Inflammatory Bowel Disease Handbook

Seattle Children's
HOSPITAL • RESEARCH • FOUNDATION

This notebook belongs to:_____

For all non-urgent needs please send us a MyChart message
Main hospital: (206) 987-2000 / toll free (866) 987-2000

Children's Gastroenterology Clinics
(Contact the clinic where your child was seen)

	Phone	Fax
Seattle **Bellevue**	206-987-2521	206-987-2721 206-985-3375
Everett	425-783-6400	425-783-6205
Federal Way	253-838-5878	253-838-1962
Olympia	360-459-5009	360-459-8785
Tri-Cities	506-582-1700	509-946-0983

Please allow for 3 business days for responses to routine messages and medication refills. For urgent questions, please call the above numbers during business hours.

Nights, weekends and holidays, please call the Seattle Children's Operator at 206-987-2000 toll free 866-987-2000 and ask for the gastroenterology (GI) provider on call.

Letter to Families

Dear Families,

Receiving news that your child has been diagnosed with **I**nflammatory **B**owel **D**isease (IBD) — whether it is Crohn's Disease, Ulcerative Colitis, or Unclassified IBD can feel overwhelming and raise many questions. This guide was created to help you better understand IBD, explore treatment options and know what to expect moving forward. Inside, you will also find a list of resources to support you on this journey.

Becoming familiar with your child's condition will help you feel more comfortable and prepared. We encourage you to write down any questions you have before your child's appointment so we can address them during your visit. If you have an urgent concern that you need addressed prior to your appointment, please reach out to your child' provider through MyChart or call the Gastroenterology clinic.

Our dedicated team is here to provide you and your child with the information you need to make the best decisions for their care. We look forward to partnering with your family on this journey towards better health.

Sincerely,

Your Seattle Children's IBD team

Contents

About the IBD Center

Your IBD Care Team

Our IBD team works together to provide the best treatment with care and kindness. Your child's medical treatment is our top priority. We are here to help your child adjust to this illness and take care of both their physical and emotional needs.

Your care team includes the following:

- Pediatric gastroenterologist
- Pediatric psychologist
- Pediatric nurse practitioner
- Physician assistant
- Registered nurse
- Dietitian
- Social worker
- Medical assistant

The Role of Your IBD Care Team

The **doctors** take care of your child's health and work with your family to decide the best treatment. The **nurses** are there to teach and support your family. Let them know about any concerns or questions you may have. They work closely with the doctors to make sure all your questions about your child's care are addressed. The **dietitians** help with any food or nutritional questions. The **social workers** help you get the right support for your family. They can work with your child's school to make sure they get the right accommodations and can also help with money-related concerns. Social workers can be your biggest supporter, advocate, and problem solver when dealing with the complicated healthcare system. Our **psychologist** may meet with you and your child at the first visit to help with adjusting to the diagnosis and making sure IBD has the least impact on your child and family.

Inflammatory Bowel Disease Defined

What is Inflammatory Bowel Disease?

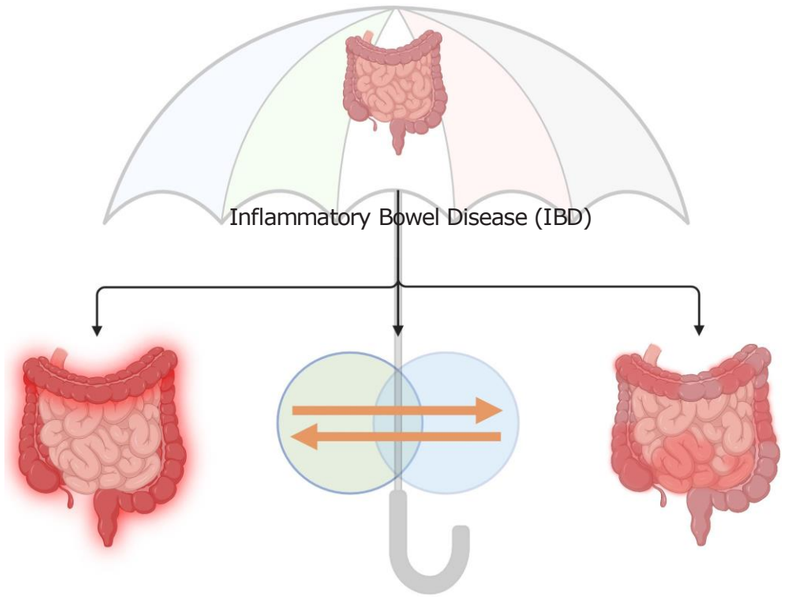
Inflammatory Bowel Disease (IBD) is a long term (chronic) inflammatory condition of the gastrointestinal (GI) tract. The most common types of IBD are Ulcerative Colitis and Crohn's disease.

In some cases, patients may be diagnosed with "unclassified IBD", which means they have findings of both Crohn's and Ulcerative Colitis, making it harder to get a clear diagnosis. It is estimated that between 2.4 and 3.1 million Americans have IBD. The disease is becoming more common, especially in people under 25 years old.

Crohn's disease and Ulcerative Colitis are chronic conditions, meaning they last throughout a person's life. With proper treatment, most people with IBD can become symptom-free (in remission) and live happy, healthy lives.

Even with treatment, people with IBD may still experience flares—periods when symptoms worsen. Flares can happen more frequently within the first few years after diagnosis while your doctor figures out the best treatment plan. They are often managed with medications.

It is important to distinguish IBD from Irritable Bowel Syndrome (IBS). IBS affects how the colon moves and feels but does not cause inflammation in the intestines. If a person with IBS were to have a colonoscopy, the results would typically be normal. While IBS is not related to Crohn's or Ulcerative Colitis, a person can have both conditions.



