level and changes in mood and sleep patterns. Those on long term corticosteroids should avoid live vaccines.

Immunomodulators – Imuran (Azathioprine), 6-Mercaptopurine (6 MP), Methotrexate, Tacrolimus (Prograf)

These are medications that alter the immune system. Since IBD is an autoimmune disease, these medications help regulate your immune system. Imuran and 6MP are common immunomodulators and are medications we commonly use when treating IBD. They are given by mouth daily and can take approximately 6-8 weeks before becoming effective. Methotrexate is another immunomodulator and can be given by mouth or as an injection weekly. Folic acid is used daily to prevent side effects from Methotrexate. Pregnant women or women planning to become pregnant should not take methotrexate.

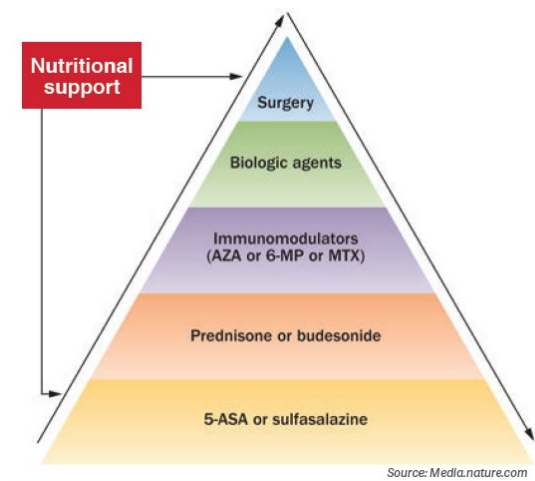
Blood test are closely monitored while patients are on these medications. Possible side effects include low white blood count and irritation to the liver or pancreas. Wear sunscreen when outside and be cautious about the amount of sun exposure. It is important to keep up with routine immunization schedule excluding live vaccines, which is not recommended for IBD patients on immunomodulators.


Biologics – Remicade (Infliximab), Humira (Adalimumab), and Entyvio (Vedolizumab), and Stelara (Ustekinumab)

Remicade and Humira are also called anti-TNFs. Tumor necrosis factor-alpha (TNF α) is a protein that is involved in systemic inflammation. It is a normal occurrence in our immune system. People with IBD may produce too much TNF α and the TNF α mistakenly injures the intestine. The anti-TNFs (Remicade and Humira) are antibodies that are created to bind and block TNF α from attacking healthy cells in the gut. Remicade is an intravenous medication that is administered at an infusion center or at home. How often the infusions are depends on your symptoms, but it is usually given every 8 weeks. Humira is given by subcutaneous injection at home every two weeks.

Entyvio is classified as an anti-integrin. It is prescribed when young patients have inadequate response with or lost response to Humira and Remicade. Entyvio binds against the integrin, a normal occurring protein in the body. This prevents part of the immune system from causing harm to the gut. Like Remicade, it is intravenously administered.

Stelara is an antibody that reduces the action of certain substances in the body that causes inflammation. The first dose is given intravenously, and the following doses are by subcutaneous injection.





The drug manufacturer of each medication has a patient rebate program to help with the out of pocket cost based on health insurance policy. Log onto the drug manufacturer's website for further information.

Antibiotics - Ciprofloxacin, Flagyl (Metronidazole), Rifaximin (Xifaxin)

These medications have been found to be effective in the treatment of IBD and often help bring flares under control. Our immune system helps provide protection from invading bacteria and helps prevent infections. In IBD, there may not be an infection, but the immune system acts as if it was responding to an infection and may attack parts of the bowel. Antibiotics may help to reduce inflammation by changing the type of bacteria in the bowel. Some antibiotics may make IBD symptoms worse or trigger inflammation. Please notify your GI doctor if your child needs to be prescribed an antibiotic ordered by your primary care doctor.

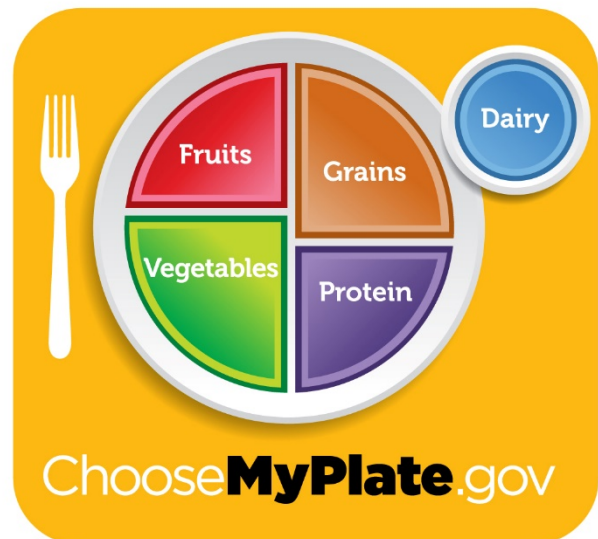
IBD Diet and Nutrition

Eating a healthy diet is important for maintaining good health with IBD. There isn't one specific diet for IBD, nor is there something in your child's diet that caused IBD.

