



CHOC's Guide for your IBD Road to Wellness





This manual is designed for parents and children living with Inflammatory Bowel Disease (IBD). Information about IBD is very important and patient education is mainstay of CHOC Children's Gastroenterology Division. We are dedicated to helping every parent and child to fully understand his/her disease and its management.

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

Items you may want to add to this binder:

- 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 Info (Crohn's and Colitis Walk)
 - Camp Oasis
 - Future Appointment Notes
 - 504 plan for school
 - Support Group Handouts and pamphlets
 - Misc.

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Meet Your CHOC IBD Team

My IBD Doctor is: _____

CHOC Gastroenterology Office Phone #: (714) 509-4099

CHOC Gastroenterology Scheduling Appointment Phone #: (888) 770-2462

IBD Nurse Coordinator: the nurse coordinator provides education about the IBD.

My IBD Nurse Coordinator: _____ Phone #: 714 509-4099

IBD ICN Coordinator: CHOC collaborates with ImproveCareNow (ICN), a national quality organization for IBD.

My ICN Coordinator: _____ Phone #: 714 509-4099

Social Worker: the clinical social worker supports your child and the family by providing counseling and community referrals in addition to collaborating with school staff.

My Social Worker: _____ Phone #: _____

IBD Dietitian: a registered dietitian's goal is to help families and children understand the role nutrition can play in IBD as well as be a resource and guide to help them achieve their nutritional goals so that they may grow and thrive.

My IBD Dietitian: _____ Phone #: _____

Office Locations:

CHOC Children's
1201 W. La Veta Avenue, Orange, CA 92868

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

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

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

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

**No matter what CHOC location you choose, your doctor will have access to all of your CHOC medical records.*

What to Expect from your IBD Team

Existing IBD Patient – New to CHOC

Upon referral, your first IBD Program visit will include:

- Physician evaluation and plan for treatment
- Education about IBD
- In-person or telehealth appointments with nutritionist for evaluation and diet planning
- Opportunity to consult with social worker for evaluation of school and mental health needs

After your first visit, subsequent visits will include:

- Physician evaluation and plan for treatment
- Nutrition and social work follow up as needed

Newly diagnosed post GI lab procedure (during follow up visit in GI clinic)

Your provider will meet you and family after the procedure in recovery to review findings. Please note, in many cases, there may not be results or a finding until the pathology report is completed, and will be shared at the follow-up appointment.

- Treatment plan
- Education about IBD
- In-person or telehealth appointments available with nutritionist for evaluation and nutrition planning
- In-person or telehealth appointments available with social worker for evaluation of school and mental health needs
- Follow up visit will be scheduled

Subsequent visits will include:

- Physician evaluation and treatment plan
- Nutrition and social work follow up, as needed

Newly diagnosed in hospital

Your provider will meet you and family after the procedure in recovery to review findings. Please note, in many cases, there may not be results or a finding until the pathology report is completed, and will be shared at the follow-up appointment.

- Treatment plan
- Education about IBD
- Due to the severity of illness, patient will be discharged when symptoms are improving and can tolerate intake of food and medication
- Nutritionist will meet with family in the hospital
- Psychologist or social worker will meet with family in the hospital
- Follow up visit will be scheduled

Subsequent visits will include:

- Physician evaluation and treatment plan
- Nutritionist and social work follow up as needed



About my Medical Condition

I was diagnosed with: _____

I was diagnosed on this date: _____

My IBD is located : _____

My first course of treatment will include: _____

Notes: _____

The CHOC IBD Program is a participant in



IMPROVECARENOW

The CHOC Inflammatory Bowel Disease Program is a participant in the ImproveCareNow (ICN) network, whose purpose it is to transform the health and care for all children and adolescents with IBD.

What is ImproveCareNow?

A community focused on getting kids with IBD better! ImproveCareNow is a nonprofit growing network of more than 80 pediatric gastroenterology centers spanning 36 states and London, with 765 pediatric gastroenterologists caring for 24,600 children with IBD. These centers are all working together to improve the care and outcomes for kids with inflammatory bowel disease (IBD). ImproveCareNow is a collaborative effort

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

How Does This Collaborative Work?

By sharing data and working together to get better, ImproveCareNow centers collect information about patients during clinic visits. Information from all of these centers is studied so that we can understand the best way to treat children with IBD. Knowledge is shared across the network, and individual centers receive reports twice a month to review their own performance and compare it to other centers and the entire network.