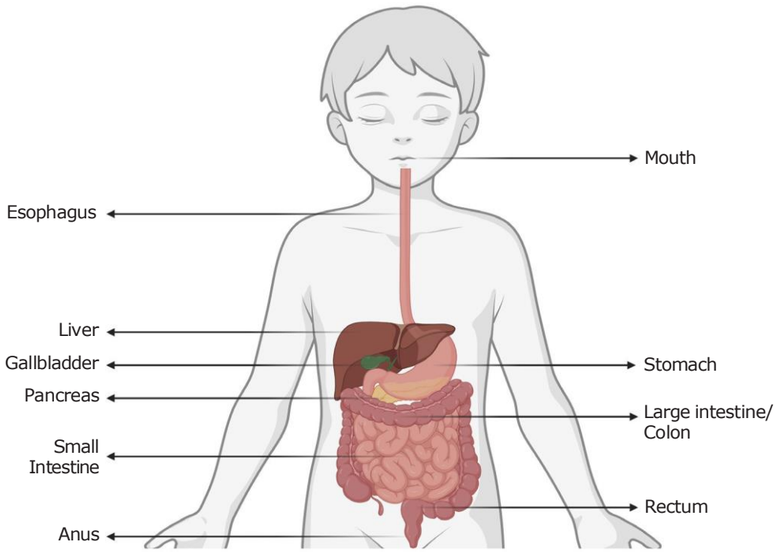
What caused IBD in my child?

IBD is caused from a combination of genetics, immune system dysfunction, and environmental factors such as diet and infections. However, we still do not fully know why some people get IBD and others do not. Research on IBD is advancing each year, with new findings helping us understand this complicated condition better. **If IBD is not treated, inflammation in the body can continue causing long-term symptoms and problems.**

It is important to understand that nothing you or your family did- or did not do - caused IBD. Even though there is a genetic link, most people with IBD do not have a family member with IBD. Also, just because you have IBD does not mean your children will get it.

What are the differences between Ulcerative Colitis and Crohn's disease?

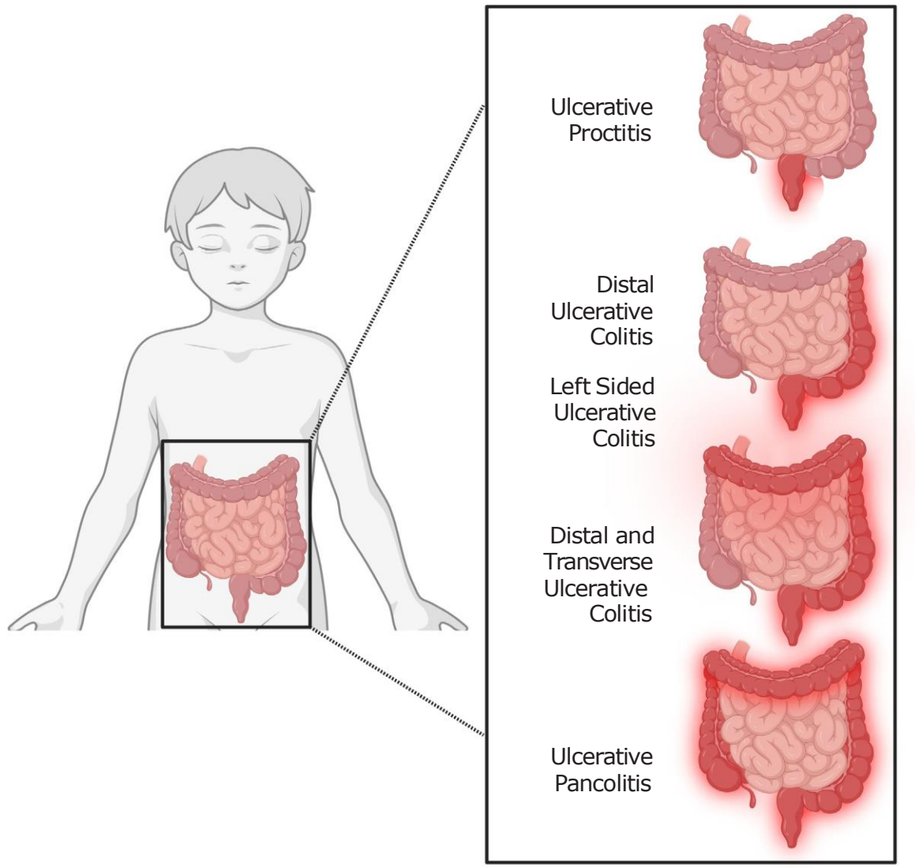
To better understand the differences between Ulcerative Colitis and Crohn's, it is important to know the basic anatomy of the GI tract.



When a person eats food, it is chewed in the mouth and swallowed. It travels down the esophagus to the stomach where it is broken down further. From there, it moves into the small intestine, where nutrients are absorbed into the bloodstream. As the food continues through the small intestine, it becomes liquid poop and reaches the colon (or the large intestine). The colon's job is to absorb the remaining water and form solid poop, which is stored in the rectum until it is time to poop.

Ulcerative Colitis

Ulcerative Colitis (UC) only affects the colon (large intestine) and does not involve the small intestine. The inflammation starts in the rectum and spreads upwards though the colon, affecting different areas in different people. Unlike Crohn's disease, the inflammation is not as deep and only affects the innermost layer of the intestine that is in contact with the poop.



The first symptoms of UC usually include loose stools that may be bloody, abdominal cramps, and a strong urge to have a bowel movement (tenesmus). Diarrhea can start slowly or happen very suddenly. Some children may also lose their appetite, which can lead to weight loss and feeling tired. In severe cases, heavy bleeding can cause anemia, or low blood counts. Symptoms of UC sometimes affect areas outside of the intestines, including joint pain, skin rashes, eye inflammation, and liver problems.

