Stanford MEDICINE
Children's Health

My IBD Care Book

Lucile Packard Children's Hospital Stanford
Location 725 Welch Road Palo Alto, CA 94304 **Phone** (650) 497-8000

Stanford Medicine Children's Health Center for IBD and Celiac Disease
Location 730 Welch Road, 2nd floor, Palo Alto, CA 94304
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Contact us

Inflammatory Bowel Disease Center
Phone **(650) 721-2250**
Fax **(650) 721-3822**
Mailing address: 730 Welch Road, Suite 116, Palo Alto, CA 94304=

Office Hours

Days: Monday to Friday

- **Open:** from 8:15 a.m. to 5:00 p.m.
- **Closed:** 12:00 p.m. to 1:00 p.m.

Stanford Medicine Children's IBD Clinic locations

Location	Address
Palo Alto	730 Welch Road 2nd floor Palo Alto, CA 94304
Mountain View	2495 Hospital Drive, Suite 625 Mountain View, CA 94040
Fremont	2299 Mowry Avenue, Suite 2A Fremont, CA 94538
Menlo Park (Integrative Medicine)	321 Middlefield Road 2nd floor Menlo Park, CA 94025

For more information on other **Stanford Medicine Children's Health Pediatric Gastroenterology, Hepatology, and Nutrition** locations in San Francisco, Emeryville, Brentwood, Novato, and Walnut Creek, visit our website at:
gastroenterology-locations.stanfordchildrens.org

Your IBD Care Team

Stanford Medicine Children's Health is a teaching hospital. This means that doctors, nurses, and other healthcare professionals in training may care for patients. Each person in training works under the supervision of a senior staff professional. Every healthcare team member has a special role. This document tells you more about how each team member can help. Whenever you hear a word or phrase you do not know, please ask any care team member.

Doctors and Nurse Practitioners

An **Attending Physician** is a doctor who has completed all medical training and is in charge of your care while you are in the hospital. They teach and supervise residents and medical students and oversee the healthcare team.

A **Nurse Practitioner (NP)** or **Advanced Practice Provider** is a nurse who has completed an advanced degree in nursing. They perform physical exams, diagnose illnesses, and prescribe medications under the supervision of a physician, also called a doctor.

Nurses and Medical Assistants

A **Nurse Coordinator (RN Coordinator)** supports patients and their families in the IBD clinic by scheduling appointments, making phone calls, and checking patient progress. They also work with the care team to make sure that your family has the patient education and medical support you need.

A **Medical Assistant (MA)** can take medical histories, record vital signs, explain treatments, give vaccines, and support you as needed during exams. They finished training and can help care for your child with the supervision of a doctor.

IBD Clinic Coordinators can help with scheduling appointments, making referrals, sending direct messages and phone calls to the team, and working with your health insurance companies.

Other healthcare providers

A **Dietitian** is a food and nutrition expert who works with you and your family about the right foods to eat to help you feel better faster. If you need a special diet, the dietitian provides information and teaches you how to follow the diet.

A **Pharmacist** works directly with the healthcare team and is involved in taking medicines safely. They will also talk with you or your child about taking medicines and answer any questions about the medicines the doctors prescribe.

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Other healthcare providers (continued)

A **Psychologist** is a health professional with special training in behavioral and mental health. A psychologist supports patients and their families throughout the IBD journey. They provide therapy and teach strategies to manage physical and mental symptoms like stress, anxiety, and depression.

General Care Providers

A **Licensed Clinical Social Worker (LCSW)** helps set up resources, support, and services for the family. Social Workers work in both inpatient and outpatient areas. In IBD, social workers work closely with IBD psychologists to figure out how to best help you and your family. They also coordinate these resources with outside community agencies.

Clinical research coordinators: Support IBD research initiatives and collaborate with other institutions to expand knowledge of IBD and IBD care, managing patient enrollment in the ImproveCareNow (ICN) network.

Analytics and clinical effectiveness specialist: Assists the IBD team in using our data to improve the quality and efficiency of our care.

Patients, Parents & Family Advisory Council

This **Council** includes parents whose children are patients in our Center for IBD and Celiac Disease. They help improve our clinic by planning events and supporting our community. You can talk with your health care to learn more about the Patients, Parents & Family Advisory Council.

Contact Us

Please visit the **Stanford Medicine Children's Health** website for general questions or more information about our hospital or the **Pediatric Inflammatory Bowel Disease (IBD) Program**.
ibd.stanfordchildrens.org

Inflammatory Bowel Disease Center phone number: **(650) 721-2250**
Email address: ibdceliac@stanfordchildrens.org

Creating a MyChart account

We **strongly** encourage you to set up a **MyChart** account for online access to appointment information and for messaging your medical team. The front desk staff can help you sign up during your visit.