Diet with IBD is very individualized as one child may be sensitive to a particular food, while another may not. Furthermore, your child may be at risk for inadequate nutrition with IBD due to the body's inability to absorb nutrients adequately or the increased needs created by the inflammation process.

The CHOC IBD Program team includes a registered dietitian who can help provide more individualized support and guidance on optimal nutrition for your child's health. This chapter will provide basic information on diet and nutrition recommendations for the following scenarios:

- Eating healthy
- Food sensitivities and intolerances
- During a flare or stricture
- Weight loss
- Medication use
- Vitamin/mineral supplementation
- Individualized nutrition and special diets




Eating Healthy

The recommended diet for IBD is no different than for a child or teen without IBD. A balanced whole food-based diet with adequate calories, protein, fiber, vitamins, minerals and fluids is best. This includes eating more vegetables and fruits, whole grains, healthy fats, and lean protein sources and eating less sugary and processed foods.

The USDA Choose My Plate website at www.choosemyplate.gov is a great resource for more information on building a healthy balanced diet. You can also discuss specific diet questions with your IBD team and IBD Registered Dietitian.

Potential Food Intolerances/Sensitivities

Some children or teens with IBD may have intolerances or sensitivities to certain foods. These may include greasy or high fat foods, dairy (lactose), caffeine, or spicy



foods. These sensitivities or intolerances can increase or decrease over time and it may be helpful to keep a food journal to track and identify any bothersome foods.

During a Stricture or Flare

If a child or teen has a stricture or narrowing of the intestine, it may be recommended they eat a “low residue diet.” This means avoiding foods high in fiber to decrease risk of foods getting stuck causing a blockage in the intestine. This is *only a temporary diet*, however, and the goal is to get the stricture/narrowing resolved so that the child or teen can return to their normal diet.

Following a low residue diet may also help decrease symptoms during a flare but it is different for every individual with IBD.

Consider the following when you have a stricture or flare:

- Peel and puree fruits and peel, puree and cook vegetables.
- Limit or reduce intake of gas producing foods like broccoli, Brussel sprouts, cabbage, beans and legumes and cauliflower.
- Limit or reduce raw fruit, dried fruit and/or fruits with skins and seeds.
- Choose soft or processed fruits like melon, ripe bananas and applesauce.
- Choose more refined grains like white bread, white rice, regular pastas and cereals instead of whole wheat option, for example.
- Choose lean protein sources like chicken, turkey, fish, eggs, nut butters and tofu.
- If lactose intolerance occurs, choose lactose free milk or non-dairy milk.
- Avoid nuts and seeds. Use nut/seed butters instead.
- Avoid popcorn and corn.
- Decrease intake of sweets like juices, candy and soda.
- Avoid greasy, fried foods.
- Chew food well, as this helps with digestion.
- Eat smaller, more frequent meals.
- It may be easier to drink than eat during a flare, so consider trying a nutritional supplement like Boost or Ensure or homemade smoothies.

Ideas for What to Eat During a Flare

- Pretzels
- Saltine crackers
- Graham crackers
- Dry cereal
- Bananas
- Strong, hot caffeine-free tea
- Diluted fruit juice without pulp

- Applesauce
- Nutritional supplements
- Homemade smoothies
- Jello
- Low-fat pudding
- Plain angel food cake
- Mashed potatoes
- Oatmeal
- Cooked, rice, noodles or pasta
- Sourdough toast with smooth peanut butter
- Watermelon/cantaloupe/honeydew
- Scrambled eggs
- Canned fruit
- Baked chicken breast

Eating After a Flare

- Add back food slowly, every 1-2 days and continue to avoid foods that cause symptoms.
- Increase fiber intake as tolerated. Start with cooked vegetables, canned or cooked fruits, cooked cereals and pastas. Increase as tolerated to more raw fruits and vegetables and whole grain pastas, cereals and breads.