About half of people with UC have mild symptoms, like occasional diarrhea or stomach discomfort. But some people may have more severe symptoms, such as bad stomach pain, nausea, heavy bleeding, and fevers. Symptoms can come and go, with periods of feeling better, followed by flares where symptoms get worse.

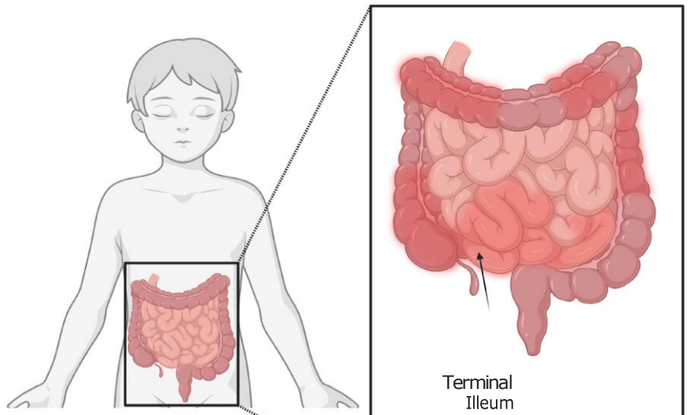
Though serious complications are rare, they can still happen if the disease is not well controlled. These complications can include an increased risk of colon cancer, especially if someone has UC for many years.

Most people with UC feel better with medication, but some do not respond to it and might need surgery to remove their colon. In UC, removing the colon stops the source of the inflammation. This is considered a cure for UC. Surgical options are explained later in the book.

Crohn's Disease

Crohn's Disease can affect any part of the digestive tract, from the mouth to the anus. Unlike Ulcerative Colitis, which causes continuous inflammation in the colon, Crohn's disease causes patchy inflammation in the intestines. This means some areas of the digestives system are healthy, while others are inflamed.

Inflammation in Crohn's can be deeper, affecting all layers of the intestine, not just the inner layer that comes in contact with the poop. The most common place for Crohn's disease to occur is in the terminal ileum (TI), which is the end of the small intestine.



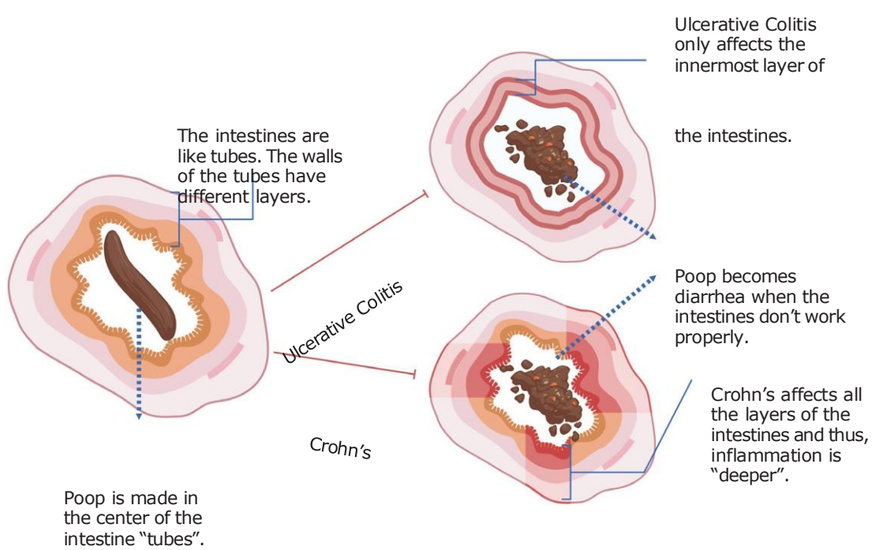
Crohn's disease involving both the small intestines and colon

The symptoms of Crohn's disease include diarrhea, abdominal cramps, fever, and rectal bleeding. It can also cause poor growth or delayed puberty. Some children may also lose their appetite, which can lead to weight loss and feeling tired. Like Ulcerative Colitis, Crohn's disease can cause problems outside the digestive system, such as mouth sore (ulcers), joint pain, eye inflammation, skin changes, and liver problems.

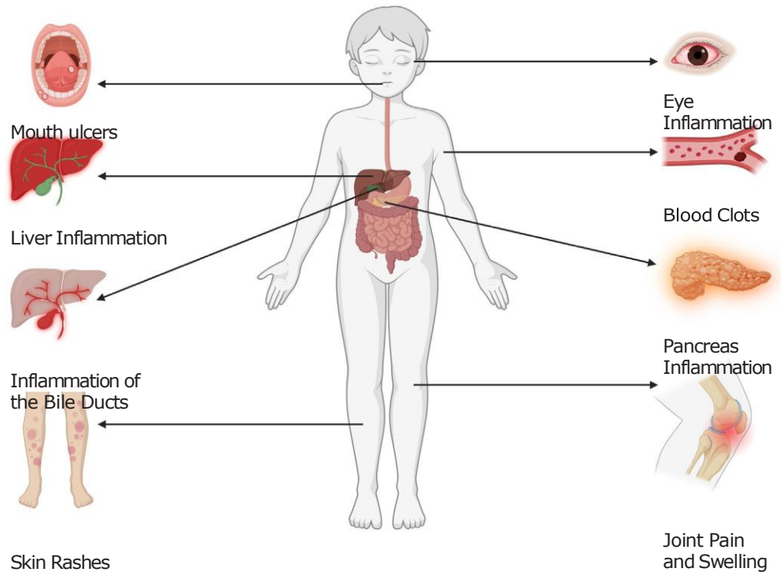
A serious complication of Crohn's disease is an intestinal blockage, caused by swelling and scar tissue. Symptoms of a blocked intestine include severe abdominal pain, bright green (bilious) vomiting, bloating, and dehydration. Another serious problem is a fistula, which is an abnormal connection between parts of the intestines or other organs. A common type of fistulas is between the rectum/anus and the skin around the buttocks (perianal fistula). While rare, fistulas can become infected and form an abscess.

