Patient Advisory Council

Health Literacy Toolkit

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patient advisory council

Disclaimer

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Table of Contents

Introduction to Health Literacy

What is Health Literacy?

Health Literacy is the ability to obtain, process, and understand basic medical information. Health literacy helps patients feel empowered when managing their healthcare. It also helps them build confidence to take charge and assume leadership of their healthcare. The goal of this resource is to help with comprehension gaps in health-related topics and provide education for patients with IBD.

Why is Health Literacy important?

IBD patients should be able to comprehend and describe all aspects of their disease along with medications and dietary changes they are employing to help push their IBD into remission. Everything revolving around IBD and its care including its diagnosis, tests, treatment and diet need to be easily understood by everyone affected by it. The majority of minors do not understand all aspects of their diagnosis and how to manage their disease independently and need to be fully informed as they get older.

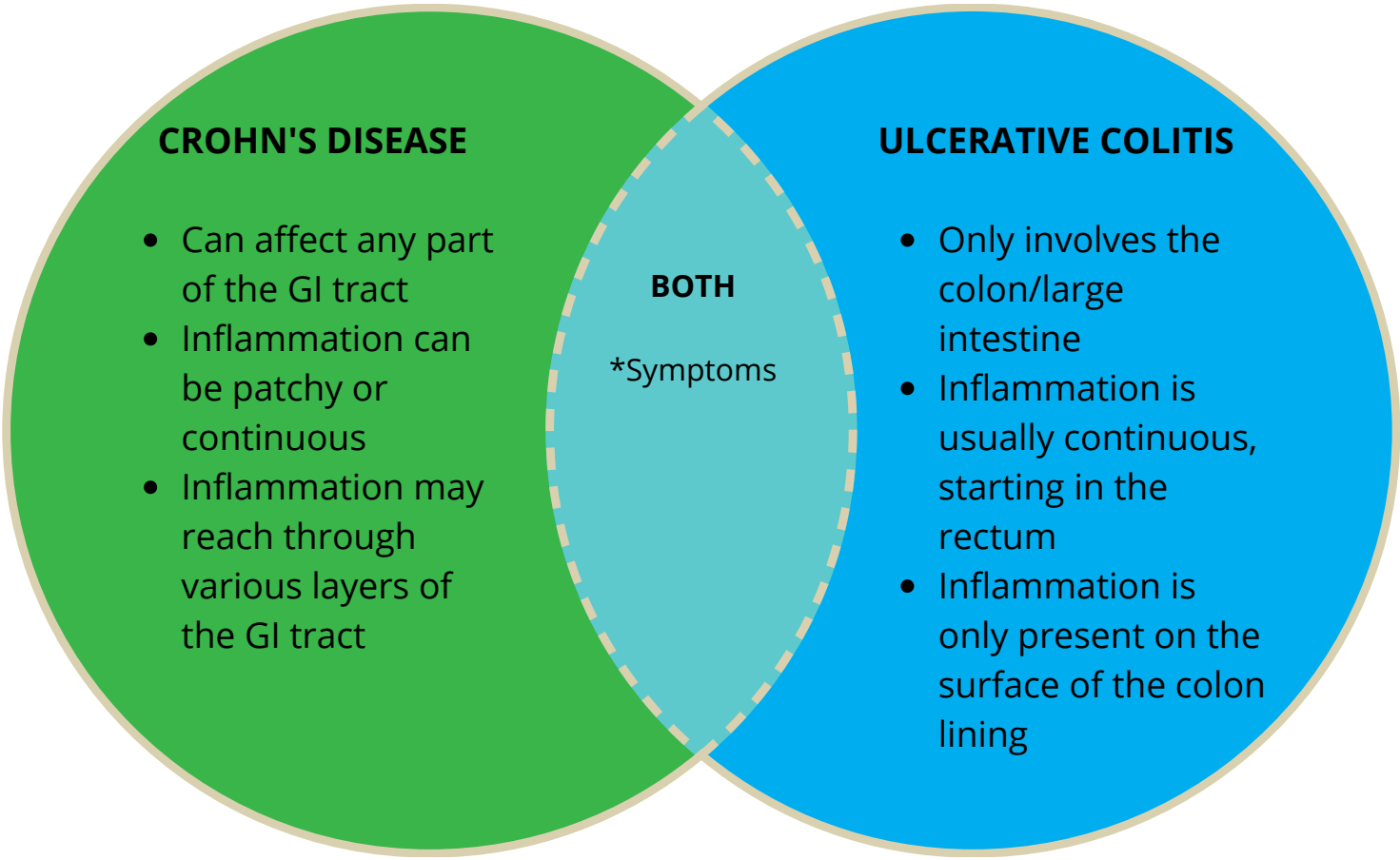
What will I learn from this toolkit?