Weight Loss

Your child or teen is at risk for weight loss or poor growth due to IBD. Diarrhea, vomiting, nausea, loss of appetite and fatigue can lead to weight loss. The inability to absorb the nutrients the body needs can also contribute to weight loss and growth failure. Close monitoring of nutritional labs, weight gain, and growth is needed. Your CHOC IBD team will be monitoring your child's growth and development closely. Speak with the CHOC IBD Team and Registered Dietitian if you notice your child is losing weight or your child's appetite has decreased.

Medication Use

IBD medications like corticosteroids may affect nutrition. While on these medications your child's appetite, blood sugar and electrolyte levels will be monitored closely. Salt intake should be monitored while on corticosteroids. Salt increases fluid retention (swelling). Corticosteroid use can interfere with calcium absorption and decrease bone mineral density. Supplementation with calcium and vitamin D may be recommended for your child if they are taking a corticosteroid. If your child/teen is taking sulfasalazine or methotrexate, folic acid supplement will likely be recommended. Discuss all medications with your CHOC IBD Program team members.

Vitamin/Mineral Supplementation

Additional vitamin/mineral supplementation may be recommended for your child. Vitamin and minerals that are of special concern:

- Vitamin B 12
- Calcium
- Vitamin D
- Folic Acid
- Magnesium
- Zinc
- Iron

Individualized Nutrition and Special Diets for IBD

Children and teens with IBD each have their own unique nutrition needs. Some may tolerate one food better than another. Others may experience more difficulties with growth or absorption. It is important to collaborate with your child's CHOC IBD Team and Registered Dietitian to determine an optimal nutrition regimen that minimizes gastrointestinal symptoms and promotes healthy eating and growth.

Nutrition can be a large portion of an IBD treatment plan. Nutrition as a primary IBD therapy is possible in some children and teenagers with careful monitoring and considerations of unintended consequences.

There are many special diets on the web that may be helpful and or promising. Should you come across a diet that interests you, please contact your IBD team and IBD Registered Dietitian to discuss the diet in more detail.

Psychosocial Issues

Inflammatory Bowel Disease, like any chronic condition, impacts the entire family.

Having IBD can be difficult at times, and we want to help your family with all the aspects of your life that can be affected by IBD. It can be stressful to have to deal with a chronic illness, come to frequent office visits and remember to take all your medications, all while trying to live a “normal” life.

Your child may deal with pain, anxiety, fear, depression, anger, body image changes and other emotions through the course of this condition. These factors are normal



for anyone dealing with a chronic illness. Our goal is to support each child and family, and to teach coping strategies with issues as they may arise. Siblings need to be kept involved as appropriate for their ages. Siblings often exhibit feelings of jealousy, fear, guilt or anger when their brother or sister experiences serious illness. Open, honest communication with the entire family will provide needed support and reassurance for siblings and help ease their fears. CHOC has many resources available to help you and your child, such as social services, child life specialists and the CHOC IBD website.

Our IBD team will be able to assist with referrals to psychology if necessary.

School and Activities



The pressures that all students feel during the school year can be magnified when IBD is part of the curriculum. Kids with Crohn's or colitis face additional challenges such as how their disease might affect their grades and their relationships with teachers and classmates. Education and communication can help to ease these concerns. The following educational tools are easily accessed through the Crohn's & Colitis Foundation website.

Crohn's Disease & Ulcerative Colitis: A guide for teachers and other school personnel: www.ccfa.org/assets/pdfs/teachersguide.pdf


Ask your teachers, school nurses and guidance counselors to download this guide. It has information specifically to help them understand IBD, its effect on you and what they can do to help.

A GUIDE FOR Teens WITH IBD:

www.crohnscolitisfoundation.org/sites/default/files/legacy/assets/pdfs/teenguide.pdf

Taking IBD to School: www.ccfa.org/resources/taking-ibd-to-school.html

Just Like Me: www.justlikemeibd.org



Your child has the right to education through Educational Accommodation Plans. This right is protected by laws including Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Educational Act (IDEA). These laws allow the schools to provide any necessary accommodations, from preschool through college.

Communication with teachers, school nurse, coaches and other caregivers so they are aware of your child's diagnosis and can help with needs as they arise.

Some examples of school accommodations:

- Hall passes for the bathroom for the entire school year
- "Stop the clock" for tests to leave for the bathroom
- Pass for the nurses' office for medications
- Access to the location of bathrooms for outdoor activities
- Any diet modifications necessary
- Exercise and activities with ability to rest as needed during times of increased symptoms
- Sit near door of classroom

This communication will also be important for times when your child might have to miss school or other activities because of doctor's appointments, procedures, hospitalization or sickness. For prolonged hospital stay, CHOC provides a teacher through our Child Life department. Homebound instruction may be needed with special circumstances for illness but should be considered a last resort. A **504 plan** provides assistance with studies or tutoring if necessary. Our social worker can work with you to develop a system for gradually returning to school after many absences.