To contact your IBD team for non-urgent issues, please send a MyChart message or call the Center for IBD and Celiac Disease at (650) 721-2250. MyChart should be used for non-urgent messages and to request medicine refills. Responses will typically be returned **within 1 to 2 business days**.

When to call the Center for IBD and Celiac Disease

We always have pediatric GI doctors on call for urgent issues, including evenings, weekends, and holidays.

- If an issue requires urgent attention during daytime hours, please call the **Center for IBD and Celiac Disease** at **(650) 721-6993**.
- For urgent problems after-hours on weekends, evenings, and holidays, please call the **GI doctor** at **(650) 497-8000** on call through the **Stanford Operator**.

When to call 911

For emergencies, please call **911** or proceed to your nearest emergency department.

When to call your provider

If the following symptoms last more than **1 or 2 days**, call your provider.

- Occasional mild cramping or stomach pain that mildly impacts your regular activities.
- Diarrhea or increased bowel movements over one or two days.
- New mouth sores.
- Constipation lasting more than one or two days that does not get better with stool softeners.

It is important to contact the provider right away if the symptoms below appear.

- New onset of fever.
- Cough, cold, or congestion.
- Any other health care concerns.

When to contact the IBD doctor: ___________________

Call the IBD Team right away at (650) 721-6993 if you have one or more of the symptoms below. Even with medical treatment, a person with IBD can experience a **flare**, which is what happens when symptoms reappear or come back.

- Stomach pain more than 7 times a day that is hard to ignore.
- Diarrhea that wakes you up overnight.
- Seeing blood in your poop often.
- New or worsening pain, swelling, or discharge around your bottom.
- New or worsening vomiting.
- New or rapid weight loss.
- Fever without other signs of illness like a cough, sore throat, or runny nose
- New or severe eye pain, redness, or vision changes.

What if I don't feel IBD symptoms anymore?

Even if you do not feel any of the symptoms in the tables below, **please continue the treatment your doctor ordered for you, including:**

- Taking your medicine as prescribed.
- Refilling your medicine when needed.
- Scheduling your infusion appointments.
- Going to your scheduled follow-up appointments.
- Looking for any blood in your poop or on the toilet paper before you flush the toilet.
- Eating a healthy diet as recommended by your doctor.

Inflammatory Bowel Disease (IBD)

Inflammatory bowel disease, also called IBD, is a type of disease that causes parts of the intestine or bowels to become painful and swollen. There is nothing patients or families could have done differently to keep IBD from developing. IBD is caused by genetics, immune system problems, and other factors like food and antibiotics.

There are many different types of IBD like Crohn's disease and Ulcerative colitis.

Crohn's disease

Crohn's disease is a type of IBD that can cause inflammation in the small and large intestines and sometimes in other parts of the body, like the skin or eyes. Crohn's can cause diarrhea, belly pain, and weight loss. Medicines can help control inflammation and keep the disease from causing symptoms. It's a lifelong condition, but the symptoms come and go in most people.

Ulcerative colitis

Ulcerative colitis causes swelling, inflammation, and sores in the lining of the large intestine, also called the colon, and causes diarrhea, belly pain, and bleeding from the rectum. It's a lifelong condition, but the symptoms come and go in most people.

Medicines can stop or reduce symptoms and prevent flare-ups. If the disease is severe, you may need surgery to feel better.

IBD-unclassified

IBD-unclassified (IBD-U) is a form of IBD that looks like both UC and Crohn's disease.

Goals of treating IBD

- Control symptoms.
- Improve quality of life, like comfort and getting back to your normal daily activities.
- Prevent future health problems.

Treat-to-Target IBD Care

Treating-to-target keeps IBD patients in remission and feeling well longer. Patients can have inflammation and damage to their intestines even when they feel well and have no symptoms.

Treat-to-Target IBD care means that the doctor will continue checking for signs of inflammation by looking at the patient's blood tests and stool studies often.

Treat-to-Target doesn't just treat the symptoms you are having today, it can help your care team prevent future IBD health problems too.

Treat-to-Target helps your care team:

- Be proactive about preventing future IBD health problems even when you are feeling well.
- Give you personalized IBD treatment.

The doctor may recommend blood tests, imaging tests, and **endoscopies** even when patients have no symptoms. Go to **page 21** to learn more about endoscopies.

Talk with your care team if you have questions about Treat-to-Target IBD care.

Medicines Used for IBD

The doctor may prescribe some of the IBD medicines below. Talk with your care team if you have any questions about the medicines your doctor prescribed.

