



Surgery for Crohn's Disease and Ulcerative Colitis



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Introduction

We know that living with a chronic (or lifelong) disease, like Crohn's disease or ulcerative colitis, can be difficult. One aspect of your disease journey that might seem particularly overwhelming is surgery. While the primary treatment for Crohn's and ulcerative colitis is medication, there are some situations in which surgery may be necessary. Approximately 7% of patients with ulcerative colitis, and 18% with Crohn's disease may require surgery within five years.¹ Surgery may be elective (you and your provider decide if it's the best option for you) or necessary due to emergencies or complications of your disease. Regardless of the reason for surgery, many patients find that having surgery can drastically improve their symptoms and overall quality of life. If surgery is in your future, we will be there for you every step of the way.

About Crohn's disease and ulcerative colitis

Known collectively as inflammatory bowel disease (IBD), Crohn's disease and ulcerative colitis cause chronic inflammation in the gastrointestinal (GI) tract. In IBD patients, inflammation occurs because the immune system mounts an inappropriate response against itself, causing damage to the GI tract. The inflammation does not go away, weakening the ability of the affected organs to work properly and leading to symptoms such as abdominal cramping, diarrhea, rectal bleeding, fatigue (feeling very tired and low-energy), and more.

While both diseases share many of the same symptoms, there are some important differences.

Crohn's disease

- Can affect any part of the GI tract from mouth to anus
- Inflammation affects the entire thickness of the intestines (all layers of the intestinal wall)
- Inflammation may appear in patches affecting some areas of the GI tract and leaving other sections in between untouched

Ulcerative colitis

- Limited to the large intestine, including colon and rectum
- Inflammation occurs in the innermost intestinal lining (surface)
- Inflammation appears continuous
- Starts in the rectum and can extend up the colon

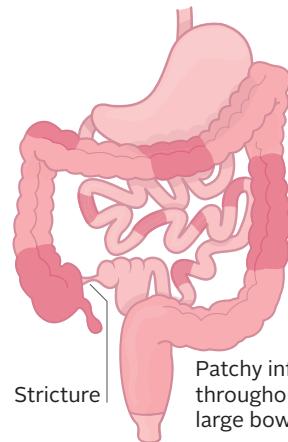


Figure 1:
Crohn's disease

Symptoms: Depends on location of disease. May include abdominal pain, diarrhea, weight loss, and fatigue.

Bloody stool: Variable

Malnutrition: Common

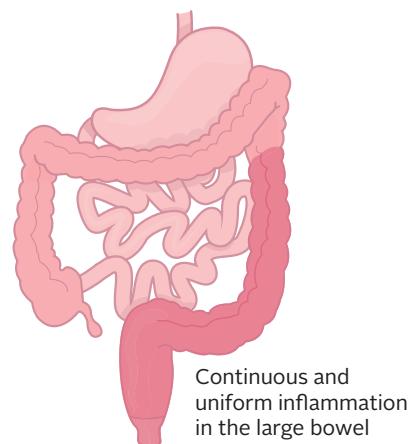


Figure 2:
Ulcerative colitis

Symptoms: May include stool urgency, fatigue, increased bowel movements, mucus in stool, and abdominal pain.

Bloody stool: Common

Malnutrition: Less common

For many patients, medication can be used to help decrease intestinal inflammation, manage symptoms, and induce and maintain remission (periods where IBD symptoms are not active). Medications available to treat IBD include aminosalicylates, antibiotics, biologic therapies, biosimilars, corticosteroids, immunomodulators, and targeted synthetic small molecules. These

medications may be used alone, or some can be prescribed as a combination therapy. Over time, adjustments in medication dose or type may be needed to maintain remission and keep your disease under control.

While the hope is that medication will keep your disease at bay, in some cases it isn't enough to control symptoms, and some patients develop complications that need more aggressive treatment. In these cases, surgery may be recommended or required. Other individuals may consider surgery earlier in their disease journey depending on their symptoms and goals for achieving an improved quality of life.

Building your IBD surgical vocabulary

To understand the descriptions of these procedures, it is helpful to know the meaning of these terms:

- **Abdominal colectomy with ileorectal anastomosis:** A procedure where the entire colon is removed and the end of the small bowel is connected to the rectum.
- **Abdominoperineal resection:** A procedure where the end of the colon, rectum, and anus are removed. A permanent colostomy is formed.
- **Bowel resection:** A procedure requiring removal of a section of the diseased part of the intestine. The intestine is then reconnected.
- **Colectomy:** The surgical removal of part of the colon (partial colectomy) or all of it (total colectomy).
- **Colostomy:** A surgical procedure whereby the colon is brought through the abdominal wall to allow the elimination of solid waste

into an ostomy pouch on the outside of the abdomen.

- **Fistulotomy:** A procedure done for the treatment of perineal fistulas (tunnel formed between anus, rectum, and skin).
- **Ileocecal/ileocolonic resection:** A surgical procedure where the end of the small bowel and beginning of the large intestine is removed and the two parts of the intestine are then reconnected.
- **Ileostomy:** A surgical procedure whereby the ileum is brought through the abdominal wall to allow the elimination of solid waste into an ostomy pouch on the outside of the abdomen.
- **Ileum:** The lower portion of the small intestine or small bowel.
- **Ostomy pouch:** A small plastic external pouch (also known as an ostomy bag, pouching system, collection pouch, or appliance) that is specifically worn over the stoma to collect stool.
- **Proctocolectomy:** Surgical removal of the colon and rectum (total proctocolectomy).
- **Proctocolectomy with end ileostomy:** A procedure where the colon and rectum are removed, and the end of the small intestine is used as a stoma (see definition below) for waste elimination into an ostomy pouch system.
- **Proctocolectomy with ileal pouch-anal anastomosis:** The surgical removal of the colon and creation of an internal pouch (often referred to as a j-pouch or an ileoanal pouch) to allow for waste elimination per anus.
- **Stoma:** A surgically created opening in the abdomen for the elimination of waste. It is pinkish in color, about the size of a quarter, and sticks out slightly. It will look moist and shiny.