How Does This Improve Patient Care?

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.”

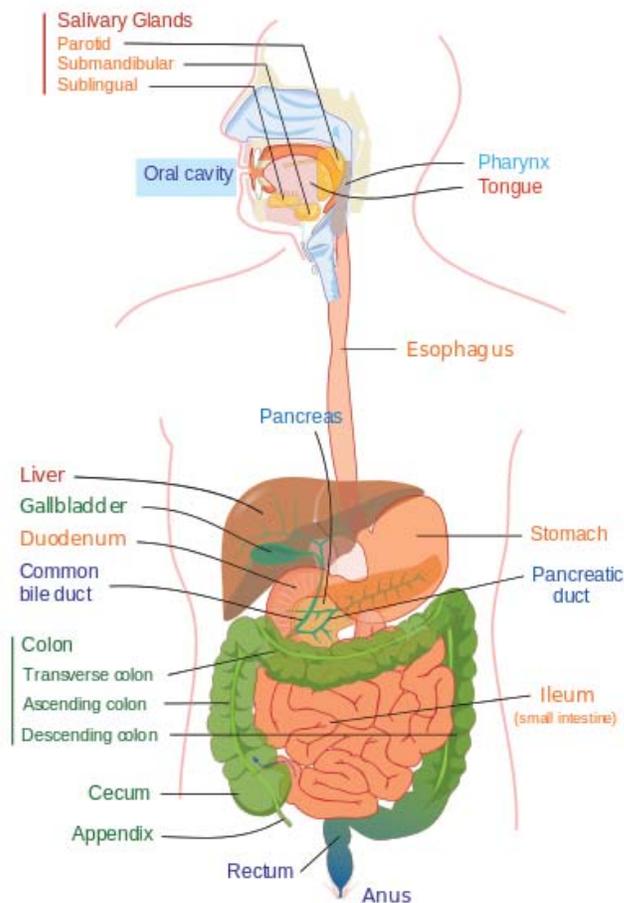
How Can You Help?

Every patient and every parent is an expert. As a strong family-centered network, ImproveCareNow values the critical role that parents and caregivers play as the people who most intimately understand their children beyond the clinic. To find out more about ImproveCareNow and how together, we can outsmart IBD, please visit www.devimprovecarenow.org/get_involved

Inflammatory Bowel Disease Overview

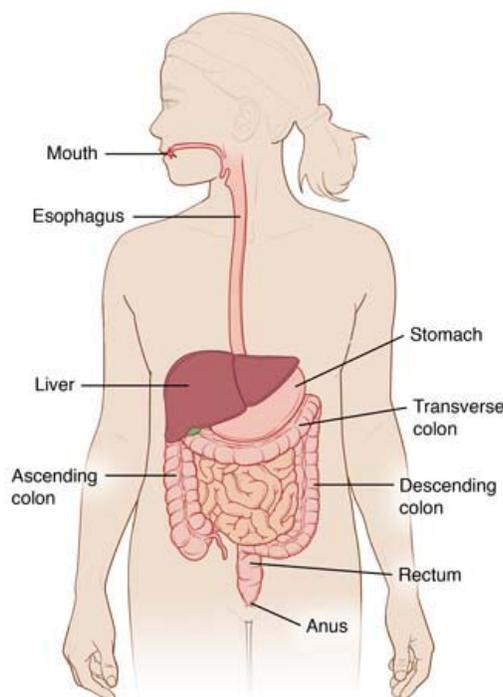
Inflammatory bowel disease (IBD) is a chronic condition caused by inflammation in the digestive tract. There are two main types of IBD—Crohn’s disease and ulcerative colitis. Each of these diseases can be disabling. Symptoms can include severe abdominal pain, diarrhea, fatigue, weight loss and cause growth failure. Because the symptoms of Crohn’s disease and ulcerative colitis are similar to those of other gastrointestinal conditions, the pediatric gastroenterology experts at CHOC Children’s Inflammatory Bowel Disease (IBD) Program use advanced diagnostics and the latest, evidence-based research to diagnose and create personalized treatment plans designed to help patients live their lives to the fullest.

It is estimated that over 1 million Americans suffer from 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 that are diagnosed with IBD.



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 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.



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 change.

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 physician experienced in diagnosing and caring for IBD.