By the end of each section, you will be able to understand what IBD is, how it affects patients, and how it is treated. You will learn common terms and language used within the IBD community that will help you get more involved with your care.

IBD 101

What is IBD?

Inflammatory Bowel Disease (IBD) is a chronic disease caused by dysfunction of the immune system that leads to chronic inflammation of the digestive tract. It can be classified in many ways including Crohn's Disease, Ulcerative Colitis, or IBD unclassified.



*Symptoms outside of the GI Tract:

- Fatigue
- Joint pain
- Nausea/vomiting
- Rashes
- Mouth sores

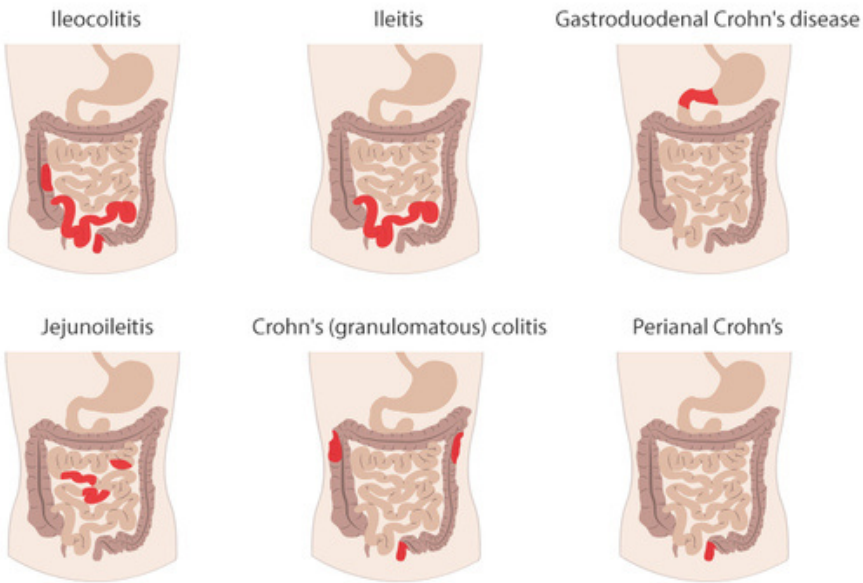
*Common symptoms include:

- Abdominal pain
- Abnormal stool
- Gas and bloating

IBD 101:

Types of Crohn's Disease

- **Ileocolitis:** affects the end of the small intestine (terminal ileum) and large intestine (colon)
- **Ileitis:** only affects the end of the small intestine (terminal ileum)
- **Gastroduodenal Crohn's:** affects the stomach and beginning of the small intestine (duodenum)
- **Jejunoileitis:** characterized by patchy areas of inflammation that affects the middle and end of the small intestine (jejunum and ileum)
- **Crohn's (granulomatous) colitis:** only affects the large intestine (colon)
- **Perianal Crohn's:** characterized by inflammation at or near the anus. Can involve skin tags, abscesses (pockets of infection), or fistulas (abnormal tracks or openings in the skin) around the anus.