Going to College with IBD



Deciding what college you want to attend can be an overwhelming process. This may be the first time in your life that you'll be living on your own and taking on some of the responsibility of your IBD. But, if you start planning campus visits early, you'll have time to think about which college is right for you and what you need. When you're making these college visits, it's important to think about how your IBD will factor into the school you choose.

Things to Consider

- Do you feel comfortable managing your own care away from home?
- Will you have easy access to medical care, and will you need supplemental health insurance?
- Does the school offer online classes, academic support or tutoring services in case of flares?

Regardless of whether you're staying local or moving:

- Contact your school's health center to find out what services they offer and if they can help coordinate care.

- Contact your GI doctor/primary care physician to request a medical summary of your care to date for your files.

If you're moving away from home, you'll also want to:

- Find a GI doctor in the area - ask your GI if they have colleagues near your college.
- Locate a pharmacy, treatment center and ER nearby.
- Contact your insurance to find out if you need a supplemental plan. Your school may offer supplemental insurance, which you may opt out of if you already have sufficient coverage.

During your visit to a college, it's helpful to be mindful of the following:


- Locating and contacting the school's disability services office. The next page will detail the benefits of accessing disability services.
- Locating and contacting the school's Student Health Center.
- Is there a local pharmacy near the college?
- Is there a local hospital, Emergency Room, Urgent Care Center, etc.?

Disability Services

Now that you've made your choice and know where you're going to college, let's talk about disability services and the benefits of registering with them. Disability services offers accommodations for students for a variety of reasons, including IBD.

Below are just some of the accommodations disability services may have available for you. However, it is important to call and speak with someone at the school.

- Potential additional privacy in campus living if you are planning to live on campus. For example, instead of having to share a bathroom with 10-15 people in a dorm building, disability services may be able to offer a living space where you only have to share the bathroom with 2-4 people.
- If you're having symptoms and end up missing class or a test, disability services can offer the potential for "attendance forgiveness" and the option to make up work or tests. This can be helpful, as some college professors make attendance part of your grade. However, if your professor is aware you're registered with disability services, you won't be penalized for missing class and any classwork or test due to your IBD.
- There is also the possibility of "priority registration" with respect to scheduling classes. Therefore, instead of scheduling classes with other freshman, you may be able to schedule classes when juniors and seniors are scheduling. This can



be very helpful in having first choice of classes within time frames that work better for you. For example, if you know mornings are tough for you, priority registration increases your chances of scheduling classes that are later morning and afternoon.


- Other accommodations that may be available are sitting close to the door in the classroom, having extra time taking test, access to an assigned note taker and more.

If you choose to access disability services, they will require medical documentation from your GI doctor, which is easily attainable. Call your doctor's nurse, who will send you a letter to submit. Rest assured that any information you submit to disability services is confidential. Your professor may know you're registered with disability services but won't know the reason unless you would like them to.

Please note: every school can be different in what they require and what accommodations they will provide. By law, colleges and universities only have to provide what they deem as "reasonable" accommodations. So, there may be accommodations you require that they won't provide. Therefore, it's important to call and talk with someone in the disability services office while you're making your college visits to help make a choice about which school is the best choice for you.

You've chosen your college and accessed disability services. Now what?

- Familiarize yourself with campus bathrooms. Locate accessible private bathrooms that may be near your classes.
- Keep a list of doctor and hospital numbers accessible to roommates in the event you become sick or have an emergency.
- Think about buying a mini-fridge and stock it with foods you know you can eat and any medications that require refrigeration.
- Keep a calendar or planner, or cell phone alerts, to remind you to take your medication. Your college routine may be very different from high school, and this system of reminders can help you to stay on track and not forget to take your medicine. If you know you have a class schedule or plans with friends that coincide with the dosing timing of your medications, think about a way to carry your medications with you to ensure medication compliance.
- Think ahead about scheduling your regular doctor appointments to coincide with school breaks. If you're attending college out of town, you may consider finding a GI doctor locally to treat you in case of flare ups or for other medical



emergencies. Your CHOC IBD team is always available to assist with care as well. We can also arrange to see you during college breaks.

- Carry your own health insurance card (and prescription card if it is separate from your health insurance card). Make copies of the card for your room in case your wallet or purse is misplaced or stolen.
- Be knowledgeable about the interactions that alcohol and illicit drugs can have with your IBD medications.