- **Strictureplasty:** A procedure intended to widen the area where a narrowing is present.

In addition to the information below, the United Ostomy Associations of America provides a plethora of resources for patients facing pouch surgery or living with a pouching system. You can learn more by visiting www.ostomy.org.

Reasons why surgery may be needed

If you are experiencing ongoing symptoms with no relief or you are experiencing complications or serious side effects from medications, it might be time to consider surgery. There are a variety of situations and conditions when surgery may be required:

• Sudden, severe ulcerative colitis

This occurs when patients experience a severe and sudden onset of symptoms from their disease that medications, even intravenous steroids, cannot control. This is the main reason for emergency surgery in ulcerative colitis patients.

Sudden, severe ulcerative colitis can include uncontrolled bleeding in the colon (which is quite rare) or toxic megacolon. Toxic megacolon is caused by inflammation that leads to rapid enlargement of the colon and is a potentially life-threatening complication requiring immediate treatment and surgery. Symptoms of toxic megacolon include pain, swelling of the abdomen, fever, rapid heart rate, constipation, and dehydration.

• Intestinal perforation

Chronic inflammation of the intestines in Crohn's or ulcerative colitis may weaken the wall to such an extent that a rupture or tear occurs, known as a perforation. This is potentially life-threatening because the contents of the intestine can spill into the abdomen and cause a serious infection called peritonitis, or abdominal sepsis.

• Intestinal obstruction or blockage

An intestinal obstruction or blockage can occur when chronic inflammation in the intestines causes the walls of digestive organs to thicken or form scar tissue. This can narrow a section of intestine (called a stricture), which may lead to an intestinal blockage. Nausea and vomiting or constipation may be signs of a stricture. Strictures are more commonly seen in patients with Crohn's disease, and unusual in patients with ulcerative colitis.

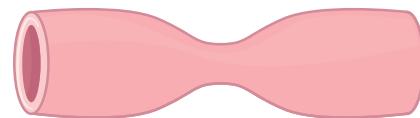


Figure 3: Illustration of narrowing of the intestine (stricture).

• Excessive bleeding in the intestine

Surgery is performed only if bleeding cannot be controlled by other therapies.

• Fistula

A fistula (or fistulae when plural) is an abnormal tunnel that occurs between the intestine and another part of the intestine, the intestine and another organ, or the intestine and the skin. Fistulae may develop when inflammation causes ulcers (sores) to form in the inside wall of the intestines or other organs. These ulcers can extend through the entire thickness of the bowel wall, creating a fistula. In addition to connections within the body or skin, fistulae can also form around the anal area and may cause drainage of mucus or stool from an area next to the anus. Fistulae in the anal area can also connect to the vagina, known as a rectovaginal fistula. Repair of a fistula often requires surgery, although occasionally medicine can be used. Up to 50% of patients with Crohn's disease develop a fistula within 20 years of initial diagnosis, with a majority involving the small intestine.^{2,3}

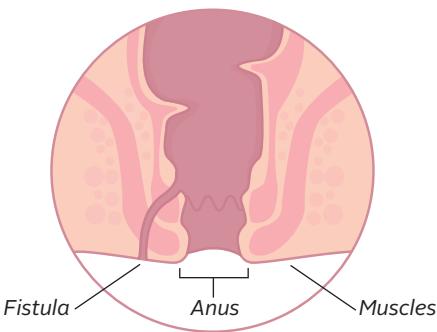


Figure 4: Illustration of a perianal fistula.

Note: a fistula may occur in other parts of the body and this perianal fistula is shown for illustrative purposes.

• Abscess

An abscess is a collection of pus, which can develop in the abdomen, pelvis, or around the anal area. Abscesses can lead to severe pain in the abdomen, fever, painful bowel movements, discharge of pus from the anus, or a lump at the edge of the anus that is swollen, red, and tender. Treatment of an abscess requires antibiotics as well as drainage of the pus cavity to allow for healing. An abscess in the abdomen can be drained surgically or by image-guided drainage where a small needle and catheter are inserted to drain the pus. An anal abscess is generally drained surgically.

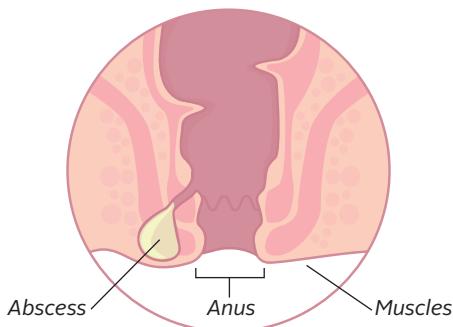


Figure 5: Illustration of a perianal abscess.

Note: an abscess may occur in other parts of the body and is shown in the perianal region for illustration purposes.

• Colorectal cancer

Patients with ulcerative colitis and Crohn's disease affecting the colon have a higher

risk for colorectal cancer than the general population. The risk of cancer increases after 8–10 years of disease.⁴ If your doctor finds precancerous tissue (called dysplasia), they may recommend surgery to reduce your risk of developing colorectal cancer. The recommendation of surgery is based on the location of the dysplasia and other factors considered by your surgeon. Surgery may also be necessary to remove any confirmed cancer that may be present in the colon. Abnormal cells can sometimes appear normal at the time of colonoscopy, so having a regular surveillance colonoscopy every one to two years is an important way to monitor risk.

Tip: We know that colonoscopy (bowel) preparation can be hard. However, it's important to ensure that your doctor is able to get a good view and detect any pre-cancerous cells. Good bowel preparation may involve limiting foods high in residue (such as raw fruits and vegetables, seeds, and nuts), drinking more liquids in the days leading up to the procedure, and following the instructions from your doctor.