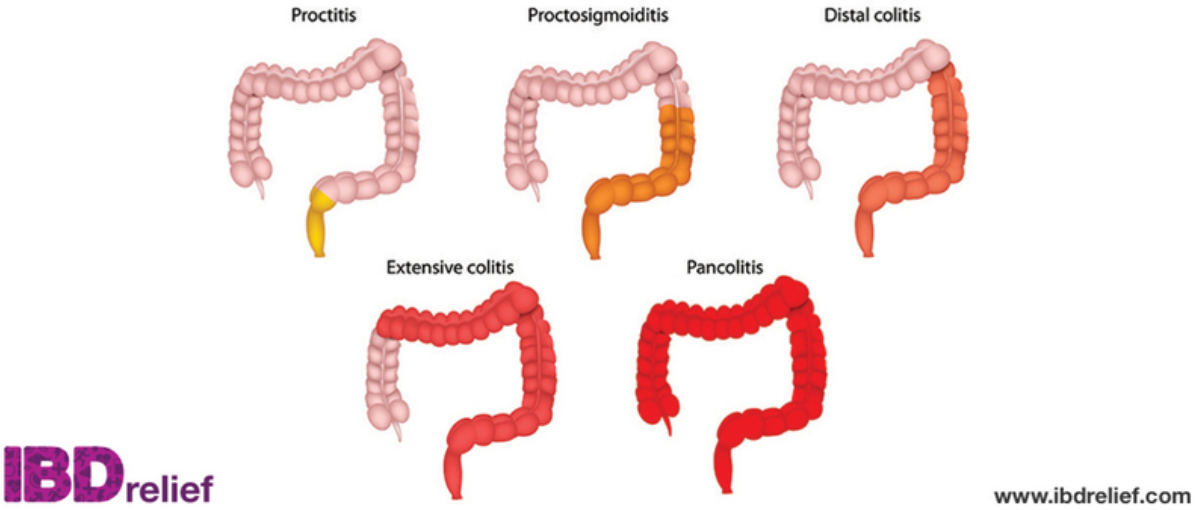
www.ibdrelief.com

"What Is Crohn's Disease?" IBDrelief, https://www.ibdrelief.com/learn/what-is-ibd/what-is-crohns-disease.

IBD 101:

Types of ulcerative colitis

- **Proctitis**: colitis involving the rectum only
- **Proctosigmoiditis**: colitis involving the rectum and sigmoid colon
- **Distal (left-sided) colitis**: involves colitis from the anus through the descending colon
- **Extensive Colitis**: this is a form of colitis that affects the transverse section of the colon to the rectum
- **Pancolitis**: colitis that affects the whole colon from ascending to the rectum



"What Is Ulcerative Colitis (UC)?" IBDrelief, https://www.ibdrelief.com/learn/what-is-ibd/what-is-ulcerative-colitis.

IBD 101

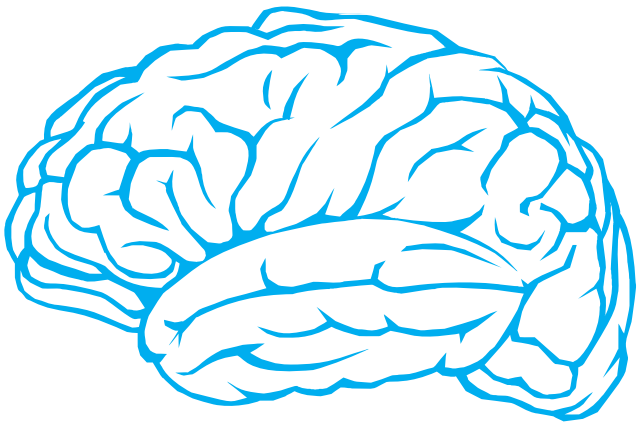
Identifying and Modifying Symptom Triggers

These are patient perspectives, so please talk to your provider about managing your IBD. Every patient has different symptoms and different triggers. Learning to identify symptoms and to avoid or modify triggers can help IBD patients feel good.

Mental Health

Mental health includes your feelings about yourself. Receiving an IBD diagnosis may be confusing, frustrating and scary. Living with IBD can feel challenging as well. There are many day-to-day stressors IBD patients have to navigate. The following list outlines factors our toolkit team has found helpful for managing mental health and overall well-being.

- Maintaining a regular sleep schedule
- Drinking plenty of water
- Incorporating relaxing activities into the day-to-day routine
- Consulting with a therapist or counselor (your doctor may be able to help connect you)



IBD 101

These are patient perspectives, so please talk to your provider about managing your IBD

Identifying and Modifying Symptom Triggers

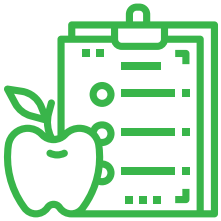
Exercise

Getting some form of regular physical activity every day can be helpful for both mental and physical health.

Make sure to listen to your body while trying these tasks, and talk to your provider if you have any questions about incorporating exercise into your routine!

Figure out what works for you and come up with a plan to stick with it. Consistency is key for habit-forming!