Medicines to avoid

Patients with IBD should avoid pain medicines that contain aspirin or non-steroidal anti-inflammatories. These medications can cause irritations in the intestines or worsen a flare.

Examples of these medicines include:

- Ibuprofen, like Advil and Motrin.
- Naproxen like Aleve and Naprosyn.

Corticosteroids

Why is this medicine prescribed?

Corticosteroids are a type of steroid medicine that can quickly relieve IBD symptoms if you are experiencing a flare. Steroids help decrease swelling and irritation caused by a flare. Examples of this medicine include:

- Prednisone.
- Hydrocortisone like Cortifoam or Solu-Cortef.
- Budesonide like Enterocort or Uceris.

What are important things to know about taking this medicine?

Steroids are not long-term medicines.

Your IBD Coordinator will work with you to make sure that you can get the medicines that you need.

Some of these medicines may require **preauthorization** from your insurance. This means that your health insurance company has already approved to pay for the medicine.

Do not change the dose of a corticosteroid medicine or stop taking the medicine without talking to your doctor. Suddenly stopping steroids can also bring on dangerous side effects, so always follow the schedule your doctor prescribes.

Antibiotics

Why is this medicine prescribed?

The doctor may prescribe different kinds of antibiotics to help relieve flares and inflammation. In patients with IBD, there is an imbalance between the good and bad bacteria in their gut. The antibiotics help relieve flares by decreasing the amount of bad bacteria and balancing the bacteria in the gut. Examples of antibiotics that may be used include amoxicillin, vancomycin, doxycycline, ciprofloxacin, metronidazole, and rifaximin.

Antibiotics (continued)

What are important things to know about taking this medicine?
Always follow the prescription schedule your doctor prescribes and complete the full course prescribed. If having side effects, please contact your IBD provider before stopping.

Mesalamine (5-ASAs)

Why is this medicine prescribed?
5-ASAs help reduce inflammation and can be taken orally or rectally. Examples of 5-ASAs are Pentasa, Lialda, Apriso, Colazal, Delzicol, Asacol, and sulfasalazine.

What are important things to know about taking this medicine?
Always follow your doctor's directions on how and when to take the medicine.

Immunomodulators

Why is this medicine prescribed?
Immunomodulators are a type of medicine that helps calm your immune system. Examples of immunomodulators are mercaptopurine and methotrexate.

These medicines require careful monitoring with blood work. Blood tests are done regularly to check for possible side effects, including low white blood count and low white blood cells.

Biologics and Biosimilars

Biologics are medicines that treat certain parts of the immune system to help reduce inflammation. They can be given by IV or injections you can do at home. Examples of biologics are infliximab, adalimumab, ustekinumab, and rizankizumab. **It is important to take this medicine exactly as prescribed. If biologics are not taken as prescribed, they may stop working.**

Your doctor will explain how and when to take your biologic medicines:

- **Induction period:** Higher or more frequent doses of biologic medicines when first starting.
- **Maintenance period:** After induction, the doctor will check your symptoms, and look at the amount of medicine in your blood. The doctor will decide the right dose and frequency to keep your IBD symptoms controlled over time.

Biosimilars are biologics that are almost exact copies of the original medicine. Biosimilars work as well and are as safe as the original medicine. For example, Inflectra is a Remicade biosimilar and both are types of the medication infliximab. **Ask your doctor if you have questions about taking or switching to a biosimilar.**

Biologics must be taken exactly as prescribed. If doses are too far apart the immune system can develop antibodies against the medication so that it does not work as well. Antibodies also put patients at higher risk for an allergic reaction.

JAK Inhibitor

Why is this medicine prescribed?

The medicine blocks Janus kinase (JAK) enzymes. These enzymes normally activate parts of the immune system that cause inflammation. While people are on this medicine, their care team will take blood tests to look at their lipid profile, blood count, and liver. Examples of JAK inhibitors are tofacitinib and upadacitinib.

How is this medicine taken?

This drug is available in tablet form.

Before taking JAK inhibitor medicines, your doctor will talk with you about:

- **The risks of blood clots.**
- **Any vaccines you may need.**
- **The safety and risks around taking certain types of birth control.**

Your doctor will talk with you about the vaccines you may need, including annual flu vaccines, shingles vaccines, and pneumococcal vaccines.

Do not get a live viral vaccine like mumps, measles, and rubella (MMR) or chicken pox (VZV) if you are taking immunosuppressors, or medicines that lower your immune system.