Common procedures for ulcerative colitis

While the standard surgery for ulcerative colitis is still a total proctocolectomy, recent surgical advances have modified the procedure to allow many patients to be reconnected in a way that restores bowel function. This procedure is typically done in patients with pancolitis (ulcerative colitis affecting the entire colon) or left-sided colitis (affecting the sigmoid colon and the descending colon). Below are descriptions of common procedures for ulcerative colitis.

Proctocolectomy with ileal pouch-anal anastomosis

Proctocolectomy with ileal pouch-anal anastomosis (IPAA) is now the most commonly performed surgical procedure for ulcerative colitis patients. This option preserves the nerves and muscles necessary for continence, and still allows stool to pass through the anus. This option is considered for many people because it restores bowel function. The pouch may be shaped like a **J**, **S**, or **W**. The most common shape of this internal pouch is in the form of a **J**. Following IPAA reconstruction, patients will have some degree of diarrhea with an average of five to seven bowel movements daily with one or two occurring overnight. In general, there may be more frequent, looser, and possibly more urgent stools. Frequency of bowel movements may get better with time. Talk to your doctor about what to expect.

TAKE NOTE: Before reading on, for the purpose of this brochure, and to avoid confusion, we refer to all internal pouches as an **ileoanal pouch** no matter what shape may be constructed. We refer to all external pouches as an **ostomy pouch**.

The construction of an ileoanal pouch can be performed in one, two, or three separate stages. The decision for how many stages you will undergo will be based on your preferences, disease severity, and any potential complications. Your surgeon will recommend what is best for you and your needs. Some patients may take some time to heal and recover (often a few months or more depending on each patient) before undergoing the other procedures to complete the ileoanal pouch.

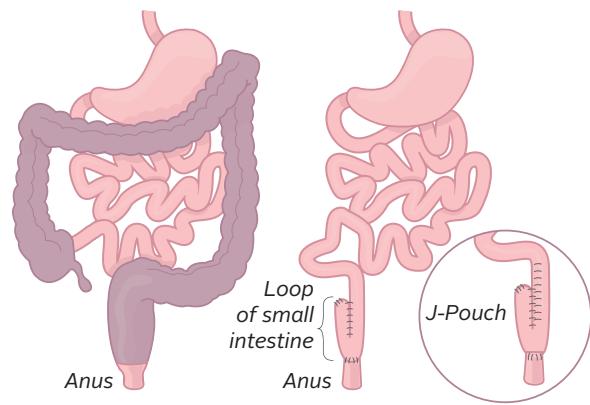


Figure 6: Illustration of a proctocolectomy (J-pouch).

The entire colon and rectum are removed. Once the colon is taken out, the end of the small intestine is folded and sewn/stapled in a "J" configuration and sewn to the anus.

Ileoanal pouch surgery in two stages

- Stage one:** The colon and the rectum are removed, but the anus and muscles that help with bowel control (called anal sphincter) are preserved. The ileum is then fashioned into an ileoanal pouch and pulled down and connected to the anus.

Typically, a temporary ileostomy is created at the same time to divert stool away from the pouch and allow it time to heal. In this procedure, a loop of the small intestine is pulled through an opening in the abdomen (known as a stoma) to allow for the elimination of waste. An ostomy pouch is worn continuously during this time to collect stool and must be emptied several times a day. Issues related to the temporary ileostomy are similar to those experienced with a permanent ileostomy.

- Stage two:** After the pouch has healed, the temporary ileostomy is reversed, the small intestine is reconnected, and the continuity of the bowel is reestablished. From this point on, the ileoanal pouch serves as an internal reservoir for waste, and stool is passed through the anus in a bowel movement.

Ileoanal pouch surgery in three stages

A three-step procedure is commonly recommended for patients with ulcerative colitis. Often those who are in poor physical health, on high doses of steroids, or experiencing toxic megacolon will require this multistage option:

- **Stage one:** The colon is removed, leaving the rectum, and a temporary end ileostomy is created during the first surgery.
- **Stage two:** In this stage, the rectum is removed, the end ileostomy is reversed, and the ileum is formed into the internal ileoanal pouch. A temporary loop ileostomy is created. As with the two-stage procedure, this is done to allow the pouch time to heal.
- **Stage three:** The third procedure is performed to reverse the ileostomy and reattach the small intestine to the pouch. You can then begin using the newly created ileoanal pouch and pass stool through the anus.

Ileoanal pouch surgery in one stage

In this case, the colon and rectum are removed and the ileoanal pouch is created and joined to the anus without a temporary ileostomy. Due to an increased risk of complications which may ultimately affect pouch function, the procedure is performed less often.

Total proctocolectomy with end ileostomy

If you require surgery, are not a candidate for a proctocolectomy with IPAA, or prefer not to have the internal pouch, your surgeon will perform a total proctocolectomy with end ileostomy. During this surgery, your colon, rectum, and anus are removed. The end of the small intestine (ileum) is brought through a hole in the abdominal wall and an end ileostomy created. An external ostomy pouch is attached to the stoma as part of a pouching

system that also includes a skin barrier. The ostomy pouch collects bodily waste and is emptied several times a day. An ileostomy is typically located on the lower abdomen just below the belt line, to the right of the navel.

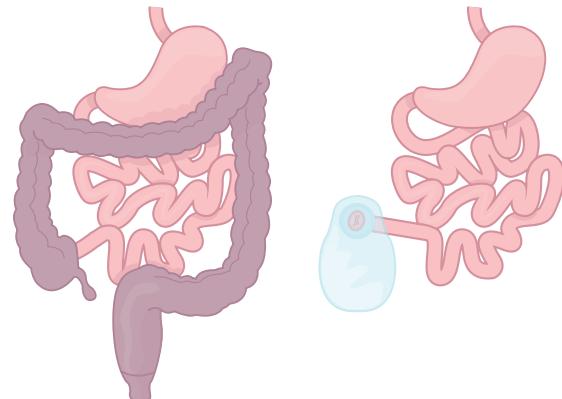


Figure 7: Illustration of a total proctocolectomy with end ileostomy.