Some patients with Crohn's disease may need surgery if medications do not work or if there are serious complications. However, unlike Ulcerative Colitis, surgery does not cure Crohn's disease.

Comparing the depth of inflammation in the lining of the intestines between UC and Crohn's



The Extraintestinal (outside the intestine) findings of IBD



Sometimes, people with IBD can have health problems outside of their intestines (extraintestinal). This seems to be connected to the immune system. Normally, the immune system helps protects us from illness, but in people with IBD, it can become too active and cause inflammation in other parts of the body.

While extraintestinal manifestations are uncommon, it is important to know about them to talk with your doctor if you notice any symptoms or changes in your condition. Catching problems early can help with better treatment and care.

Lower your risk of extraintestinal complications

You can take steps to lower your chances of having extraintestinal complications:

- Keep up with your IBD treatment to help control inflammation and support your immune system.
- Live a healthy life - eat fruits and vegetables, exercise or play regularly, and avoid smoking.
- See your doctor regularly and ask about eye exams and bone density testing.

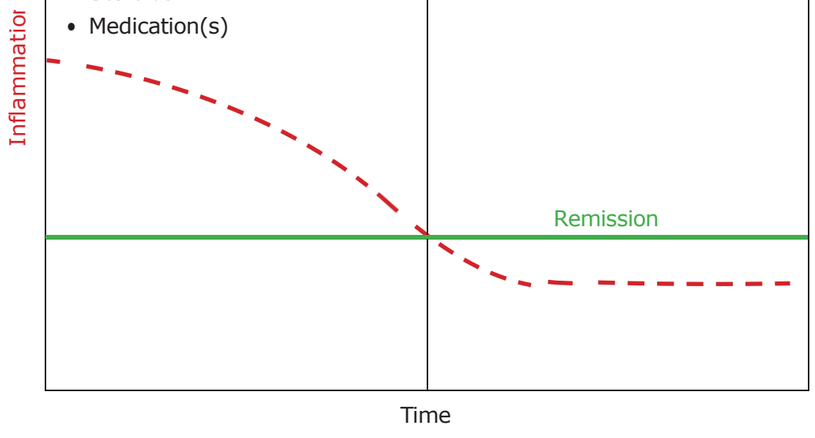
Treatment Options

Every child with Inflammatory Bowel Disease (IBD) needs a plan that fits them best. Doctors create treatments based on how serious the disease is and where it affects the digestive system. This helps manage symptoms and keeps your child as healthy as possible.

We treat IBD in 2 steps:

1. **Induction phase (feeling better and achieving remission):** At first, the goal is to quickly reduce inflammation in your child's digestive system. This typically starts right after they are diagnosed.
2. **Maintenance phase (sustaining remission and staying healthy):** As symptoms like loose/bloody stools or abdominal pain improve, our team will work with your family to find the best long-term plan to keep your child's IBD under control. Our goal is for your child to achieve and maintain remission. While many children respond well to early treatment, some might need extra time or changes to their treatment plan in the first few months or years after diagnosis to find what therapies work best for them.

Induction Phase	Maintenance Phase
• Exclusive enteral nutrition (Crohn's only) • Steroids • Medication(s)	• Medication(s)



Nutritional Therapy

Some treatments for Crohn's disease and Ulcerative Colitis focus on diet. Here are some options that may help manage symptoms and improve health. Managing IBD through nutrition can be a powerful tool - your doctor and dietitian are here to help every step of the way.

Exclusive Enteral Nutrition (EEN)

EEN is a special nutrition plan where your child only drinks a nutrient-rich formula for 4 to 8 weeks, either by mouth or by a feeding tube. During this time, they can only have formula and water, with no other foods or drinks. While this might sound tough, EEN has very few side effects and is proven to heal the intestines better than standard medicines.

EEN changes gut bacteria, reduces inflammation, and helps the intestine heal. It is used to treat active Crohn's disease and help children feel better and move into long-term treatment. However, EEN is not a treatment option for Ulcerative Colitis.

Other benefits of EEN include better weight gain, stronger bones, and overall improved nutritional status. Throughout the treatment, your child's weight, growth, and labs will be closely monitored. A GI dietician will also be available to support you through the process.

Mediterranean Diet or a Traditional Whole Foods Diet

The Mediterranean diet or a traditional whole foods diet are less strict and focus on high fiber, low fat, while limiting red meat, processed, and sugary foods. This diet can help both Crohn's and Ulcerative Colitis when used with medications. Research shows that eating whole, natural foods improve nutrition, helps with symptoms, and lowers inflammation. This diet is commonly recommended for most patients with IBD, as it has also been shown to benefit other chronic medical conditions. Be sure to discuss it with your doctor.

Specific Carbohydrate Diet (SCD)

This diet is for patients with Crohn's disease and Ulcerative Colitis. It is a nutritionally complete diet that removes grains, sugars (except for honey) and dairy (except for hard cheese and yogurt fermented for more than 24 hours). The SCD also removes highly processed foods.

The idea behind SCD is that some carbohydrates are hard to digest and may lead to the growth of bad bacteria, causing more inflammation. By limiting these carbohydrates, this diet aims to lower inflammation and possibly help achieve remission. While many patients have seen benefits, there is still research being done to better understand the diet's effectiveness. Our GI dietician will work closely with you to explain the details and provide support for this diet.