Integrative Medicine and IBD

Many patients with IBD are interested in integrative medicine to treat their disease. Integrative medicine combines traditional and alternative therapies. Integrative medicine may include acupuncture or acupressure, probiotics, herbs, and mind-body practices like meditation or mindfulness. You should always talk with your doctor before starting any new herbs or supplements.

Talk with your doctor and dietitian about any integrative medicines you are currently using or are thinking about using. It is important to make sure that these medicines are safe for you.

Our **Integrative Gastroenterology Clinic** in Menlo Park has doctors who specialize in integrative medicine and can partner with your IBD team. Talk with your IBD team about being referred to the **Integrative Medicine Clinic**.

Diet and Nutritional Therapies

Patients with IBD often pay special attention to what they eat to help them to feel well. Our dietician partners with families to find foods that help patients get healthy and balanced nutrition. In some special cases, your doctor may prescribe one of the following therapeutic diets. These diets should only be used under your IBD team and dietician's supervision.

Talk with your doctor and dietitian before trying any diets. It is important to make sure that the diet is safe for you. If you want to make an eating plan, talk with your IBD provider for a referral for an IBD dietitian.

Exclusive or Partial Enteral Nutrition (EEN or PEN): EEN and PEN both use a specialized nutritional formula. With EEN a patient gets all their nutrition from the formula. In PEN the patient eats a combination of food and formula. These diets can allow the gut to rest when it is inflamed but they do not work in all forms of IBD.

Crohn's Disease Exclusion Diet (CDED): This diet uses a specialized nutritional formula and a restricted list of whole foods to help relieve symptoms in some patients with Crohn's disease.

Specific Carbohydrate Diet (SCD): The SCD is a balanced but restrictive diet that removes all grains, processed foods, sugars, and most dairy. The SCD does not work in all forms of IBD.

Surgery and IBD

Patients with IBD usually start with treatment that involves medicines. Some patients may still need surgery to get the best results from treatment and to manage complications from their IBD. Surgery can help manage some serious problems caused by IBD. It can also treat symptoms that do not respond well to medicines. There are many different types of surgery that the care team may recommend. Please talk with your IBD provider and IBD surgery team to learn more about surgery for IBD.

Reasons why patients may get surgery for IBD

Your care team may recommend surgery for IBD if you have the following:

- Blockage in your intestine.
- Bleeding that doesn't stop with medicines.
- Intestines that become too tight or narrow.
- Tear or hole in the intestine.
- Fistula, or an abnormal connection from the intestine to another part of the body.
- Abscess, or collection of pus and inflammation.
- Toxic megacolon, or bacteria and gas build up in the intestine. Toxic megacolon causes the intestine to become very dilated or stretched out.

Support after your IBD surgery

Nutrition plays a critical role in supporting success before surgery, and healing and recovery after surgery. For more information on nutrition before and after surgery, you will meet with your IBD dietitian and surgery teams to help you figure out when and what to eat.

Some patients may need an **ostomy** as part of their IBD surgery. An ostomy is where the intestine is connected to the abdominal wall, and stool passes from an opening, also called the stoma, into a bag. Your care team will help you through the ostomy process with special attention to nutrition and caring for your stoma at home.

Living with IBD

There are some things that can be helpful for you to do while living with IBD.

To keep healthy with IBD, we recommend:

1. Seeing your primary care doctor for a checkup every year.
1. Getting the vaccines you need, including your annual flu vaccine.
2. Taking your medicines exactly as your doctor prescribes, even when you have no IBD symptoms.
3. Seeing your IBD team at least every 6 months, even when you feel well.
4. Contacting your IBD team as soon as you notice any new symptoms.

Getting vaccines

It is important to get all the vaccines and shots you need to prevent infections. **Talk with your doctor to learn more about which vaccines they recommend for you.**

We highly recommend young people with IBD to get these vaccines:

- **COVID vaccines**
- **Yearly flu shots**
- **Pneumococcal vaccine:**
    - For those on immunosuppressive medicines, we recommend getting **Prevnar (PCV 13)** if you did not receive it with your childhood vaccines. You should then get **Penumovax (PPSV 23) 8 weeks later**.
    - For all patients, we recommend **Pneumovax (PCV23)** at least **8 weeks after a PCV13**. We recommend **getting PCV23 again after 5 years**.

Do not get live viral vaccines if you are taking immunosuppressive medicines.

Tell your doctor as soon as possible if you are planning to travel outside the country.
They may recommend certain vaccines based on where you are traveling.

Other tests your IBD team may recommend

Bone screening: People with IBD can have weaker bones because of steroid treatment or weight loss. The IBD team will order special tests to check your body's calcium and vitamin D. Your care team may recommend you:

- Get more calcium and vitamin D.
- Get more daily physical activity.