Treatment Options for Crohn's

At this time, there is no cure for Crohn's disease. However, there are things that can be done to help control Crohn's disease. At CHOC, treatment plans are developed based on each patient's unique medical, physical, 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 extent and location of the Crohn's disease
- The child's tolerance for specific medications or therapies
- The family's opinion 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 aminosalicyclates, antibiotics, corticosteroids, immunomodulators and biologic therapies.

Diet and vitamin supplements: See IBD Diet and Nutrition section.

Integrative medicine: Some patients may benefit from integrative medicine techniques such as acupuncture and guided imagery. Additional approaches to therapy are discussed on a case-by-case basis.



Hospitalization: Children with Crohn's disease are sometimes sick enough to require 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 or, 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.

Types of surgery include:

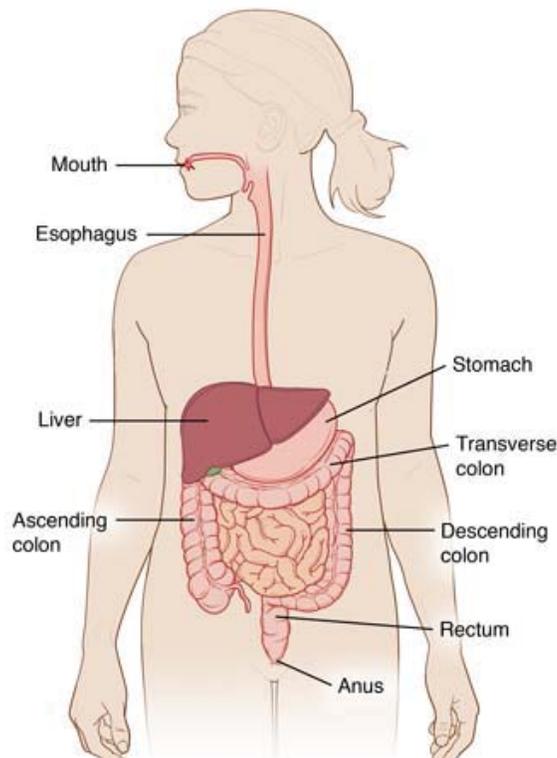
- Drainage of abscesses.
- Removal of a section of bowel due to blockage, stricture or fistula. This type of surgery may result in a shortened bowel that requires additional nutrition support.
- Some people must have part of their intestines removed and a new method of removing the stool from the body is created. The surgery to create the new opening is called ostomy 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 or 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 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 are able to control their bowel movements. This surgery is more common in ulcerative colitis patients but may be necessary 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. 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.

Treatment Options for Ulcerative Colitis

At CHOC, treatment plans are developed based on each patient's unique medical, physical, 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 will be 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 opinion or preference



Treatment may include the following:

- **Medication therapy:** The child's gastroenterologist may recommend one or a combination of medications that will help the intestine heal. The classes of medications available include aminosalicyclates, antibiotics, corticosteroids, immunomodulators and biologic therapies.
- **Diet and vitamin supplements:** See IBD Diet and Nutrition section.
- **Integrative medicine:** Some patients may benefit from integrative medicine techniques such as acupuncture and guided imagery. Additional approaches to therapy are discussed on a case-by-case basis.
- **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. The patient 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 massive 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. Learn more about surgery at CHOC.

The common surgical options:

- 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 waste). 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 are able to control their bowel movements.

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 his or her needs change.



What are the symptoms of ulcerative colitis?

The following are the most common symptoms for Ulcerative colitis. However, each child may experience symptoms differently. Symptoms may include:

- Abdominal pain
- Bloody diarrhea
- Urgency to stool
- Fatigue
- Weight loss
- Loss of appetite
- Rectal bleeding
- Fever
- Growth failure

Diagnosis 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. 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