- Walking
- Stretching/Yoga
- Lifting (be cautious while doing this and increase weight incrementally)
- Running (a little or a lot- some of our PAC members think participating in marathons is a fun activity!)



Diet

Ask your doctor before you try these diets

- **FODMAP diet** - This diet involves removing certain sugars and carbohydrates that frequently cause intestinal distress. Often, foods are gradually reintroduced over time to learn which foods trigger a particular patient's symptoms.
- **Mediterranean Diet** - A generally balanced diet: it focuses on plant-based foods, seafood and healthy fats with very little red meat, packaged foods/preservatives, and added sugar.
- **Specific Carbohydrate Diet** - grain-free, low in sugar and lactose to reduce the amount of complex carbohydrates eaten and potentially decrease bowel inflammation and symptoms.
- **Crohn's disease exclusion diet** - whole foods diet to exclude or limit exposure to foods that may lead to inflammation in the digestive tract.

Medication

These are patient perspectives, so please talk to your provider about managing your IBD

Some IBD patients use medication to manage their inflammation and symptoms. There are many different types of medications that are used to treat IBD, and it can be helpful to know some of the names of the most common ones. We've compiled a list of some common medications in the following pages.

Corticosteroids (steroids): fast-acting medications used to suppress the immune response that causes inflammation in IBD. Steroids are not typically used for long periods of time because they can lead to uncomfortable side effects. Some examples of steroids include prednisone and budesonide. These medicines can be given by mouth, through an IV, or rectally in the form of enemas. Common side effects from these medications include increased vulnerability to infection, weight gain, nausea, headache, acne, or difficulty sleeping.

Aminosalicylates: medications that work to soothe inflammation in the lining of the GI tract. These medications don't impact the immune system. Some examples of Aminosalicylates include Mesalamine, Balsalazide, and Olsalazine. These medicines are taken by mouth and there are also forms administered rectally like enemas and suppositories. While this class of medication has fewer side effects than steroids, it may lead to symptoms of stomach pain, nausea, loss of appetite, or headaches.

Immunomodulators: medications that down-regulate the immune system, helping to stop inflammation from occurring in the GI tract. Some examples of these medications include Azathioprine and 6 mercaptopurine. Sometimes side effects can occur, which might include increased vulnerability to infection, nausea, vomiting, abdominal pain, diarrhea, fatigue, liver irritation, and headache.

Medication
(continued)

Biologics: medications that work to block certain proteins that are involved in the IBD inflammatory process. By doing this, biologics can specifically target the IBD-related immune response. Biologics are given either through an IV infusion or an injection, depending on the medication. Some examples of biologics include Remicade, Humira, and Stelara. Some common side effects that may occur with Biologics use include headaches, nausea, rash, runny nose, fatigue, increased infection risk, or pain at the site where the medication was injected.

Antibiotics: A type of medication used to treat infections associated with IBD. These infections may look like an abscess (pocket of pus) or pouchitis (inflammation of the ileal pouch (j-pouch). Antibiotics attempt to kill the bad bacteria that are colonizing in your GI tract and causing inflammation. Some examples of antibiotics include Ciprofloxacin and Metronidazole. The most common side effects of antibiotics are nausea, vomiting, abdominal pain, and diarrhea.

Interpreting Test Results

Monitoring IBD activity requires different tests to be run over time. These can include imaging, blood and stool tests, and scopes.

Imaging

X-ray: beams pass through your body, and they are absorbed in different amounts depending on the density of the material they pass through. These are most helpful to look at air, fluid and stool in your bowels, and the bones of the body

Computerized tomography scan (CT): series of X-rays to make a 3D image of soft tissues and bones. CTs use **contrast**, a special dye that helps highlight certain areas of your body and can be administered in three ways:

- By mouth - drink that contains contrast; for esophagus or stomach
- By IV - injection through a vein; for gallbladder, urinary tract, liver, or blood vessels
- By enema - inserted into rectum; for intestines

Magnetic resonance imaging (MRI): radio waves and a powerful magnet are used to create detailed pictures of organs and tissues in your body (use the same type of contrast as mentioned aboved for CT)

Blood and Stool Studies

- Blood and stool tests alone cannot be used to diagnose IBD.
- However, blood and stool tests are used to monitor inflammation in the body as well as complications of disease and side effects from treatments.

Interpreting Test Results

Specifics in Blood and Stool Studies

Albumin: A blood test done to check for malnutrition and indications of active disease.