A small opening (stoma) is created in the abdominal wall. The small intestine is brought through the abdominal wall to create an ileostomy. Any waste is released into a pouch that is affixed on the outside.

There may be some cases where this type of surgery may be recommended or more convenient over ileoanal pouch surgery, including:

- Weak anal sphincter muscles that can cause fecal incontinence
- Other complications or health issues
- Personal or lifestyle preferences

Common procedures for Crohn's disease

If you have Crohn's disease and need surgery, your surgeon will select the procedure that conserves as much bowel as possible, alleviates complications, and helps you to achieve the best possible quality of life. Because Crohn's

disease can occur anywhere in the GI tract and can cause a variety of complications, there are many different types of surgeries that may be performed.

Surgery to remove damaged bowel may involve removal of a section of the intestine, or the entire organ (colon and/or rectum) depending on the extent of the disease. Crohn's disease is a chronic condition and symptoms will return in many (most) patients if medical treatment is not restarted after surgery. Inflammation may appear in the site near the previous surgery or in a different part of the gastrointestinal tract. Your healthcare provider will recommend a treatment plan with the goal of decreasing the risk of future recurrence.

Strictureplasty

When Crohn's disease affects the small intestine, areas of bowel damage may alternate with areas of normal bowel. The areas of active disease may narrow, forming strictures, which can block the passage of digested food. The sections of normal bowel compensate by pushing against this strictured area, causing severe cramps and pain. Strictures often lead to bowel obstructions or blockages.

A strictureplasty is a surgical option for treating strictures. During a strictureplasty, the narrowed area of intestine is widened without removing any portion of the small intestine. Several strictures may be treated during one surgical procedure.

A strictureplasty is generally safe and effective for people who do not have cancer (usually gastrointestinal), or a fistula.

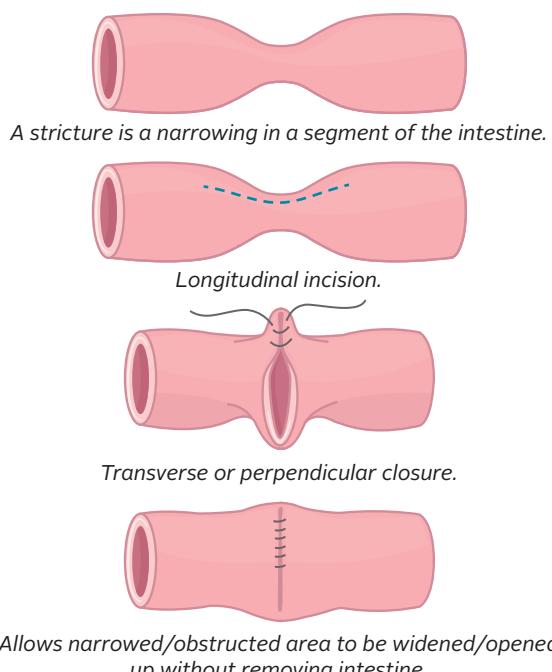


Figure 8: Illustration of a strictureplasty procedure.

Small bowel resection

This is a surgery commonly performed to treat complications of small bowel strictures, perforation, abscess, or fistula, and when inflammation does not improve with medication(s). During a bowel resection, a portion of the small intestine is removed and the two ends of healthy intestine are joined together (known as the anastomosis).

When you undergo a bowel resection, you may get many years of symptom relief; however, the disease usually returns at the surgical site. Medications can be used to successfully treat and/or prevent a recurrence of Crohn's disease, especially after areas of damage from inflammation have been removed.

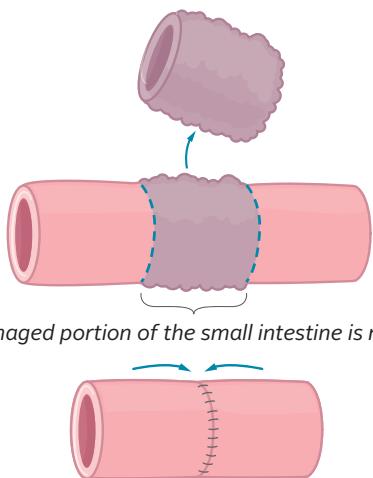


Figure 9: Illustration of resection.

Ileocolic/ileocecal resection

During an ileocolic/ileocecal resection, the first segment of the large intestine (cecum) is removed, along with the appendix. This includes removal of the ileocecal valve (ICV), which separates the large and small intestines as well as the appendix.

Large bowel resection

In a large bowel resection, the diseased portion of the colon and/or rectum is removed and the healthy intestine on either side of the removed area is reconnected. This is similar to a small bowel resection (described above).

Colectomy and proctocolectomy

If you have severe Crohn's disease that affects the colon and/or rectum, you may need surgery to remove the entire colon (total abdominal colectomy), the colon and rectum (proctocolectomy), or a portion of the colon (partial colectomy).

If the colon must be removed entirely but the rectum and anus are unaffected by the disease, a colectomy will be performed. Once the colon

is taken out, a total colectomy is performed and the ileum may be connected to the rectum. This allows the person to continue to pass stool through the anus, although some degree of loose and frequent stool will be present. This can be controlled with medications.

If your rectum is affected and must be removed along with the colon, your surgeon will perform a proctocolectomy with end ileostomy. This procedure is the same as the one described on page 13 for people with ulcerative colitis. Unlike ulcerative colitis patients, Crohn's disease patients generally do not undergo the variation of this procedure that creates an internal ileoanal pouch (proctocolectomy with IPAA). This is because the disease can recur in the internal pouch or in the anus, making pouch excision, or removal, more common.

Surgery for perianal disease and fistula

As we mentioned on page 7, a fistula is an abnormal connection between the intestine and another loop of the intestine or organ (bladder, vagina, or skin). Fistulae typically require surgical treatment. In some cases, emergency surgery is necessary to prevent the spread of infection.