Other tests your IBD team may recommend (continued)

Skin checkups: Some IBD medicines can increase the risk for skin cancer. We recommend all patients:

- Wear sunscreen every day.
- Go to a dermatologist for an appointment every **1 to 2 years.**

Eye checkups: Visit your eye doctor **every 1 to 2 years** to see if you have inflammation caused by IBD. Contact your IBD team and your eye doctor if you have any changes in vision, new sensitivity to bright lights, eye redness, or pain.

Things you can do to care for yourself when living with IBD

Substance use

Some IBD medicines are not safe to take if you are using substances like alcohol, nicotine, or other recreational drugs. Talk with your care team if you have questions about using substances. Your care team can help you learn more about the risks and ways you can stay safe.

Pregnancy, contraception, and sexual health

Talk with your IBD care team about any questions you have about contraception and family planning. They can tell you more about how these topics relate to your IBD. For example, some birth control can increase the risk of blood clots, and some IBD medicines can harm an unborn baby. Your care team can also answer questions about:

- Sexual health after having surgery or during an IBD flare.
- Your ability to have sex when living with IBD.
- Contraceptive options when living with IBD.

Nutrition

Eating healthy looks different for everyone. What's most important is that you eat foods that are easy to get, enjoyable, and helpful to your health goals. Talk with your IBD dietitian to learn more about healthy foods you can eat and get easily. Your care team also has resources to help you get enough food.

Exercise

Healthy exercise looks different for everyone. What's most important is that you find time to move your body and find exercises that you enjoy doing. Talk with your IBD care team to learn more about exercises that you can do.

Mental health

IBD can impact your emotional well-being and mental health. Managing your emotional well-being and mental health with IBD looks different for everyone. Emotions and feelings about IBD can also change over time. Your IBD care team is here to support you on your IBD journey.

At our Center for IBD and Celiac Disease, we have an IBD psychologist and social workers who care for children, teenagers, young adults with IBD, and their families. Please see the section **Getting Support**, on **page 23**, for more information on these services.

Blood and Stool Testing

Labs are tests that are done to look at how your body is working. The information below tells you more about blood and stool lab tests that your provider may order for you. Talk with your provider if you have any questions about your lab tests and results.

Blood tests

Your provider will order the following labs regularly and based on your treatment plan to check your health:

Hemoglobin (Hgb) is a part of the red blood cell that carries oxygen. Bleeding can cause the body to lose red blood cells. Chronic illnesses may cause the body to make less red blood cells than normal. If you have low hemoglobin, you may look pale, feel dizzy, and feel tired.

White blood cells (WBC) help the body fight germs like viruses and bacteria. Some of the medicines used to treat IBD can cause the body to make less white blood cells. This can make it easier for you to get sick or get an infection.

Platelets (PLT) are blood cells that can stick together to stop bleeding. The body often makes more platelets when there is active inflammation. The care team will look at the number of platelets to learn more about the inflammation.

Albumin (ALB) is a protein in the blood that keeps fluids in your blood vessels. Low albumin can make fluids stay in other parts of the body and make your face, feet, or chest look puffy.

C-reactive protein (CRP) is a protein created in the liver. C-reactive protein gets released in the blood when there is inflammation in the body. Your doctor may test your C-reactive protein to check for inflammation inside your body. Your doctor may also use this test to check your body's response to treatments.

Erythrocyte sedimentation rate (ESR) is also called sed rate. This test is done to see if you have inflammation in your body. Your doctor may order this test with CRP to check for inflammation and see your body's response to treatments.

Liver function tests (LFTs), or a hepatic function panel, help your doctor tell how healthy your liver is. These tests include AST, ALT, GGT, and alkaline phosphatase. Inflammation and certain medicines can increase these levels.

Therapeutic drug monitoring, or checking the level of medicine in your blood, that applies to certain biologic medicines. If you are taking biologic medicines, your doctor may order this test to make sure you are getting enough medicine.

Blood tests (continued)

The Thiopurine metabolite blood test helps the doctor figure out how well your body will react to certain medicines. Your doctor will check this test to make sure it is safe to give you 6MP medicine.
Vitamin D is important for keeping your bones and immune system healthy. Your doctor will check your vitamin D level regularly.

Stool tests

Stool or poop tests are important tests to help your doctor know if you are having a flare or infection. You may be asked to collect poop samples at home and bring them to your local lab. Some common stool tests include:

Fecal calprotectin looks for inflammation in your gut. Your doctor will use this test when diagnosing IBD, if you are having flare, and to see your body's response to treatment.