You are not alone in making this transition from high school to college. The following is a resource that can offer you support as you make your way through these changes: www.cdfa.org/campus-connection/connect.

Transition to Adult Care

Because IBD is a lifelong condition, we will help your teenager learn to manage his or her own health care as they transition into a young adult. The IBD transition team's goal is to help promote independence, encourage decision-making and teach important skills for managing health needs.

As your child gets older, the transition team and your child's doctor will work with you and your child to gradually shift disease management responsibilities from parent to patient. These skills will be necessary as your child prepares to transfer from pediatric to an adult GI doctor.

We will assist with the process of transferring care to an adult gastroenterologist as your child becomes a young adult. Generally, this transfer of care will occur around the time of high school graduation or somewhere between your child's 18th to 21st birthday. However, some are not ready to transfer until after college graduation. We encourage young adults to participate in their medical care. The decision of when to transition the care of the patient is a discussed between the GI doctor, patient, parent and sometimes a social worker.

Some topics that will be addressed during this process:

- Changes to disease management responsibilities
- Adult health concerns such as work, school, sexuality, cancer surveillance and osteoporosis
- Worries or fears about transferring to an adult doctor
- Choosing a primary care physician and a gastroenterologist
- Medication and life insurance
- Obtaining medications
- Exercise and fitness
- Using alcohol and tobacco products

The IBD team at CHOC will assist with the transition of care including a list of adult gastroenterologists. We will strive to follow the hospital's vision of providing the highest quality care available for your child. We look forward to working with you to help your child lead a healthy and active lifestyle.

Sexual Relationships and IBD

A common cause for concern, although people do not always like to talk about it, is the potential impact of IBD on sex and sexual relationships.

Practicing Safe Sex with IBD

If you are having sex, it is important to consider use of condoms to protect against sexually transmitted infections (STIs) and pregnancy. Women with IBD taking oral contraceptives can be at increased risk of developing blood clots. Speak to your IBD team or Primary Care Physician if you have any concerns about contraception, how it might be affected by your IBD or drugs you take for your IBD.

Reproductive Health and IBD

Research suggests that in general men and women with Crohn's or ulcerative colitis who have not had surgery are just as fertile as those who do not have IBD. Most of the drugs prescribed for IBD do not affect fertility, but there are a few exceptions, including sulphasalazine and methotrexate, that should be avoided if you are trying to conceive a child.

**See: recommendations for medications and pregnancy*

Understanding the Impact of Smoking, Alcohol, Drugs and OTC Medications

- **Smoking:** Cigarette smoking increases the risk of lung cancer and birth defects. In Crohn's disease, it also increases the risk of having a flare. Smoking is known to trigger disease activity, increase the need the surgery and impair both intestinal and surgical healing.
- **Alcohol:** Consuming alcohol can affect the gastrointestinal tract and the liver. It can increase the risk of developing nausea, vomiting, GI bleeding and diarrhea. It can worsen IBD effects on the liver and lead to liver failure.
- Some IBD medications may interact with alcohol:
 - Metronidazole (Flagyl) can interact with alcohol and cause severe vomiting, flushing, sweating and headaches.
 - Alcohol can cause Methotrexate toxicity.
- **OTC Medications and Other Drugs:** Most non-steroidal anti-inflammatory drugs (NSAIDs) carry a risk of GI inflammation, even to a person without IBD. This risk is elevated in people with IBD. Examples of NSAIDs include Aspirin, Ibuprofen and Naproxen. Talk to your care team about what other pain medications are safe for you to use instead.

Herbal teas or supplements may have hidden ingredients that could interact with your IBD medications. Talk with your GI provider before considering herbal supplements.

Recommendations: Medication and Pregnancy

You should never start or stop taking medication while pregnant without first consulting your health care provider. If you become pregnant, here are some steps to help make sure you and your developing baby are properly cared for:

- **Always consult your doctor:** This is the first and most important step.
- **Read the Label:** Look for warnings or pregnancy indications. You should also look for potential allergic reactions as well as expiration dates.
- **Be aware of side effects:** Consult your health care provider or the pharmacist about potential side effects. Some medications cause side effects like sleepiness, headaches or vomiting, which may be enhanced because of pregnancy hormones.
- **Organize your medications:** Be careful to not mix up your medications to avoid overdosing.
- **Do not skip medications:** Take medications as prescribed by your health care provider.
- **Ask Questions:** It is always appropriate to ask questions about medication safety for you and your developing baby. Ask about the medication name, generic alternatives, benefits and risks and problems to watch for.
- **Keep Records:** It is always beneficial to keep a record of medications taken, whether pregnant or not. This becomes even more important if you are expecting.
- **Check Pregnancy Medication Registries:** The FDA has a new pregnancy and medication registry that you may find helpful:

Pregnancy medication categories:

- **Category A:** Controlled studies show no risk or find no evidence of harm.
- **Category B:** Animal studies show no risks, but there are no controlled studies in pregnant women.
- **Category C:** Animal studies have shown risk to the fetus, there are no controlled studies in women, or studies in women and animals are not available.
- **Category D:** There is positive evidence of potential fetal risk, but the benefits from use in pregnant women may be acceptable despite the risk (i.e. life-threatening condition to mother).
- **Category X:** Studies in animals or human beings have demonstrated fetal abnormalities, or there is evidence of fetal risk. The drug is contraindicated in women who are or may become pregnant.

IBD & Vaccines

It's important to keep up with childhood immunization to protect children against many infectious diseases. It is especially important for children with IBD to keep with the recommended vaccination schedule to prevent infections that can sometimes lead to flare-ups in IBD. If your child has IBD and is not taking any immunosuppressant medication, then there are no restrictions placed on receiving vaccinations, including the yearly flu vaccine.



Live vaccines are not recommended and should be avoided for IBD patients taking medications that weaken the immune system. Live vaccines can cause infection.

The flu vaccine injection (shot), which is **not** a live vaccine, should be given annually during the flu season.

People who are in close contact with someone whose immune system is suppressed can also pass on a disease to them after being vaccinated with a live virus vaccine. Always tell the doctor that your child is taking immunosuppressive medications, such as prednisone, immunomodulators or biologics, before any vaccine is administered to your child or other family members.

Inactivated Vaccines - The vaccines below are recommended for all patients with IBD, regardless of medications prescribed.	Live Vaccines - Avoid the vaccines listed in red while taking medications that weaken the immune system.
Diphtheria (DTaP, TDap)	Rotavirus (RotaTeq®)
Haemophilus influenza (HiB)	Intranasal flu vaccine (FluMist®)
Hepatitis A (Havrix®, Vaqta®, Twinrix®)	Measles, Mumps, Rubella (MMR)
Hepatitis B (Recombivax HB®, Twinrix®)	Chicken pox (Varicella, Viravax®)
Human Papilloma Virus (HPV) (Gardasil®, Cevax®)	Shingles (Varicella Zoster, Zostavax®)
Meningitis (Meningococcus) (Menactra®, Menveo®)	Smallpox
Pertussis (DTaP, TDap)	Yellow Fever
Pneumonia (Pneumococcus) (Pneumovax-23, Prevnar-13)	Oral Polio - The version taken by mouth is a live virus vaccine.
Tetanus (DTaP, TDap)	Typhoid (Oral vaccine)
Polio - The version given as a "shot" or injection is inactivated vaccine.	
Flu vaccine (Influenza) - The version given as a "shot" or injection is an inactivated vaccine. It is recommended annually.	
*Format modified from Crohn's and Colitis Foundation	

Recommended vaccination schedule can be retrieved from the CDC website:
<https://www.cdc.gov/vaccines/schedules/index.html>

Annual Reminders

Those with IBD can maintain the best possible health and well-being by keeping up with annual appointments or exams. Routine monitoring and screening of laboratory studies and special surveillance should occur.

This should include:

- **Eye exams with an ophthalmologist:** Approximately 10% of people with IBD experience eye problems. Most of these are treatable and do not pose any significant threat. If you notice any eye irritation or inflammation, bring it to your doctor's attention sooner rather than later. Although not everyone with Crohn's disease or ulcerative colitis will experience IBD-related eye conditions, a regular examination by an ophthalmologist is very important. Early detection of eye problems generally results in successful treatment and preservation of healthy vision. See <http://www.crohnscolitisfoundation.org/resources/eye-complications.html> for more information.
- **DEXA or bone scan to monitor evolution of bone strength/density**
- **Dermatology to monitor for any sores or rashes**
- **If on biologics:**
 - TB skin test or chest x-ray
 - Hepatitis vaccine
 - Flu vaccine
- **Depression screening**
- **Assessment of growth, development and nutritional status by a registered dietitian**

Reliable Websites

The internet is a great tool for information, research and support. With all the sites available, it can be hard to know if the information you find is trustworthy. Following a list of doctor-approved links to trusted online resources:

American College of Gastroenterology: www.gi.org

American Gastroenterological Organization: www.gastro.org

CCFA GI Tract Guide - Interactive Resource: www.gitract.ccfa.org

CHOC Inflammatory Bowel Disease (IBD) Program: www.choc.org/programs-services/gastroenterology/inflammatory-bowel-disease-ibd-program