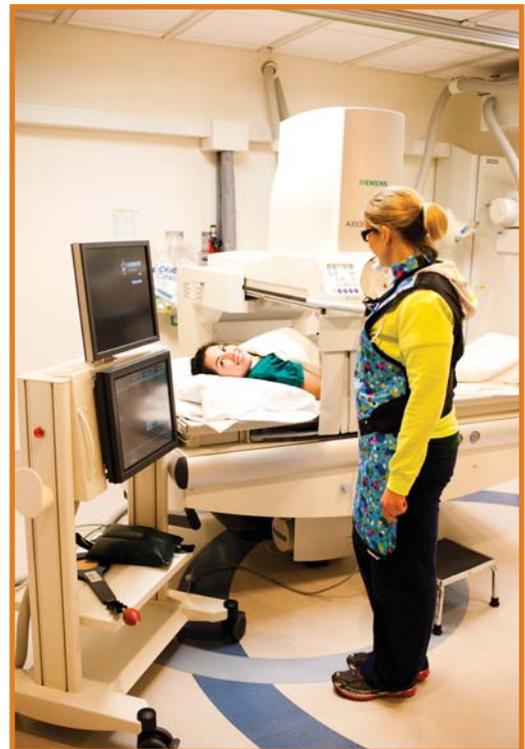
These tests look for evidence of blood loss or inflammation in the stool, or an infection by a parasite or bacteria causing the symptoms.

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 patient's status.



Push enteroscopy (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 similar to an EGD. Biopsies can be taken during this study. Note, that sedation is required for this procedure.

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.

Computed 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 show strictures (narrowed areas) and obstructions (blockages) of the large intestine. It does not show abnormalities in the lining of the intestine as well 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. Be sure to alert us of all allergies.
3. Your child will need to take medications as prescribed by the physician. 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 approval for refills. Call at least four days before you need the medication to give us time to process the request.
4. Maintain a list of ALL medications (prescription 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.
5. 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 regularly scheduled dose. DO NOT take a double dose. Contact your GI provider or the IBD team for advice about missing a medication dose
 - a. For medications that are three times per day: take at breakfast, after school and bedtime.
 - b. For medications that are four times per day: take at breakfast, lunch, supper and bedtime.
6. Many over-the-counter and prescription pain relievers containing 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 health provider. Products such as Tylenol® containing acetaminophen are fine for use.
7. Unless a physician 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, reduce inflammation and decrease discomfort. They may be given orally or rectally. There are 5-ASAs that are released at different parts of the bowel, which allow treatment where the disease is located.

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

These are drugs that usually bring on 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. Therefore, these medications may only 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, another 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.

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 the 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. We monitor labs closely while patients are on these medications, in order to determine if a child is tolerating the medication.

Biologics – Remicade (Infliximab), Humira (Adalimumab)

These are also called anti-TNFs (anti-tumor necrosis factor) and are newer treatments for IBD. These medications are given by IV Infusion or subcutaneous injection. Currently Remicade and Humira are the only pediatric approved anti-TNF medications. There are other biologics available and being developed that are available for adults and younger patients who have failed other therapies. There are possible side effects, so lab work is monitored closely. Entivyo (Vedolizumab) and Cimzia (Certolizimab) are other biologics that are considered for our patients.

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. Please let 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 a 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 process of inflammation.

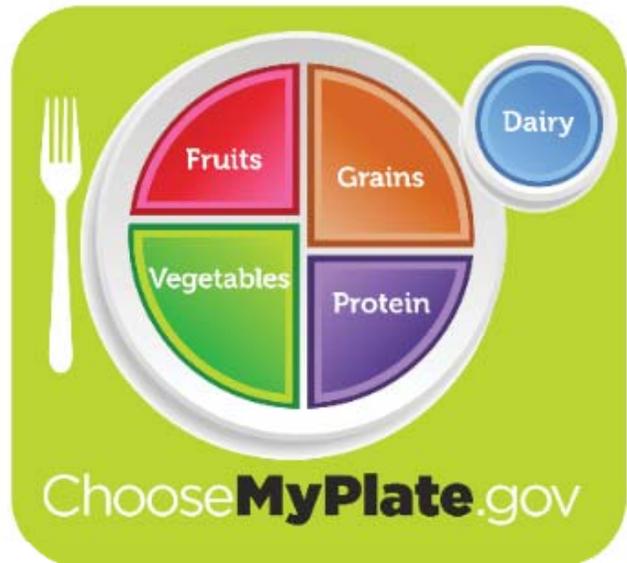
The CHOC IBD Program team includes a Registered Dietitian that can help provide more individualized support and guidance on optimal nutrition for your child's health. This chapter will provide basic information on diet and nutrition recommendations for the following scenarios:

- Eating Healthy
- During a Flare or Stricture
- Weight Loss
- Medication Use
- Vitamin/Mineral Supplementation

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, vitamins, minerals and fluids is best. This includes eating vegetables and fruits, whole grains (if not on low fiber diet), low-fat dairy, healthy fats, and lean protein sources.