Clostridium difficile (C. diff.) is a bacterium often found in the gut or stomach. Sometimes antibiotics used to treat an infection kill helpful bacteria, allowing *C. difficile* to grow too much. One of the symptoms is diarrhea.

Ova and parasite (O&P) helps your doctor figure out if you have a parasitic infection. People are exposed to these types of infections from crowded places or places that may have untreated water, like day care, a community pool, camping grounds, or lakes.

GI PCR helps your doctor figure out if you have an intestinal infection from common bacteria. GI PCR can find many infections, including infections from bacteria, parasites and viruses by looking at a single stool sample. It is not available at all laboratories.

Depending on your diagnosis, your provider may check your nutrition by giving you nutrition lab tests. Please talk with your provider if you have questions about these nutritional lab tests.

Imaging Studies

There are several types of imaging studies that can be helpful for patients with IBD.

Magnetic resonance enterography (MRE) uses a strong magnet to take pictures of your intestines. Before the imaging study, you will drink a special contrast solution and have an IV placed.

Ultrasound (US) uses sound waves to look inside the body. Your care team will put gel on your stomach and move a painless wand over the area where the gel is applied.

> **Point-of-care**, also called **POC**, is an intestinal ultrasound. **Intestinal ultrasounds** are done during routine care visits. They are done by one of the IBD gastroenterology doctors in the IBD clinic or if you are admitted to the hospital.
>
> - You can eat as you normally do before this ultrasound.
> - You **do not** need to drink any contrast or have an IV placed for this ultrasound.
>
> **Contrast Enhanced Ultrasounds**, also called **CEUs**, are ultrasounds used to get more information than a normal ultrasound and are done in the Radiology Department. Before you get a Contrast Enhanced Ultrasound, you will need to get an IV placed. The ultrasound uses IV contrast to help the doctor see your GI tract in more detail.

Abdominal X-rays, also called KUB or flat plate, are X-rays that look at how much air, fluid, and stool are in the intestines. You do not need to do any preparation before getting an abdominal X-ray done.

Lateral spine X-rays are done to measure how healthy your bones are. Your bones may get thinner or weaker because of disease, not getting enough nutrition or some medicines.

Computerized tomography (CT) is a special type of x-ray used to look at your stomach and intestines. Before you get a computerized tomography x-ray, you will either drink a special contrast solution or have an IV placed.

Endoscopy and Colonoscopy

Your doctor may order an upper endoscopy, also called an esophagogastroduodenoscopy or EGD, and colonoscopy. These tests are used to diagnose IBD or to see your body's response after a new treatment is started. The care team will give you medicine to help you stay asleep and feel more comfortable and relaxed during the procedure. Your IBD team can talk with you about what to expect with your procedure.

Esophagogastroduodenoscopy (EGD) is a test done to check the lining of the esophagus, stomach, and the first part of the small intestine. The test is done with a flexible tube called a **scope**, which has a light and a camera on the end. The doctor:

- Will look for redness, swelling, bleeding, ulcers, or infections.
- Will collect small tissue samples called **biopsies** to be looked at under a microscope.

Colonoscopy is a test done to look at the entire **colon** or large intestine and last part of the small intestine, also called the **terminal ileum** or TI. The test is done with a flexible tube called a **scope**, which has a light and a camera on the end. The doctor:

- Will look for redness, swelling, bleeding, ulcers, or infections.
- Will collect small tissue samples called **biopsies** to be looked at under a microscope.

Sigmoidoscopy is a test done to look at only the last part of the **colon**, also called the **sigmoid colon**, and **rectum**, which is at the very end of the large intestine. The test is done with a flexible tube called a **scope**, which has a light and a camera on the end.

Video capsule endoscopy is a test done to look at the gastrointestinal tract while patients are awake. This test takes **about 8 hours to finish**. During the test, you will swallow a small video capsule. The video capsule:

- Is the size and shape of a pill and has a tiny camera inside of it.
- Leaves your body when you poop.
- Can be swallowed like a pill or placed in your body as part of an upper endoscopy.

Cleanout for colonoscopy

Before a colonoscopy patients will be asked to drink special laxative medicine. This medicine helps get rid of the poop in the body to help prepare for the test.

If the clean out is not done the doctor cannot see the colon and may need to repeat the procedure on another day. Colonoscopies are generally very safe procedures but can be less safe when the colon has not been fully cleaned out.

When your doctor orders a colonoscopy you will receive instructions for the clean out. Please read all instructions carefully as soon as you get them. **If you have questions or need help getting the laxative medicines covered by insurance, please contact your IBD team right away.**

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What to expect after an EGD or colonoscopy

You can usually go home on the same day as your procedure.