An anal fistula is a tunnel that forms between the inside of the anus and the skin surrounding the anus. A fistula may first present as an anal abscess causing a painful bulge around the anus. The abscess is usually drained surgically. At that time, if a fistula is seen, a seton or a thin surgical thread may be placed through the fistula tunnel to keep the infection draining. In a surgical procedure called fistulotomy, the fistula tract is divided, obliterating the communication between the rectum and the skin. For this procedure, the recurrence rate following surgery is fairly low. Fistulae that involve minimal or no anal sphincter muscle are responsive to fistulotomy.

Some patients may need a temporary colostomy to divert stool from passing through the fistula. This helps to facilitate fistula healing.

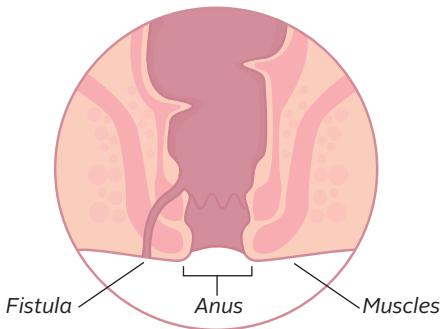


Figure 10: Illustration of perianal fistula.

Note: a fistula may occur between the intestine and other organs in the body. This is for illustrative purposes only.

Women with Crohn's disease can develop a fistula between the rectum and vagina, called a rectovaginal fistula. Surgery is often required to treat rectovaginal fistulae, and the type performed will depend on the individual circumstances. Unfortunately, rectovaginal fistulae are often difficult to treat, and the failure of surgery to close these fistulae is not uncommon.

Minimally invasive approaches to surgery

Many of the surgical procedures described above can be performed using minimally invasive techniques, such as:

- **Laparoscopic procedures:** This approach typically involves making small incisions (cuts) about half an inch in size around the abdomen. Tubes, or trocars, are inserted that allow for surgical instruments and cameras that your surgeon needs during the procedure. Images are projected on a screen and are visible to the surgeon while they are working.⁵

- **Robotic procedures:** This technique uses a robot to help the surgeon perform the procedure. Instrument arms are attached to the robot. The instruments used in this technique bend easily to move the way a surgeon's hand would. The surgeon controls the movements of the robot.

Performing surgeries using a minimally invasive technique should be discussed with your doctor. Not all patients are candidates for minimally invasive surgery. While some studies show that these approaches can be helpful for patients in the short-term, many considerations need to be made about you and your health beforehand.⁶

TIP: Ask your surgeon what type of approach or technique will be used during your surgery. What are the risks and benefits of this technique?

Potential complications in IBD surgery

Every surgery comes with both benefits and risks. It's important to talk to your surgeon and healthcare team to learn about the potential risks and complications that may arise post-surgery. It's important to remember that not everyone will develop complications—it all depends on the type of procedure performed as well as your health before and after surgery. Examples of potential complications seen in IBD surgery include:

Postoperative ileus describes a slowing or stop in intestinal motility or bowel movements after surgery. It can lead to abdominal bloating, nausea, and vomiting. Postoperative ileus generally resolves with several days of bowel rest (not eating for a few days) and intravenous hydration. You will not be released from the hospital after surgery until you have a bowel movement.

Common surgeries in IBD

Adapted from Clinical Pearls from 2018-2021 Advanced Practice Provider Committee of the Crohn's & Colitis Foundation.

Surgical options	Condition	Advantages	Considerations to discuss with your doctor
Strictureplasty (small bowel)	• Crohn's	• Opens diseased portion of bowel (decreased risk of obstruction at the affected site) • Avoids resection/removal of bowel (bowel-sparing procedure)	• Is the risk of recurrence or complication higher? • If I am experiencing nutrient deficiencies, is there anything I need to do differently?
Ileocolic/Ileocecal resection	• Crohn's	• Primary anastomosis (reconnection of ends of bowel)	• What is the risk that my Crohn's will return around the connection site?
Partial colectomy	• Crohn's	• Effective in patients with disease limited to a segment of colon (i.e., stricture, obstruction)	• Is this surgery recommended if I have rectal or anal disease?
Total colectomy with end ileostomy	• UC • Crohn's	• Can be the first stage when an ileotrectal anastomosis is later planned	• Do I still need to have surveillance colonoscopies for colorectal cancer?
Total abdominal colectomy with ileorectal anastomosis	• UC • Crohn's (in rare circumstances)	• Colon is removed • Maintains intestinal continuity	• Is there a chance my disease will return in my rectum? • How does this surgery change stool frequency? • Do I need continued surveillance for colorectal cancer?
Total proctocolectomy with end ileostomy	• UC • Crohn's	• Removes all diseased colon, rectum, and anus; single operation	• Are there any side effects of this surgery?
Total proctocolectomy with ileal pouch-anal anastomosis (J-Pouch, IPAA)	• UC	• Removes all diseased colon • Preservation of the anal sphincter complex and intestinal continuity	• Is this surgery a good option for people with Crohn's disease? • How many surgeries are best for me? • How often might complications occur? • How does this surgery change stool frequency? • Should I expect incontinence? • How much surveillance is needed if I have a pouch?
Procedures for anorectal disease (e.g., incision & drainage of abscess, seton placement, diverting ostomy, advancement flap repair)	• Crohn's	• Controls perianal disease, often with medications	• What are the risks of perianal sepsis? • Is there any risk of stool leakage or damage to the sphincter muscle?
Partial colectomy	• Crohn's	• Can be useful in cases of isolated, severe perianal disease that has not been successfully treated	• Will I have a permanent stoma? • Will my disease recur in another part of my bowel? • Is there a risk of decreased fertility or changes in sexual function?

Blood clots (also known as deep vein thrombosis) are a potential risk for anyone having surgery. It's important to note that while there is an increased risk, blood clots do not occur in every IBD patient. Anticoagulants (blood thinners) may be prescribed post-surgery to limit your risk. Examples of symptoms associated with blood clots may include leg swelling, and/or discoloration of the leg.