The USDA ChooseMyPlate website www.choosemyplate.gov is a great resource for more information on building a healthy balanced diet.



Potential Food Intolerances/Sensitivities

Some children or teens with IBD may have intolerances or sensitivities to certain foods. These include high fiber or fat, lactose, caffeine, sugar alcohols or spicy flavors. It may be helpful to keep a food journal to track and identify any bothersome foods. Below is more information on these foods and recommended modifications:

Fruits and Vegetables:

- Peel, cook or puree fruits and vegetables to reduce roughage and improve tolerance
- Juice raw vegetables to remove the fiber
- Limit or reduce intake of gas producing vegetables like broccoli, Brussel sprouts and cabbage
- 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
- Limit fruit serving to 4 ounces per day

Grains:

Fiber content of whole grain foods may make it hard to digest. Choose more refined grains like white bread, white rice, regular pastas, cereals

Dairy:

- Lactose intolerance can occur
- Choose dairy free milk but make sure it is fortified with Calcium and Vitamin D. Options include lactose free milk, almond milk, coconut milk and rice milk

Protein:

- Lean meats, chicken, eggs, nut butters, tofu are excellent and generally well tolerated protein sources
- Whole beans, nuts and seeds may be more difficult to digest. Consider pureeing or blending when consuming

During a Flare or Stricture

This may also be referred to as a “Low Residue Diet.” During a flare, it is important choose foods that are easiest to digest. With a stricture, certain foods are at risk of getting stuck causing a blockage. This means avoiding foods high in fiber and fat as well as sugar. Consider the following when you are having a flare or stricture:

- Eat cooked, pureed or peeled fruits and vegetables
- Choose refine (white grain) products instead of whole grain
- Avoid high fat, greasy or fried foods
- Avoid nuts and seeds
- Avoid sweetened beverages like juice, soda and sugary foods like candy and desserts
- Consider using lactose free dairy products if regular dairy products are bothersome
- Eat more small frequent meals instead of large meals
- Chew food well as this helps with digestion
- Drink lots of water



Weight Loss

Your child or teen is at risk for weight loss or poor growth due to IBD inflammation, which can cause diarrhea, vomiting, nausea, loss of appetite and fatigue. This leads to weight loss and the inability to absorb the nutrients the body needs from the foods being eaten. Malabsorption can also contribute to weight loss since important nutrients aren't being absorbed well. Close monitoring of nutritional labs and growth is needed with IBD. 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), a side effect of steroids. Steroid 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 and methotrexate, a 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 mineral levels can be monitored using blood tests. Below are a few of the vitamins and minerals that are of special concern:

- Vitamin B12
- Calcium
- Vitamin D
- Folic Acid
- Magnesium
- Zinc
- Iron

Individualized Nutrition

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 promote healthy eating and growth.

There are many special diets on the web that may be helpful and or promising. Should you come across a diet that you want more information on, please contact our IBD 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 of 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 Children’s has many resources available to help you and your child, such as social services, child life, and the CHOC IBD website.

Our IBD team will be able to assist with referrals to our CHOC psychology department 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.

Educational Tools:

- **Crohn's Disease & Ulcerative Colitis: A guide for teachers and other school personnel**
 - www.ccfa.org/assets/pdfs/teachersguide.pdf
 - A guide to help teachers and other school personnel understand these chronic intestinal illnesses.
 - Ask your teachers, school nurses, & guidance counselor to download this guide.

It has information specifically to help them understand IBD, its effect on you, and what they can do to help.

- **Taking IBD to School:** www.ccfa.org/resources/taking-ibd-to-school.html
- **Just Like Me: Teens with IBD – School & IBD:** www.justlikemeibd.org/life/school/



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 Education Act (IDEA). These laws allow the schools to provide any necessary accommodations, from preschool through college.

Communicate 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 and location of bathrooms for outdoor activities
- Any diet modifications necessary
- Exercise and activity with the 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 stays, CHOC Children's provides a teacher through our Child Life Department. Homebound instruction may be needed with special circumstances for illness, but should be considered as 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



Choosing a college

Deciding what school 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 for 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. During your visit to a college, it's helpful to locate and be mindful of the following:

- Locating and contacting the school's disability services office (we'll talk more in detail below about 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, ED, 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 for additional privacy in campus living, if you're planning to attend college out of town or live on campus. For example, instead of having to share a bathroom with, let's say 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 tests due to your IBD.
- There is also the possibility of "priority registration" with respect to scheduling classes. Therefore, instead of scheduling classes with other freshmen, 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 and your IBD. 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 to take tests, assigned note taker, or more.