In the **first 24 hours after the procedure**, it is normal to have some:

- Bloating.
- Cramping or pain in your stomach.
- Nausea.
- Sore throat.
- A few drops of blood in your stool or poop.

When to call your care team

For non-urgent questions, please contact your care team through MyChart. It may take **up to 2 business days** for your care team to respond to MyChart messages.

To schedule urgent sick visits or leave a message for your care team about urgent medical questions, please call the IBD Clinic Coordinator at (650) 721-6993.

- Clinic hours: Monday to Friday, from 8:30 a.m. to 4:30 p.m.

For urgent medical questions after hours or on the weekend, please call (650) 497-8000 and ask to speak to the on-call GI provider.

- **More blood in your poop** after the first 24 hours after the procedure.
- **Stomach pain gets worse** after the first 24 hours after the procedure.
- **Fever**.
- **Vomiting**.

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Getting Support

Your IBD care team is here to support you and your family with all parts of your life that can be affected by IBD. The information below tells you more about resources you can use for IBD support. Talk with your care team to learn more about these resources.

It is important to follow your treatment plan even when you are feeling well. If you stop taking your medicine, you are more likely to get an IBD flare. If you have questions about taking your medicine, please talk with your care team.

Psychologist

Our **psychologist** supports our IBD patients and families. They can meet with patients and families about any concerns about IBD including:

- Mental health like stress, anxiety, and low mood.
- Pain management.
- Worries about your treatment like being nervous about IVs or taking pills every day.
- How IBD can affect your family.

The psychologist can give patients and families tools to help manage these concerns.

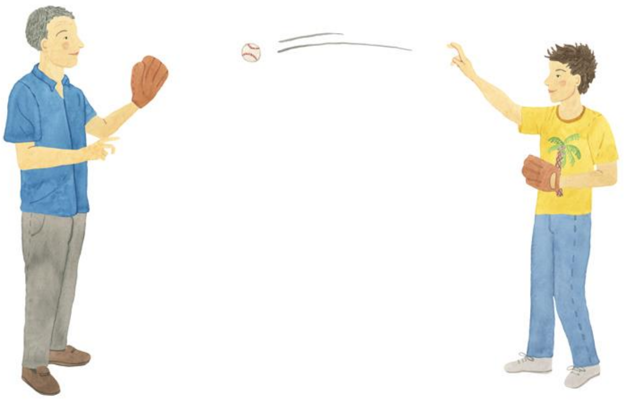
Social worker

Our **IBD social worker** can meet with patients and families for emotional support or to talk about resources and school accommodations. Additionally, Stanford offers Child Life and Community Services to support patients and families during hospitalizations.

Support groups

Hearing from other people your age who also have IBD can be helpful. This can be through:

- **Center for IBD and Celiac Disease support groups and community events**. Ask your IBD care team to learn more.
- **Community support networks** like the Crohn's and Colitis Foundation, Power of Two, and ImproveCareNow.



Other resources

Name	Website
Stanford Pediatric IBD Program Resources	ibd-resources.stanfordchildrens.org
The Painted Turtle Camp	www.thepaintedturtle.org
Camp Oasis	www.crohnscolitisfoundation.org/get-involved/camp-oasis
Crohn's and Colitis Young Adult Network	www.ccyanetwork.org
ImproveCareNow (ICN)	www.improvecarenow.org
ICN Circle Newsletter	www.improvecarenow.org/join_circle_signup
Family Advisory Council (FAC)	Talk with your **IBD social worker** to learn more about the FAC.

Meet other students at your school with IBD through the **Crohn's & Colitis Foundation** Campus Connection.

School

Patients with IBD can get support from their schools through resources like a 504 Plan, the Individualized Education Plan, and our Child Life services.

It is important to tell your teachers, school nurses, school counselors, coaches, and school administrators about your IBD-related needs.

Ways to get IBD support in school

IBD symptoms, doctor's appointments, and treatment can affect your progress in school. Some patients may need to miss school days or need more time to finish their homework because of their IBD symptoms or treatment.

504 Plan

Public and charter schools are required by law to support **504 Plans**. The 504 Plans are care plans created by the IBD social worker, student's parents and their school administrative team. The plan helps students with disabilities and illness get the support they need. Resources can include:

- Hall passes for the bathroom whenever they need them.
- Nurse's office passes for rest, medicines, and time to take care of IBD symptoms.
- A choice to sit near the door in the classroom.
- Access to foods for any special IBD diets.
- Easier things to do in P.E. class when symptoms are more severe.
- Longer deadlines to finish schoolwork or tests due to IBD symptoms, doctor's appointments, and treatment.