Wound infections are relatively frequent following colorectal surgery. If you are taking steroids or other immunosuppressive medications, you may have an increased risk of developing an infection. Examples of symptoms to look out for may include increasing swelling, redness, warmth, and pain at the wound site. Discuss any concerns with your doctor so that they can detect a possible infection.

Leaking at reconnection site is a potential complication following an intestinal resection or internal pouch procedure. This occurs if the site of the bowel reconnection comes apart (anastomotic leak). Potential causes of leakage include active disease, use of steroids, and infection. Another surgery is often required to resolve this issue. Contact your doctor immediately if you experience abdominal pain accompanied by fever.

Abscesses are collections of fluid that can gather in abdomen, pelvis, or perianal tissues. They are a potential complication of IBD generally, not just post-surgery. When surgery is performed, an abscess can form at the surgical site or the connection point of the bowels. An abscess drainage will be required. Examples of symptoms to look out for may include pain in the abdomen, discharge of pus from the anus, and swollen, tender lumps near the anus.

Diarrhea can be common after IBD surgery and is often resolved within a short period of time. Diarrhea can be a result of bile reaching

the colon, which can cause irritation. Bile is released by the liver to help in the digestion of fat. Bile diarrhea can be seen in the long term, but medication is commonly prescribed to help address this issue. If diarrhea is prolonged or has not improved, it is important to let your physician and healthcare team know to avoid additional complications, such as dehydration.

Potential long-term complications

Specific nutrient deficiencies: Nutrition is a highly important aspect of your health after surgery. Similar to preparations for surgery, your healthcare team will monitor your nutritional status and make recommendations if any nutrients are lacking in your body. For example, in patients who have had an ileocecal resection, the doctor may test for vitamin B12 levels. Vitamin B12 (also known as cobalamin) is a nutrient that helps prevent anemia and keeps your blood cells and nerve cells healthy. This vitamin is absorbed in the ileum, and therefore monitoring of levels is important. Talk to your doctor and dietitian on their recommendations to keep your levels adequate.⁷

Pouchitis: A complication specific to people who have undergone the ileoanal pouch procedure, this occurs when the pouch becomes irritated and inflamed. The problem is typically resolved with a course of antibiotics. Approximately half of ulcerative colitis patients who have an ileoanal pouch will experience pouchitis in their lifetimes.

Other possible complications of the pouch may include pelvic abscess and pouch fistulae which may require additional treatment. A small percentage of patients may develop newly diagnosed Crohn's disease of the pouch, which can generally be managed with medications. In a small fraction of patients, pouch failure may occur, requiring the removal of the pouch and conversion to a permanent ileostomy.

Small bowel obstruction due to adhesions

can occur as a result of scar tissue forming during the healing process. If the scar tissue forms in a way that causes an obstruction by sticking to other parts of the bowel (known as adhesions), your doctor may take various approaches to resolving this. Your doctor may recommend bowel rest and insertion of a nasogastric (NG) tube to drain any fluid buildup. It is possible that he/she may need to perform another surgery to remove the obstruction if the NG tube and bowel rest do not resolve the blockage. Examples of symptoms to look out for may include abdominal pain and swelling, inability to have a bowel movement or pass gas, and vomiting.

Short bowel syndrome (SBS): This condition occurs when the body is unable to absorb nutrients from food because there is not enough small intestine function. This is a concern for patients with Crohn's disease who have undergone multiple small bowel resections, where large portions of the bowel have been removed. The treatment for SBS can include nutritional support therapy and medications that aim to promote cell growth in the intestinal surface area. Nutritional recommendations are typically maximized first. Medication options target the symptoms of SBS and may also work to increase the absorptive area in the bowel, increase absorption of fluids and other nutrients, or protect the lining of the GI tract.

Parastomal hernia: This condition occurs when the intestines protrude or press on your stoma, creating a bulge. Your doctor may recommend adjustments in your activities to limit symptoms (example: no heavy lifting). Surgery may be required to place the stoma in a different area.

TIP: If you are going to undergo a resection of your small bowel, talk to your doctor about your risk for SBS and how this condition could be managed if you were to develop it. You can learn more about SBS by requesting a free copy of our SBS brochure or reading it online.

Living with an ostomy

You might be nervous about adjusting to your new normal after ostomy pouch surgery—that's completely normal. Life with an ostomy pouch doesn't have to be any different than life without one. In fact, you might find that you are able to do even more with your ostomy than you were before! In most cases, you can engage in the same activities as before the surgery, including sports, gardening, outdoor activities, water sports, traveling, work, and much more. You will have an initial period of adjustment to life with your ostomy pouch as you figure out how to use your pouching system and care for the skin around your stoma. There are no specific dietary restrictions for a person with an ostomy, but it is important to drink plenty of fluids to avoid dehydration and loss of electrolytes (salts and minerals). It



is also helpful to eat foods high in pectin, such as applesauce, bananas, or peanut butter, to thicken your stool output and control diarrhea.

Coping emotionally with the changes to your body after ostomy surgery can be hard at first. Many people initially feel self-conscious about their pouch. However, the pouch is fairly flat under clothing and not visible. No one needs to know that you have an ostomy pouch unless you decide to tell them. If you find that you are struggling emotionally, we encourage you to seek help from family, friends, a mental health professional, or a support group.

Preparing for surgery

If you are having nonemergent surgery, your healthcare team will make recommendations to help you prepare in the days, weeks, or months prior to the procedure. The preparation recommended will depend on the type of surgery you are having and your health condition, and may include:

Tests

Your doctor will recommend important tests to detect any problems that can bring on complications during surgery, including:

- Endoscopy (such as a colonoscopy) with biopsies to assess for terminal ileal and large bowel disease
- Imaging tests, such as magnetic resonance imaging (MRI) and computerized tomography (CT scan), to determine how widespread your disease is or if there is an infection (like an abscess)
- Blood tests looking at other functions in your body, how your blood clots in your body, if blood thinners may work effectively, and nutritional status

Nutrition

Prior to surgery, it is ideal for you to be in good nutritional status, as this can improve your level of health and well-being after surgery. Malnutrition can be a result of:

- Insufficient diet
- Inability of the body to absorb nutrients
- Inflammation
- Side effects of medications

Nutritional imbalances can be addressed in several ways, including eating a healthy, balanced diet, taking supplements, or through nutritional support therapy (enteral or parenteral nutrition). Enteral nutrition is usually taken in the form of a nutrient-rich formula delivered through a feeding tube directly into your stomach. This formula can either supplement your caloric intake or stand in as your main source of nutrition. Parental nutrition delivers necessary nutrients and calories directly into your bloodstream through a thin intravenous tube called a catheter that is inserted directly into a large vein in the chest, arm, or neck.