Crohn's & Colitis Foundation of America: www.ccfa.org

Empowered by Kids: www.EmpoweredByKids.com

GIKids: A Resource for Pediatric Digestive Disorders: www.gikids.org

IBD University: A Site for Older Teens with IBD: www.ibdu.org

I'll Be Determined: www.ibdetermined.org

ImproveCareNow: www.improvecarenow.org

Just Like Me! Teens with IBD: www.justlikemeibd.org

North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASP-GHAN): www.naspghan.org

PDF versions of CCFA's most popular brochures and fact sheets are available online:

www.ccfa.org/science-and-professionals/programs-materials/patient-brochures

The Great Bowel Movement: www.thegreatbowelmovement.org

You and IBD: An Animated Patient's Guide to Inflammatory Bowel Disease: www.youandibd.com

Check out a full list of trusted online resources at:
CCFA.org/living-with-crohns-colitis/helpful-links.html

Reliable Apps

GI Monitor (Free - iPhone & Android) When it comes to IBD, providing accurate personal information to your doctor is vital. One patient went searching for an app that would help him do just that. When he couldn't find one, he created GI Monitor.

GI Buddy (Free - Desktop, iPhone & Android) GI Buddy has everything you need to stay on top of managing IBD. It is designed to help you easily and conveniently track important aspects of your IBD and create comprehensive views of your health to share with your healthcare team.

MyIBD (Free - iPhone & Android) Developed by doctors and patients for people living with diseases like Crohn's and colitis, it's packed with features that will help you and your doctor better understand your treatment.



SitOrSquat: Restroom Finder (Free - iPhone & Android) With SitOrSquat, we put clean public toilets on the map. Literally. Clean locations have with a green "Sit" rating. Less desirable ones have a red "Squat." You can even rate and review a bathroom and share your experiences to help others.

Doc4Me (Free - iPhone & Android) is a mobile application developed by The NASP-GHAN Foundation in collaboration with the Crohn's & Colitis foundation of America to help adolescents and young adults with IBD identify an adult practitioner whom to transition from pediatric to adult centered care.



FAQs

What is the difference between Crohn's disease and ulcerative colitis?

Crohn's disease and ulcerative colitis are the two types of inflammatory bowel disease (IBD).

Crohn's disease:

- Crohn's disease can affect any part of a child's intestinal tract
- Symptoms include diarrhea, bleeding, abdominal pain, tiredness, fever or weight loss
- Can affect the entire thickness of the intestinal wall
- Can affect any segment of the intestine, and can skip areas between affected segments

Ulcerative Colitis:

- Affects the colon
- Symptoms usually include abdominal cramps and diarrhea with bleeding
- Involves only the innermost lining of the intestinal wall
- Inflammation does not skip sections of the intestine

Is inflammatory bowel disease (IBD) the same as irritable bowel syndrome (IBS)?

No. While the symptoms may appear to be similar, IBD and IBS are very different. IBS causes pain, but there is no inflammation of the intestine, and it doesn't lead to serious disease, as with IBD.

How common is IBD?

Approximately 1.6 million Americans currently have IBD, and approximately 80,000 are children. The Crohn's and Colitis Foundation reports that as many as 70,000 new cases of IBD are diagnosed in the United States each year, with approximately 5% of all IBD cases in the US of Pediatric age, up to 20 years old.

Will my child always have IBD?

Currently, there is no cure for Crohn's. One treatment for ulcerative colitis is a colectomy, which will remove the diseased portion permanently. Research into better treatments and possible cures are ongoing.

Is IBD caused by stress?

No, there is no evidence that IBD is caused by stress. However, living with chronic illness can be stressful, and stress can contribute to a flare-up. At CHOC, psychologists are available to provide specialized care for children and teens with IBD.

Does my child need to follow a special diet?

There is no one single diet or eating plan that will do the trick for everyone with IBD. Dietary recommendations must be individualized, depending on which disease you have and what part of your intestine is affected. Furthermore, these diseases are not static. They change over time and eating patterns should reflect those changes. The key point is to develop a plan with your medical provider and strive for a well-balanced and nutritious diet.

Should my child restrict her physical activities?

If your child is feeling well enough to participate, physical activity is encouraged. In addition to many other benefits of exercise, it can help maintain bone density, which can be helpful for children with IBD. Your child's doctor will give you more specific advice about good activities for your child.

Will my child need to be hospitalized?