If you choose to access disability services, they will require medical documentation from your GI doctor, which is easily attainable. Just call your doctor's nurse and she will send you a letter to submit. Also, please be reassured 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 that every school can be different in what they require to 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 request which 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 and your IBD.

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 which need to be refrigerated.
- 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 scheduled or plans with friends that coincide with the dosage 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 other emergencies. CHOC providers are always available to assist with care as well. We can also make arrangements to see you during college breaks.
- Make two copies of your health insurance card (and prescription card, if you have one). One copy is for your wallet or purse. Keep the second copy in your dorm room, in case your wallet or purse is stolen.
- We know that alcohol and drugs can be a part of the "college culture". Be knowledgeable about the interaction of alcohol and drugs can have with your IBD medications.



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

Transition of 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 providers 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 the pediatric setting 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 discussed between the GI provider, 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
- Medical and life insurance
- Obtaining medications
- Exercise and fitness
- Use of alcohol and tobacco products

The IBD team at CHOC Children's 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 life.

IBD & Vaccines



Patients with IBD should receive vaccines on the same schedule as other children. This includes a yearly flu vaccine. This is especially important because many IBD medications can suppress or slow down the immune system. Infections can be more serious for patients that are taking these medications.

If you are taking medications that affect your immune system, you should not receive live-virus vaccines such as the nasal flu mist and the chicken pox vaccine.

The status of your immunizations should be checked before you start many IBD medications, if possible. If you have any questions about vaccines, please discuss with your gastroenterologist.

Annual Reminders

Your child will be asked to keep up with health maintenance. Some of these may include:

- **Eye Exams with an ophthalmologist:** Approximately 10% of people with inflammatory bowel disease experience eye problems. Most of these are treatable and do not pose any significant threat as far as loss of vision is concerned. Still, if you notice any type of 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. (<http://www.crohnscolitisfoundation.org/resources/eye-complications.html>)
- **DEXA or bone scan**
- **Dermatology**
- **If on biologics:**
 - TB skin test or chest x-ray
 - Hepatitis vaccine
 - Flu vaccine
- **Depression Screen**
- **Dietitian and Nutrition update**

Reliable Websites

The internet is a great tool for information, research and support. With all of the sites available, it can sometimes be hard to know if the information you find is trustworthy. We have put together 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: Brand New Interactive Resource: www.gitract.ccfafa.org

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

Crohn's & Colitis Foundation:

www.crohnscolitisfoundation.org/living-with-crohns-colitis/helpful-links.html

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.naspgghan.org

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

Reliable Apps

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 inflammatory bowel disease and create comprehensive views of your health to share with your healthcare team.

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

MyCrohnsandColitisTeam: Free ~ iPhone & Android. Social networking app dedicated to those who are living with Crohn's or colitis designed to connect you with others battling the same challenges as you.

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.

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FAQ's

What's 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 different segments of the intestine, skipping some of the middle

Ulcerative Colitis:

- Affects the colon, and occasionally the lowest part of the small intestine
- Symptoms usually include abdominal cramps and diarrhea with bleeding
- Involves on 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 can cause 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 are of Pediatric age, which is up to age 20 years old.

Will my child always have IBD?

Currently, there is no cure for Crohn's. A last resort of treatment for Ulcerative Colitis is a colectomy, which will remove the diseased portion permanently. Research into better treatments and possible cures is ongoing.

FAQ's

Is IBD caused by stress?

No, there is no evidence that IBD is caused by stress. However, living with a 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 come up with a plan with your medical provider and strive for a well-balanced, healthy diet.

Should my child restrict her physical activities?

If your child is feeling well enough to participate, physical activity is encouraged. In addition to the many other benefits of exercise, it can also help maintain bone density, which can be very 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 the loss of blood, fluids 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-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-up. If your child seems to be showing symptoms of a flare-up, it's a good idea to check in with your child's primary care doctor or gastroenterologist.