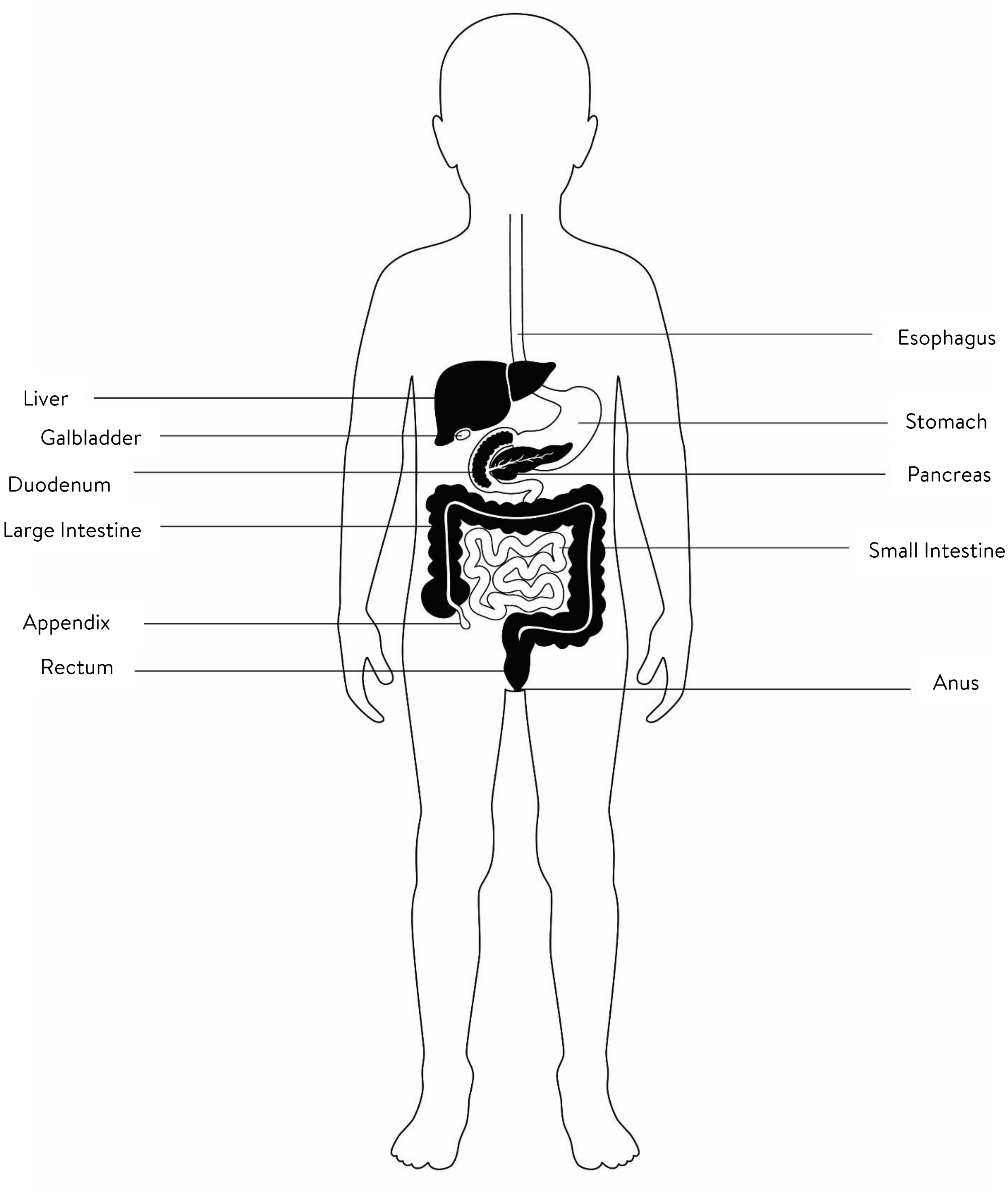
Child Life Services

If you have to miss a lot of school due to IBD-related health needs or symptoms, our **Child Life Services** can help. Child Life Services can give you access to tutors who can help with schoolwork. **Please talk with your IBD care team if you want to learn more.**

Colleges and universities

Your IBD social worker can help you with finding resources and accommodations at your college or university. Many of these schools have services that can support students with learning or healthcare needs. For example, some schools have resources and support like 504 Plans. **Please talk with your IBD social worker if you want to learn more.**

Notes


Esophagus
Liver
Stomach
Galbladder
Pancreas
Duodenum
Large Intestine
Small Intestine
Appendix
Rectum
Anus

Stanford MEDICINE
Children's Health

Notes

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