Typically, children can manage their IBD at home and do not require hospitalization. If symptoms become severe, a brief stay in the hospital may be needed so that we can correct malnutrition and stop diarrhea and loss of blood, fluid and mineral salts. Your child will be treated with a special diet, feeding through a vein, medications or, in some cases, surgery.




What is a flare or flare-up and what should I do if my child experiences one?

A flare-up is usually a recurrence of one or more of the symptoms that originally led your child to be diagnosed with IBD, such as diarrhea, rectal bleeding and cramping. Most people with IBD experience an occasional flare. If your child seems to be showing symptoms of a flare-up, it's a good idea to check with your child's primary doctor or gastroenterologist.

Patient Transition Checklist

	Basic Knowledge About IBD	I can do this on my	I can do this with some	I cannot do this, or I need a lot of help
1	I can tell others what my diagnosis is			
2	I can explain how my illness affects my body			
3	I can tell when I'm having a flare-up or when I need to go see the doctor			
4	I can list the foods and/or activities that make me feel bad or uncomfortable			
	Doctor Visits			
1	I can tell others the name of my Gastroenterologist (GI doctor)			
2	I answer questions during medical appointments			
3	I ask questions during my medical appointments			
4	I feel comfortable talking with my doctors/nurses if I don't like my treatment regimen or have difficulty			
5	I tell my doctors/nurses if I don't understand what they are talking about during medical appointments			
	Medication & Other Treatments			
1	I can name my medications and/or treatments			
2	I can tell others when I take each medication and how much			
3	I can tell others why I take each medication			
4	I can make changes to my medication as recommended by my Gastroenterologist (GI doctor)			
5	I can tell others what will happen to me if I do not take my medications correctly			
6	I can tell others what medications I cannot take because they might interact with the medication I already take			
	Disease Management			
1	I tell my parents/guardians when I'm running low on medication			
2	I call the pharmacy to get refills on my medications			
3	I call the doctor to schedule my medical appointments			
4	I know what other health services (ex., CCFA, social worker, dietitian, psychologist) are available to me			
5	I can prepare my medication in advance to accommodate long trips, vacations, overnights, etc.			
6	I know the name of my medical insurance company and carry the card with me always			

Bristol Stool Chart

	Type 1	Separate hard lumps	SEVERE CONSTIPATION
	Type 2	Lumpy and sausage like	MILD CONSTIPATION
	Type 3	A sausage shape with cracks in the surface	NORMAL
	Type 4	Like a smooth, soft sausage or snake	NORMAL
	Type 5	Soft blobs with clear-cut edges	LACKING FIBRE
	Type 6	Mushy consistency with ragged edges	MILD DIARRHEA
	Type 7	Liquid consistency with no solid pieces	SEVERE DIARRHEA

IBD Flare Guidelines: Know Your Body Signals and Stay Healthy



IBD Flare – Symptoms and Intervention Tool

When To Call Us

STOP & CALL

Any one or combination of these symptoms may show that you are having a FLARE

RED ZONE

IF YOU HAVE

- Ongoing, intense or worsening abdominal (belly) pain
- Abdominal distention
- Worsening fatigue or decrease in activity level – severely affected
- Persistent blood in bowel movements (above your baseline)
- Diarrhea/increased bowel movements (above your baseline)
- Nausea and/or vomiting
- Fever without an obvious source
- Joint pain not associated with overuse or trauma
- Change in appetite lasting longer than two days
- Skin changes; rash or open draining sores anywhere on the body

SLOW DOWN AND MONITOR

YELLOW ZONE

IF YOU HAVE

- Occasional abdominal (belly) pain
- Mild cramping
- Decrease in activity level – mildly affected
- Mild increase in bowel movement frequency lasting 1-2 days
- Increase in urgency to have bowel movement
- Waking up at night to have bowel movement or due to pain
- Change in appetite or energy lasting 1-2 days
- Increase in stress level

GREAT JOB!

Keep up the good work

GREEN ZONE

- Know your disease: Type (CD or UC), Location of Your Disease and Behavior
- Know your medicines and take them as ordered by your provider

STAY HEALTHY

- Manage your stress level: try yoga and deep breathing, stay social, get enough sleep, listen to music, exercise regularly, talk with friends, consider support group meetings
- Keep your follow-up doctor visits
- Complete your recommended IBD laboratory tests and procedures
- Refill your medications BEFORE they run out
- Look Before You Flush to check for blood and/or mucus in the stool on the toilet paper
- Eat a healthy diet – avoid trigger foods
- Let your parents/caregiver and your GI provider know EARLY when flare symptoms start

Source:
Arnold Palmer Hospital for Children, Orlando, FL.



www.choc.org