- Albumin is a protein found in the blood. It can be low when a patient has active inflammation or is losing a lot of protein in their stool.

CBC (Complete Blood Count): blood test that can indicate inflammation, infections, and anemia.

CRP (C-reactive protein): blood test that is done to measure levels of non-specific inflammation throughout the body. For IBD patients, elevations can be a better marker of short-term inflammation in comparison to the ESR (see next page).

Vitamin D: Used to monitor bone mineral and nutritional status

Iron panel: Checks for iron deficiency, a common cause of anemia, which is more common in IBD patients. This may include ferritin, which is an indicator of blood iron stores.

Interpreting Test Results

Specifics (Continued)

Electrolytes: (such as sodium, magnesium, and potassium) are minerals taken in through food and drinks, and lost when your body loses liquid (i.e. from sweating, vomiting, or going to the bathroom). Electrolyte panels are often part of a Complete Metabolic Panel

- Dehydration from symptoms (such as diarrhea) can deplete electrolytes, which may require treatment with oral rehydration solutions or IV fluids

Calprotectin and Lactoferrin (stool protein): these stool tests are used as markers of inflammation in the bowel. In IBD care, they can be used regularly to follow disease activity and predict flares. They can also be from other causes of bowel inflammation not specific to IBD.

ESR (SED rate): Non-specific marker of inflammation, often used to measure inflammatory IBD activity. It is a better marker of long-term inflammation compared to CRP (see previous page)

Scopes

Below are examples of typical procedures and preps, but please consult your provider for specific information.

Endoscopy: A long flexible tube with a camera at the tip (called a scope) is inserted to look at different parts of the gastrointestinal tract (upper endoscopy, colonoscopy, sigmoidoscopy, etc.) while the patient is sedated.

Upper endoscopy: A scope is inserted into the patient's mouth to look at the inner lining of the upper digestive tract (esophagus, stomach, and duodenum). This is also called an Esophagogastroduodenoscopy (EGD). You will usually be asked not to eat or drink the day of your EGD.
Capsule endoscopy: You will swallow a small capsule (the size of a large vitamin pill) or sometimes your doctor will place the capsule in your small intestine (during an upper endoscopy) that will take pictures of your digestive tract as it passes. The pictures are then sent to a recording device for your doctor to look over.

Typical prep for a capsule endoscopy, colonoscopy, enteroscopy, flex-sig, or proctoscopy:

- *You may be asked to consume only liquids the day before these procedures.*
- *Closer to the procedure, you will be asked to have nothing to eat or drink*
- *You will likely also have to take medication to help empty your bowels either by mouth or enema.*

Colonoscopy: A procedure where a doctor uses a camera to look at the rectum, colon, and lower part of the small intestine.

Scopes

Balloon-assisted enteroscopy: A scope is inserted either through the mouth or the rectum to examine the small intestine. The scope has balloons attached to it which helps it move through the digestive tract and look much further into the small intestine.

Preparing for a Balloon-assisted enteroscopy:

- For a lower GI tract procedure: liquid diet and a laxative or enema to cleanse the bowel before
- For an upper GI tract procedure: do not eat or drink for 12 hours before

Flexible sigmoidoscopy: A scope is inserted into your rectum to examine the lower part of the colon.

Preparing for a Flexible sigmoidoscopy:

- 7 days before: talk to a doctor for instructions about any medications you may take
- day before: follow a special diet the day before the exam (may be asked not to eat, drinks may be limited to clear liquids)
- A few hours before: use an enema kit to empty your colon (may be asked to take two enemas)

Proctoscopy: A scope is inserted to examine the end of the colon

Preparing for a Proctoscopy:

- 7 days before: talk to doctor for instructions about any medications you take
- 1 day before: follow a special diet the day before the exam (may be asked not to eat, drinks may be limited to clear liquids)

Glossary

Common terms used and their definitions:

Acid Reflux: Acid from the stomach flows back into the esophagus, which can cause heartburn or indigestion
Adhesions: Scar-tissue like connections in the abdomen that can occur after surgery and cause intestinal blockages
Anesthesia: Medication used to prevent pain in certain medical procedures
(general vs. local) - local anesthesia numbs a portion of the body, general anesthesia makes the patient unconscious
Anti-inflammatory: Category of medication for IBD patients; goal of reducing inflammation
Chronic: Symptoms or illness that is ongoing or lasts a long time (months or years)
Colectomy: Removal of the colon (can be part of the colon or the entire organ)
Colostomy: A surgical operation where a piece of the colon is brought through the abdominal wall and stool is collected in a bag worn on the abdomen
Constipation: Experiencing hard, infrequent, or difficult-to-pass bowel movements
Distension: swelling or bloating in the abdomen
Enema: Procedure where fluid is delivered through the rectum. This can be a medication or contrast for an imaging study (ie. barium enema)
Exclusive Enteral Nutrition (EEN): A type of nutritional therapy for IBD where 100% of a patient's nutritional needs are provided as formula, either by mouth or through a feeding tube.
Fatigue: Persisting mental and physical exhaustion that exceeds normal tiredness

Glossary

Common terms used and their definitions (continued):

Fistula: A complication of Crohn's disease where an abnormal connection forms between two different parts of the body. For example, a connection between the intestine and skin or intestine and bladder.
Flare: An increase in intensity or number of symptoms, which varies for each patient.
Gastroenterologist: A doctor who focuses on gastroenterology
Gut Motility: Related to movement of the intestines
Ileostomy: A surgical operation where a piece of the ileum (small intestine) is brought through the abdominal wall and stool is collected in a bag worn on the abdomen.
Immune System: A part of the body made up of cells and organs that help protect the body from infection. In IBD, the immune system is dysregulated, and sends excess immune cells to the digestive tract, causing inflammation
Immunosuppression: State where a disease or medication lowers the activity of the immune system
Indeterminate Colitis: Inflammation of the colon that does not completely fit the diagnosis of Crohn's or Ulcerative Colitis.
Inflammation: The body's natural response to infection or injury. In IBD, the inflammation is due to the dysregulation of the immune system and can lead to swelling, redness, or ulcers in the digestive tract
Irritable Bowel Syndrome (IBS): GI disorder that includes symptoms similar to those in IBD, but instead of being related to inflammation, is related to abnormalities in the way the nervous system in the digestive tract (enteric nervous system) communicates with the brain.
J-Pouch: A pouch (shaped like a J) created with the small intestine after a total colectomy.

Glossary

Common terms used and their definitions (continued):

Laxative: A medication that increases the frequency of bowel movements or makes stool softer and easier to pass
Liquid Diet: A diet that consists of only liquids (some include broth, water, juice, etc.)
Maintenance Therapy: Medication or treatment used to maintain remission and prevent flare-ups
Malnutrition: Condition from lack of proper nutrition, which may lead to deficiencies in necessary nutrients
Malabsorption: problem related to difficulty absorbing nutrients from food and drink
Nasogastric Tube (NG Tube): Sometimes used for nutritional therapy like EEN, an NG tube is a thin tube placed through the nose and into the stomach to provide nutritional formula
Obstruction: A blockage in the digestive tract that prevents things from moving through normally
Ostomy: A surgical operation where a piece of the digestive tract is brought through the abdominal wall. In IBD, this is usually the small intestine or colon. Stool is collected in a bag worn on the abdomen. This operation can be temporary or permanent.
Pouchitis: inflammation or infection (often caused by "bad" bacteria) in the J-Pouch
Probiotic: Type of “good” gut bacteria that is naturally in certain foods or sometimes added to supplements
Remission: This can be clinical remission (a decrease or absence of IBD symptoms) or deep remission (usually a combination of clinical remission and healing on scopes)
Rectum: final portion of the colon into the anus

Glossary

Common terms used and their definitions (continued):

Short Bowel Syndrome: Not enough of the small intestine to fully absorb nutrients from food (ie. from surgical removal of parts of small intestine)
Sigmoid Colon: An s-shaped part of the colon that connects to the rectum
Small Intestine: The portion of the intestine between the stomach and the colon with three parts (duodenum, jejunum, and ileum). Its primary function is the absorption of nutrients.
Stool: A medical term for solid waste (poop)
Stricture: A narrowing of the intestine, like a pinch, often caused by inflammation or scar tissue.
Subcutaneous: To be under multiple layers of skin
Suppository: A medication that is inserted into the rectum in pill form
Taper: Slow reduction in dosage and frequency of medication with intention of weaning off the treatment
Total Colectomy: removal of the whole colon
Toxic Megacolon: A condition, often caused by inflammation or infection, where the colon dilates (stretches)
Total Parenteral Nutrition (TPN): Liquid nutrition provided directly into the blood stream through a long intravenous (IV) catheter, often used when someone is unable to get adequate nutrition by mouth
Ulcer: A sore or "raw area" on the lining of the digestive tract. Can occur in the mouth, esophagus, stomach, small and large intestine.
Ultrasound: imaging tests that creates pictures of the inside of your body using sound waves

Please reach out to your GI doctor for more information or with questions on terms!