Online resources for SCD

- Nutrition in Immune Balance: nimbal.org
- Nutritional Therapy for IBD: nutritionaltherapyforibd.org
- Crohn's and Colitis Foundation: youtube.com/watch?v=siLnfV46NpA&t=2s

Crohn's Disease Exclusion Diet (CDED)

The CDED is a flexible diet plan that helps manage Crohn's disease using a whole foods approach. It removes dairy, wheat, red meat, animal fats, additives, and highly processed foods. Instead, it recommends eating chicken, eggs, potatoes, apples, and bananas every day.

Most children on CDED also use partial enteral nutrition (PEN) which means they drink a special formula to make sure they get all the nutrients they need. The diet happens in 3 phases, slowly adding more foods overtime. Our GI dietitian will work closely with you to outline the details of what your child can eat at each phase.

A free mobile app is available to make following the CDED easier. If you are interested, your doctor can help get you signed up.

The 3 Phases of CDED

Phase	Calories from formula	Calories from food
Phase 1 (6 weeks)	50%	50% from select foods
Phase 2 (6 weeks	25%	75% from expanded food list
Phase 3 (12+ weeks)	25%	75% from even more expanded food list

For more information on the CDED visit: mymodulife.com

Medical Therapies

Disclaimer: Therapies are being developed and can change quickly. This list of medications may also change. Check with your doctor about the most updated list of medications.

Your doctor will help you choose the best medicine for your child based on the type of IBD they have and how severe it is. Below are some commonly types of medicines used to treat IBD.

Corticosteroids

- What they do: Reduce inflammation quickly, usually within a few days to a week.
- Used for: Short-term treatment of Crohn's and Ulcerative Colitis.
- Side effects: Weight gain, sleep problems, mood swings, weak bones and can increase the risk of infections (usually mild).
- Important: Not for long-term use.

Aminosalicylates

- What they do: Reduce inflammation in the intestines by targeting the inflammation directly in the colon and rectum.
- Used for: Mild to moderate Ulcerative Colitis.
- Side effects: Rarely, can worsen colitis symptoms.
- Important: Does not suppress the immune system.

Immunomodulators

- What they do: Reduces inflammation in the intestines.
- Used for: Often combined with biologics to make them work better. Can also be used alone for Crohn's and Ulcerative Colitis.
- Side effects: Suppresses the immune system which can increase the risk of infection (usually mild).
- Important: Helps maintain remission.

Biologics/Biosimilars

- What they do: Target specific proteins in the immune system to reduce inflammation.
- Used for: Crohn's and Ulcerative Colitis.
- Side effects: They suppress the immune system and can increase the risk of infections, usually mild.
- Important: There are many different kinds of biologics.

Antibiotics

- What they do: Treat infections in the intestines or abdomen.
- Used for: Additional treatment for IBD, especially during flares or when other medications do not work.
- Important: Help reduce bacteria in the gut to decrease inflammation.

Targeted Synthetic Small Molecules

- What they do: Reduces inflammation in the intestines.
- Used for: Crohn's and Ulcerative Colitis
- Important: All medications are oral

For the most up to date information on medications, please visit
https://www.crohnscolitisfoundation.org/

Medical Therapies for IBD

	5-ASA or the Mesalamines	Immunomodulator	Anti-TNF (biologic)	Integrin Inhibitors (biologic)	JAK Inhibitors (small molecules)
Medication Brands	Asacol Lialda Pentasa Colazal Apriso Rowasa enema Canasa Suppository	Azathioprine Methotrexate	Infliximab (Remicade) Adalimumab (Humira) Golimumab (Simponi)	Vedolizumab (Entyvio)	Tofacitinib (Xeljanz) Upadacitinib (Rinvoq)
Form of Medication	Tablet/Capsules/ Liquid Rectal enema/ suppository	Oral tablets/Liquid	Infusions Injections	Infusions	Oral Tablets
Side Effects	Allergy Headache Nausea Dry skin Pericarditis (rare) Kidney injury (rare)	Allergy Pancreatitis Infection Hepatitis Anemia Skin cancer (rare) Lymphoma (rare)	Allergy Psoriasis Lymphoma (Rare) Infusion site irritation Injection site irritation	Allergy Headache Joint pain Nausea Extremity pain Muscle pain Infusion site irritation	High Cholesterol Acne Folliculitis Flu symptoms Vomiting Diarrhea Low blood counts Blood Clots

Medical Therapies for IBD

	IL-23 and IL-12 Inhibitors (biologics)	IL-23A Inhibitors (biologics)	S1p1 and S1p5 receptor binders (small molecule)	Corticosteroids	Antibiotics
Medication Brands	Ustekinumab (Stelara)	Risankizumab (Skyrizi) Guselkumab (Tremfya) Mirikizumab (Omvoh)	Ozanimod (Zeposia) Etrasimod (Velsipity)	Prednisone Prednisolone Methylprednisolone Budesonide Hydrocortisone	Vancomycin Doxycycline Metronidazole Amoxicillin Ciprofloxacin
Form of Medication	Infusion to start, then injections	Infusion to start, then injections	Tablets	Tablets/Liquids/IV/ Enema	Tablets/Liquids
Side Effects	Allergy Sore throat Headache Diarrhea Stomach pain Joint pain Infusion site irritation Injection site irritation	Allergy Sore throat Headache Diarrhea Stomach pain Joint pain Infusion site irritation Injection site irritation	Infections Progressive Multifocal Leukoence-phalopathy Low heart rate Liver injury Increased blood pressure Skin cancer (rare)	Increased Appetite Mood instability Acne Difficulty sleeping Decreased bone density Poor Growth C. Diff Infections	Abdominal pain Diarrhea Nausea Loss of appetite Heart beat irregularities Skin Rash

Medication Administration

Here are some ways to make taking medication easier:

- **Numb the taste buds:** Give your child something cold like a popsicle before the medication
- **Use an oral syringe:** Direct the medicine to the back of the tongue or between the cheek and gums to avoid the taste buds
- **Wash down the medicine:** Use a beverage like white grape juice or chocolate syrup. DO NOT use grapefruit juice.
- **Mix with marshmallow cream:** Put the medication in ½ teaspoon of marshmallow cream
- **Coat the tongue:** Use peanut butter or maple syrup before giving the medication
- **Crush tablets:** Check with your doctor or pharmacist to see if a tablet or capsule can be crushed or opened. If yes, mix it with a small amount of Hawaiian punch, juice, applesauce, pudding, or peanut butter

Taking Pills

It is a great idea to start teaching your child how to swallow pills and capsules as early as possible. Many of the most effective medications do not come in a liquid form, so learning this skill can make treatment easier.