You may be required to fast (temporarily limit or stop food intake) before and/or after surgery. Your healthcare team will provide specific instructions about any necessary fasting, and how long this should be followed. We encourage you to work with a dietitian and your healthcare team to ensure that your nutritional health is considered and that there is an action plan to address any concerns prior to surgery.

Medications

You may need to adjust your medications prior to surgery. If you are taking steroids, you may need to lower your dose to increase your body's ability to heal and reduce your risk of developing complications. Antibiotics may also be prescribed prior to surgery to prevent

infection. Part of the preoperative preparation may also require consideration of other immunosuppressing medications that you may be taking. Because immunosuppressing medications such as immunomodulators and biologic therapies work by targeting a specific part of the body's immune system, they increase the risk of certain infections. Your healthcare team will discuss any changes to your medication regimen with you prior to surgery.

Smoking cessation and alcohol

Patients, particularly those with Crohn's disease, are advised to stop smoking before having surgery. Studies show that Crohn's patients who smoke are at increased risk of developing complications, such as fistulae and strictures, which in turn lead to higher rates of surgical resection. There is also an increased risk of disease recurrence for smokers who have Crohn's disease. The same increased risk is not seen in ulcerative colitis,⁸ compared to non-smokers; however, the overall health risks of smoking should be evaluated prior to surgery.

If you drink alcohol, discuss any risks with your healthcare provider and limit your consumption prior to surgery.

Mental health and emotional well-being

Treating your emotional health is just as important as your physical health. In fact, there is some evidence showing that patients with less anxiety before their surgery feel less pain postoperatively and their wounds may heal more quickly. It's important to build a support team of family members, friends, and others who can provide you with both emotional and physical support such as transportation, meal preparation, and other daily tasks, before and after surgery. If you find that you are having trouble coping with the mental impact of your

disease and/or surgery, reach out to a mental health professional. You can find a list of professionals with experience working with IBD patients on the Rome Foundation's website (romeigipsych.org).

Employment and school

In order to decrease stress, you should try to resolve any work and/or school obligations before your surgery. Some important things to discuss with your employer before scheduling procedures and time off from work include:

- Reviewing information about their Family Medical Leave (FMLA) policy
- Understanding your short-term disability (STD) eligibility requirements
- Asking about reasonable accommodations and sick leave balances

For children, try to schedule procedures when school is not in session. If this is not possible, secure a tutor for your child and make other school accommodations. If you have a child who needs surgery, you may want to utilize a 504 Accommodation Plan to help with needs for younger school-aged children. A guide and other resources for children with IBD can be found on the Crohn's & Colitis Foundation website by searching for [youth and parent resources](#).

If you are a student in college, talk to your disability services office to find out if there are support resources that can provide accommodations for you as needed. You should also discuss any need for extended time off or other accommodations with your professors. Additional resources for college students is available on our Campus Connection website (www.crohnscolitisfoundation.org/campus-connection).

TIP: Make the necessary arrangements for work or school ahead of time so that you can focus on rest and recovery. Pushing yourself back to a full schedule too quickly can delay the recovery process.

Life after ileoanal pouch surgery

If you undergo ileoanal pouch surgery, you can expect an adjustment period of up to one year as you get used to the new way your intestines are structured. Your stool may be soft or liquid, and you may experience urgency and leakage of stool. As your ileoanal pouch gradually increases in size and your anal sphincter muscles strengthen, stools will become thicker and less frequent. Although your bowel function is unlikely to be the same as it was prior to you developing ulcerative colitis, after several months, most people are down to six to eight bowel movements per day. The consistency of the stool varies but is mostly soft, almost putty-like. Medications can be used to help with your bowel movements.

While there are no specific dietary restrictions, it's advisable to chew food thoroughly and avoid foods that may cause gas, diarrhea, or anal irritation. It's also important to drink plenty of fluids—six to eight glasses a day, preferably between meals.

Intimacy with an ostomy or an ileoanal pouch

After surgery, you can return to sexual activity after a period of recovery. In fact, some patients find that their sex lives improve because the pain, inflammation, and other symptoms they had been dealing with are better or even gone. Despite this, it is common to have concerns

about how surgery will impact your sexual activity. We encourage you to speak with your healthcare provider prior to surgery about any concerns, including erectile dysfunction, retrograde ejaculation, decreased fertility, and pain during intercourse. There may be some adjustments you'll need to make to accommodate the presence of an ostomy pouch.

Managing health insurance and costs

The last thing you want to think about after having surgery is medical bills. It can be helpful to contact your health insurance company prior to surgery to:

- Ensure that your health insurance is up to date and current.
- Clarify what you may be expected to pay, including copayments or coinsurance. If you pay coinsurance, clarify what your percentage may be (example: 10%, 20%, etc.).
- Ensure that your surgeon is in your health insurance plan's network in order to limit out-of-pocket costs. It is also a good idea to discuss with your physician any additional services that may be needed after surgery. For instance, if an ostomy-wound, ostomy, and continence nurse, will visit you, or if physical therapy is needed, it is good to ask in advance what your coverage may be.
- Confirm that the hospital or medical center where your surgery will be performed is also in-network.
- Check any price differences for a double room versus a single room during your hospital stay. Are there extra fees to pay for a single room, and what portion would be covered by your plan?