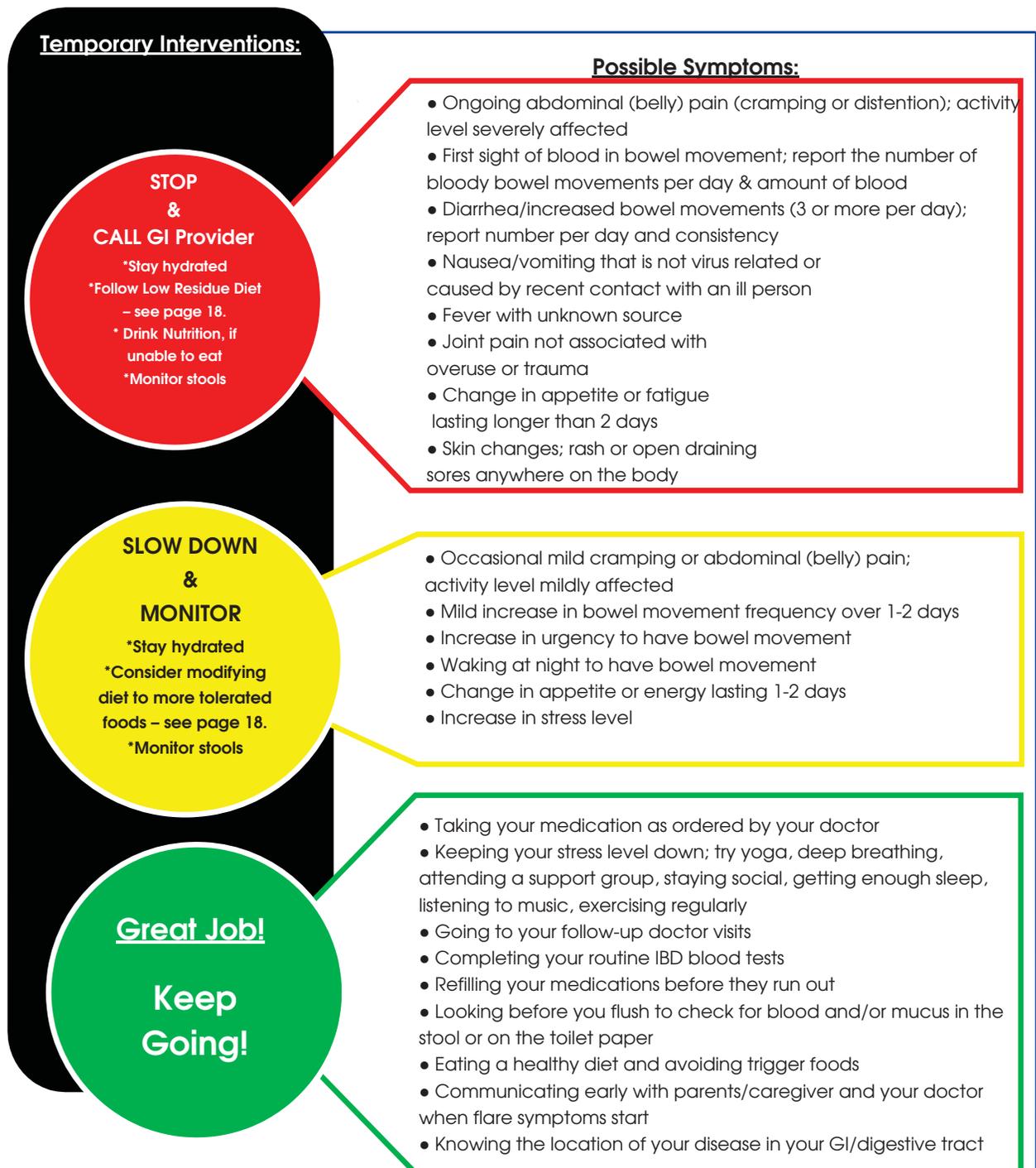
Patient Transition Checklist

	Basic Knowledge About IBD	I can do this on my own with no help from others	I can do this with some help from others	I cannot do this or I need lots of help from others
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 following it.			
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 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, dietician, 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

BRISTOL STOOL CHART			
	Type 1	Separate hard lumps	Very constipated
	Type 2	Lumpy and sausage like	Slightly constipated
	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	Inflammation
	Type 7	Liquid consistency with no solid pieces	Inflammation

IBD Flare Guidelines know your Body Signals and Stay Healthy



Note: The above information is to be used as a patient education guide. We encourage you to call our office if you have any questions or concerns.

Modified from document originally created at Miller Children's & Women's Hospital in Long Beach, CA. Thank you for sharing this very helpful document.