- **Start early:** Teach your child to swallow pills and capsules as early as possible.
- **Practice with candies:** Use small candies like Tic-Tacs or Skittles to practice.
- **Be patient:** Practice twice a day and do not get discouraged. With time, your child will get better at swallowing pills.

Surgery

Our goal is to avoid surgery, if possible, but it may be necessary depending on your child's condition. If a surgery is needed, your gastroenterology team will work closely with the IBD surgeons to create the best plan for your child's care.

Fistulectomy
A fistula is an abnormal connection between 2 areas in the body. They often form due to excessive inflammation in the GI tract and usually only happens in Crohn's disease. Common types of fistulas in IBD include:

- **Perianal fistula:** an abnormal connection between anus and skin
- **Enteroenteric fistula:** an abnormal connection between 2 sections of the intestine
- **Ileocolonic fistula:** an abnormal connection between the small intestine to large intestine

A fistulectomy is a surgery to remove the fistula.

Colectomy
A colectomy is a surgery to remove the entire colon (large intestine). This surgery is usually recommended for patients with severe Ulcerative Colitis who are very sick or whose condition does not get better with medications.

After the colon is removed, most patients will have a temporary ileostomy. This means the end of the small intestine is brought to the surface of the skin, and all stool passes into a bag worn on the outside of the body (ileostomy bag).

After the body has healed, the ileostomy is reversed, and the small intestine is reconnected to the rectum so stool can pass through the rectum again.

Partial Intestinal Resection
A partial intestinal resection is a surgery to remove part of the small or large intestine that is very inflamed. This surgery is often used to treat strictures (narrowing of the intestine) or perforations (a hole in the intestine) seen in Crohn's disease.

If a stricture is not treated, it can cause a serious blockage in the intestine. After the strictured area is removed, the healthy ends of the intestine are connected (anastomosis).

While this surgery can help a patient to live without symptom for years, it is not a cure for Crohn's disease. Your child will still need to be on medicine after the surgery.

Preventative Care

Vaccines
Some IBD medicines can weaken the immune system, making it harder for your child to fight infections. If this occurs, it is usually mild in nature such as symptoms from a cold lasting a few days longer than usual. On rare occasions, it can lead to an infection that needs antibiotics or even hospitalization. To help protect your child, you can have them:

- Wash their hands well and often
- Wear a mask in crowded places, such as airports
- Keep up with routine and annual vaccines
- **Routine vaccines:** Your child's pediatrician will know which vaccines are needed
- **Annual vaccines:** Influenza (flu shot) and COVID
- **Important:** if your child is on an IBD medication that suppresses the immune system including steroids, they **CANNOT receive LIVE VACCINES**. If you are unsure if the IBD medication is in this category, contact your GI team.

Healthy Eating
A well-rounded diet can help heal the gastrointestinal tract. Right after diagnosis, it is important to avoid:

- Foods high in refined sugars (like juice, soda, or pop)
- Excessive dairy
- Foods that do not break down easily, like popcorn kernels
- Foods high in insoluble fiber that cannot be chewed well and are hard to digest (like fibrous part of the celery)

Cooked or raw vegetables and fruit with soluble fiber and are ok if your child can chew them well. As your child's IBD improves, they can slowly return to a regular healthy diet. Aim for:

- At least 5 servings of fruits and vegetables a day
- A variety of carbohydrates, proteins, and healthy fats.
- Minimize fast food, high sugar foods, and highly processed foods

Probiotics are safe but not necessary. Consider fermented foods instead like yogurt, pickles, kimchi, and sauerkraut. A well-balanced diet is the best way to keep the good bacteria in the gut microbiome.

Supplements
Vitamin and mineral deficiencies are not uncommon in IBD, especially vitamin D and iron. We will monitor levels with regular blood tests. Your doctor will let you know if supplements are needed.

Other Routine Things to Think About
IBD is a systemic disease meaning it can affect other parts of the body outside of the intestines. In addition, side effects from IBD medications can affect other organs like the liver, eyes, skin, and bones. To monitor and protect these areas, the following routine exams and precautions are recommended:

- **Eyes:** Yearly eye (optometry/ophthalmology) exams
- **Skin:** Use sunscreen when outside on sunny days for prolonged periods
- **Bones:** IBD and some medical treatments can affect bone density over time. Regular exercise supports bone health. Vitamin D supplementation may be recommended. A bone density scan (DEXA scan) might be needed a few years after remission.
- **Liver:** Routine blood tests during clinic visits

Psychological Needs
Managing IBD can be tough for your child and family. Because mental health is an important part of overall health, we offer support through our specialized GI psychologist. Our goal is to minimize the impact of IBD on your child's daily life and your family dynamics. Our psychologist can provide a safe space for your child to talk about any difficulties they are having, help them develop coping skills, and offer ongoing emotional support. Additional psychological care is available when there are specific issues that may require more support.