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Sources

May 28, 2019. Crohn's & Colitis Glossary. Crohn's and Colitis Foundation. Retrieved from https://www.crohnscolitisfoundation.org/glossary.

February 4, 2020. ROLE OF LABS. Crohn's and Colitis Foundation. Retrieved from https://www.crohnscolitisfoundation.org/emr/emr-ibd-education-tool/role-labs

June 2018. Diagnosing and Monitoring IBD. Crohn's and Colitis Foundation. Retrieved from https://www.crohnscolitisfoundation.org/sites/default/files/2020-03/diagnosing-monitoring-ibd-brochure-final-rev062518.pdf

May 2010. DIAGNOSING CROHN'S DISEASE AND ULCERATIVE COLITIS . Crohn's and Colitis Foundation. Retrieved from https://www.crohnscolitisfoundation.org/sites/default/files/legacy/assets/pdfs/diagnosingibd.pdf

Xavier, R. and Podolsky, D. July 26, 2007. Unravelling the pathogenesis of inflammatory bowel disease. *Nature.* Retrieved from https://www.nature.com/articles/nature06005.

Signs and Symptoms of Crohn's Disease. Crohn's and Colitis Foundation. Retrieved from https://www.crohnscolitisfoundation.org/what-is-crohns-disease/symptoms

April 2021. Understanding IBD Medications and Side Effects. Crohn's and Colitis Foundation. Retrieved from https://www.crohnscolitisfoundation.org/sites/default/files/2021-03/understanding-ibd-medications-brochure-final-rev032021-A.pdf

MEDICAL TERMS USED IN IBD. Crohn's and Colitis UK. Retrieved from http://www.ibdclinic.ca/media/uploads/medical-terms-used-ibd.pdf

Inflammatory Bowel Disease (Overview). Cleveland Clinic. Retrieved from https://my.clevelandclinic.org/health/diseases/15587-inflammatory-bowel-disease overview#symptoms-and-causes

Sources

Drugwatch. (2021, February 25). Ulcerative colitis | causes, symptoms, types & treatments. Drugwatch.Com. https://www.drugwatch.com/health/digestive-health/ulcerative-colitis/

Mayo Clinic. (2020a, May 6). Flexible sigmoidoscopy - Mayo Clinic. https://www.mayoclinic.org/tests-procedures/flexible-sigmoidoscopy/about/pac-20394189

Mayo Clinic. (2020b, November 7). Inflammatory bowel disease (IBD) - diagnosis and treatment - Mayo Clinic. https://www.mayoclinic.org/diseases-conditions/inflammatory-bowel-disease/diagnosis-treatment/drc-20353320

Michigan Medicine. (2021). Gastrointestinal diagnostics & procedures | Michigan Medicine. University of Michigan Health. https://www.uofmhealth.org/conditions-treatments/digestive-and-liver-health/gastrointestinal-diagnostics-procedures

Nall, R. M. (2021, May 4). How should you prepare for a colonoscopy? Medical News Today. https://www.medicalnewstoday.com/articles/321930

North Shore University Healthy System. (2021). EGD (esophagogastroduodenoscopy) test prep & procedure | NorthShore. https://www.northshore.org/gastroenterology/procedures/egd-test/

Northwest Gastroenterology Clinic. (2019, March 27). Capsule endoscopy preparation instructions | NGC | Portland, OR. https://www.nwgastro.net/patient-info/prep-instructions/capsule-endoscopy/

Seladi-Schulman, J., PhD. (2019, September 18). What's the length of your small and large intestines? Healthline. https://www.healthline.com/health/digestive-health/how-long-are-your-intestines

Standford Health Care. (2017, September 12). Preparing for the procedure. https://stanfordhealthcare.org/medical-tests/e/egd/what-to-expect/before-procedure.html