WA Mental Health Referral Service:
seattlechildrens.org/clinics/washington-mental-health-referral-service/

Choosing a Mental Health Provider:
seattlechildrens.org/pdf/pe1739.pdf

Sleep and Exercise
Getting enough sleep and exercise is essential for reducing inflammation, minimizing flares, optimizing the healing process, and improving overall quality of life. Encourage outdoor activities for physical and mental well-being.

One great way to enjoy the outdoors is with an America the Beautiful Pass. This pass lets children with chronic conditions, like IBD, to explore all the national parks in the US for free! Your doctor can provide a letter of support for your child.

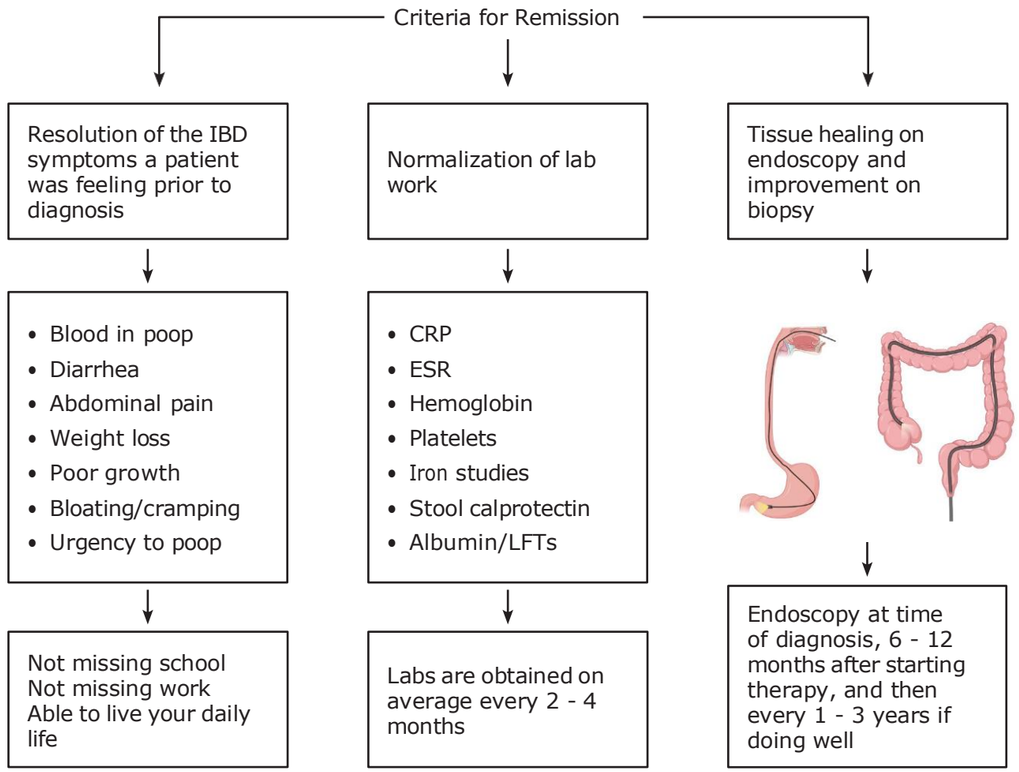
America the Beautiful Pass:
nps.gov/subjects/accessibility/interagency-access-pass.htm

What does remission look like?

When treating IBD, the goal is to achieve remission, which means controlling the disease. Thanks to new treatments, more patients are reaching remission now than ever before! To reach full remission, 3 key things must happen:

1. Resolution (or near resolution) of IBD symptoms – Your child should feel much better with little to no ongoing symptoms.
2. Normal lab work – Blood and/or stool test should show no signs of inflammation.
3. Tissue healing – Repeat endoscopy or colonoscopy should confirm that the intestines have fully healed.

The timing of blood work and endoscopy/colonoscopy will be different for each child. Both are important steps to make sure we are managing and controlling the disease well. These evaluations help us confirm that the treatment plan is working and that the IBD is under control.



Note: The timing of labs and endoscopy may vary. This could be because of the medication that is being used, patient preference, and provider preference.

How do I contact my GI team between appointments?

There will be times when you need to contact your GI team. The best way to get in touch for non-urgent things is through MyChart. MyChart is useful for:

- Medication refill request
- Non-urgent questions
- Scheduling clinic visits and procedures

For urgent questions or concerns, please call the clinic where your child receives care. The phone numbers are listed on the front page of this book and directly below.

What number should I call?
Monday through Friday 8am to 5pm, please call the clinic where your child receives care.

- **Seattle:** (206) 987-2521
- **Bellevue:** (206) 987-2521
- **Everett:** (425)-783-6400
- **Federal Way:** (253) 838-5878
- **Olympia:** (360) 459-5009

For after hour emergencies, weekends, and holidays, please call the hospital operator at (206) 987-2000 and ask for the GI provider on-call.

What type of problems should I call my team about?

- Diarrhea more than 5 times a day and that has lasted more than 2 days
- Small amount of blood in the stool for more than 3 days
- Moderate/large amount of blood in the stool for more than 24 hours
- Abdominal pain that is keeping you awake at night or interferes with normal activities
- Vomiting lasting longer than 24 hours
- Rectal or peri-anal drainage
- Fever over 101° F (38.3 ° C) with abdominal pain or fever over 100.4° (38° C) on the day your IBD medications are due

How can I request prescription refills?
There are many ways to request a prescription refill. It is important is to keep track how many doses you have left and reach out to the GI team at least 3 business days before you run out.

- MyChart (preferred): Request a refill through a MyChart message
- Call the clinic: Contact the clinic where your child receives care
- Pharmacy request: Ask your pharmacy to send an electronic refill request for you

Note: Do not call the emergency line after hours, holidays, and weekends for routine medication refills!

When to go to the ER

- Bloody vomit
- Diarrhea causing dehydration (less than 3 wet diapers/urinary voids in a 24-hour period)
- Severe, constant abdominal pain lasting or pain that prevents your child from walking upright
- Severe abdominal pain with a fever greater than 102°F (38.9°C)

School Accommodations

504 plans
It is important for families to work with their child's school and healthcare team to create a successful learning environment. A **504 plan** helps design a program to meet the student's individual needs. The plan will address possible absences, access to the restroom, and other special considerations. Ask your healthcare team to create a 504 letter for your child.

Some modifications that may be appropriate include:

- Anytime bathroom pass for easy access
- Permission to carry water bottle during school
- Dietary modifications
- Ability to participate in extracurricular activities
- Ability to participate in field trips
- "Stop the clock" test taking

It is important for children to understand their 504 accommodations and that they have a copy of the document.

College
College can be challenging and may require students to advocate for themselves. If accommodations are needed for college entrance testing such as SAT or ACT, you can request them. Your school guidance counselor can help you with this process. Start by assessing if you need accommodations and get a letter from your doctor to support your request.

College students with health challenges can benefit from scheduling classes later in the day. Early in the term, talk to the professors to address any issues that may arise. Most campuses have an office of disabilities that can give support like note taking assistance and other accommodations. Take advantage of tutoring or study groups to stay on track academically.

If your school offers priority registration, use it to better structure your day to support your health. Consider housing accommodations, like requesting a private room or bathroom shared by fewer students. A letter from your gastroenterologist can help explain your needs and advocate for you.

Camp Oasis

Camp Oasis is a co-ed weeklong summer camp program hosted by the Crohn's & Colitis Foundation (CCF) in partnership with the IBD center at Seattle Children's Hospital. Designed specifically for children with Inflammatory Bowel Disease, the camp offers a supportive environment where kids can try new activities, build lasting friendships, and just have FUN!

A typical day at Camp Oasis is packed with fun and adventure! Campers enjoy many activities such as swimming, canoeing, art, team sports, giant swing, rock climbing wall and more. Evenings feature exciting activities like campfire, talent show, and scavenger hunts. Each day also includes three meals, a snack, and downtime to relax in the cabin. The outcome? Plenty of smiles, new friendships, and a boost in confidence!

At Camp Oasis, our goal is for kids to focus on having fun! Campers stay in comfortable, enclosed cabins with clean bathroom and shower facilities. To ensure convenience, bathrooms are also located throughout the camp. The camp takes place at YMCA Camp Colman in Longbranch, WA, on the beautiful Olympic Peninsula. Typically held during the last full week of May or June, this program has been running at this location since 2009.

Camp Oasis welcomes campers entering grades 2 through 10 in the school year following camp. For those entering grades 11 and 12, we offer a unique Leaders in Training (LIT) Program. This leadership development program runs throughout the camp session and blends the excitement of camp activities with age-appropriate responsibilities and leadership-building opportunities.

Camp Oasis has a 24-hour on-site Health Hut, staffed by a physician, nurse, and mental health professional experienced in working with IBD patients. All medical care, including the distribution of camper medication, is handled through the Health Hut.

Learn More: crohnscolitisfoundation.org/events/camp-oasis-of-washington

FAQ

Is there a cure for Inflammatory Bowel Disease (IBD)?
Currently, there is no cure for IBD. However, many therapies are available to help individuals manage the condition and lead a fulfilling life.

What happens if Inflammatory Bowel Disease is not treated?
Treating IBD is very important. Without proper management, children can have challenges like poor weight gain, stunted growth, ongoing bleeding and diarrhea, colon rupture, an increased risk of colon cancer, and the potential need for surgery.

What should I do if my insurance company does not cover my medications?
Many families have trouble with insurance coverage at first. If your insurance changes or medications become too expensive, tell your doctor. Your IBD care team can help by providing extra information to your insurance company and may conduct a peer-to-peer review with them to get approval for your medicines.

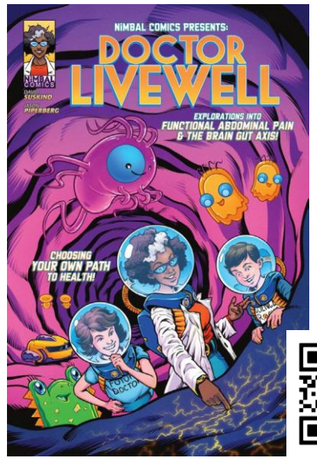
How often will I need endoscopies?
The frequency of endoscopies is different for each patient. Usually, an endoscopy is done at the time of diagnosis and about 6 to 12 months after starting treatment to check for healing. Discuss with your doctor the appropriate schedule for follow-up endoscopies based on your condition.

Should my family members be checked for Inflammatory Bowel Disease?
If your family members have symptoms of IBD, they should see a doctor for testing. Even though IBD can run in families, only those with symptoms need to be checked. A healthcare provider will decide if testing is needed.

Additional Resources

Professor Nimbal IBD Comic Book

Doctor Livewell DGBI Comic Book



Crohn's and Colitis Foundation

crohnscolitisfoundation.org
Find information about local CCF IBD events and support groups

To Learn More

- Clinic
  206-987-2521
  Evenings and weekends
  206-987-2000
  ask for the resident on call
- Ask your child's healthcare provider
- seattlechildrens.org/patient-education

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

Seattle Children's
HOSPITAL • RESEARCH • FOUNDATION

Seattle Children's offers free interpreter services for patients, family members and legal representatives who are deaf or hard of hearing or speak a language other than English. Seattle Children's will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201. This handout has been reviewed by clinical staff at Seattle Children's. However, your needs are unique. Before you act or rely upon this information, please talk with your healthcare provider.

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