- Ask about any follow-up procedures that may be needed. If you need a readmission for complications, how soon can you return to the hospital and what will your insurance coverage be?

After surgery and being discharged from the hospital, you may work with a social worker to help you address questions or needs with your health insurance plan. Below are some questions to help you plan ahead:

- What is coverage like for a wound, ostomy, and continence nurse or home health aide to come to my home? How many visits would be approved and how often?
- What is coverage like for ostomy supplies and/or any necessary medical supplies post-discharge (drains, etc.).
- Are postoperative visits with my surgeon covered? If so, for how long?

Care and recovery after surgery

The most important thing you can do after surgery is take it easy and follow the specific instructions your surgeon gives you for postoperative care. Take medications (such as pain medications or antibiotics) as prescribed and follow their instructions regarding diet, physical activity, and other lifestyle issues. You will also need to follow up with your gastroenterologist and your surgeon after surgery to prevent complications or recurrence of disease (especially in Crohn's patients).

Several organizations, including the Crohn's & Colitis Foundation, offer support and advice for people undergoing surgery for IBD. You can visit the Foundation's website (www.crohnscolitisfoundation.org), call the Irwin M. and Suzanne R. Rosenthal Inflammatory Bowel

Disease Resource Center (IBD Help Center) at 888-MY-GUT-PAIN (888-694-8872), or join an online or in-person support group. The American Society of Colon & Rectal Surgeons provides information on colorectal conditions, treatment, and screening information, and help locating surgeons in your area (www.facs.org). The United Ostomy Associations of America (www.ostomy.org) has patient guides and support groups to help provide information to patients before and after pouch surgery.

Dietary recommendations

Each organ of the digestive tract (from the mouth to the anus) has a highly specialized function in the breakdown and absorption of essential nutrients from food, and the elimination of waste material. Many people who have undergone surgery for IBD have had a portion of their digestive tract removed. Depending on the type of surgery you have, you may or may not need to make some temporary or permanent adjustments to your diet. Dietary recommendations will be based on the nature of your surgery, the health of your remaining bowel, and your overall health.

In general, it is important for everyone to have a well-balanced diet that provides necessary vitamins and minerals, and includes foods from all the major groups (grains, vegetables, fruit, milk, meat, and beans). Following ostomy surgery, a low-fiber diet may be recommended for the first six to eight weeks.

Because some surgeries impact the ability of the body to properly absorb nutrients from food, many people need to take nutritional supplements post-surgery. Daily vitamin supplements may be recommended, especially for patients who have both IBD and anemia. Your physician or dietitian can make recommendations for specific supplements, or a multivitamin may be taken.

TIP: Having ostomy surgery? There will be a lot to learn after the procedure. Start preparing in advance by consulting with a wound, ostomy, and continence nurse (a healthcare provider who specializes in caring for patients with all types of ostomies).

Building your healthcare team

No matter the type of surgery that is performed, you'll want to work with a healthcare team that you feel comfortable with. If surgery becomes necessary or is decided on as the course of treatment, a surgeon who specializes in surgery of the gastrointestinal tract (known as a colorectal surgeon) should be consulted to perform your operation. Your regular gastroenterologist will also play an essential role in your treatment before and after surgery.

Here are some tips and questions you can ask to help you find the right surgeon for your needs:

- Find a surgeon and hospital that is right for you. Ensure that the surgeon is board certified in general surgery and/or in colon and rectal surgery. Don't be afraid to seek a second or third opinion to find someone you are comfortable with.
- Ask the surgeon about his or her experience with the procedure you will undergo. How many of those procedures have they performed, and have they been done successfully?
- Ask the surgeon how he or she will work together with your gastroenterologist and healthcare team.

- Ask if they can connect you with others who've had the same procedure for IBD. Some state health departments publish outcome data about certain procedures performed at specific hospitals.

Your gastroenterologist or other healthcare provider can recommend surgeons, or you can check with the American Society of Colon & Rectal Surgeons (www.facs.org), the American College of Surgeons (www.facs.org), or the Crohn's & Colitis Foundation (www.crohnscolitisfoundation.org) for more information.

Frequently asked questions about IBD surgery

How do I know if medication alone is no longer working and that I should consider surgery?

This depends on your individual experience. Sometimes medication is effective at the start, and then stops working or brings on additional complications. Or perhaps there hasn't been a treatment option that has successfully helped control your symptoms or inflammation. If your disease continues to progress and medication isn't helping manage it, your healthcare team may recommend surgery as a consideration. Medications that you may have taken before may work better for some patients after surgery in maintaining your health.

Once I have a bowel resection for Crohn's disease, will I still need to continue taking medication?

This is a great question to ask your healthcare provider. In order to prevent a recurrence of disease, many patients do need to continue on their medication or make changes to their treatment regimen to ensure that the inflammatory response in the immune system is still targeted and inflammation and symptoms are being kept under control.

Once I have a colectomy for ulcerative colitis, am I cured?

While a colectomy involves removing the colon (the area where ulcerative colitis is present), some patients may still experience symptoms and/or complications following surgery. This may require further medical management after surgery.

If I have a partial colectomy, does this mean I am still at risk for developing colorectal cancer?

While a colectomy removes the diseased intestine, it is important to continue having surveillance for cancer and discuss your risk with your healthcare team.

Knowledge and support are power!

Find the answers you need to help control your IBD by joining the Crohn's & Colitis Foundation:

• Education and Support Programs

The Foundation has chapters across the country covering all 50 states. Visit our website at www.crohnscolitisfoundation.org to find programs, support groups, and events.

• Power of Two

The Foundation's Power of Two program allows patients seeking guidance on a specific issue to speak with another peer within the IBD community who can share their experience and provide support. To find out more, email powerof2@crohnscolitisfoundation.org.

• Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center)

The IBD Help Center is a free service designed to provide you with disease-specific information, guidance, and support. Our Information Specialists can be reached by calling 888-MY-GUT-PAIN (888-694-8872) Monday through

Friday, 9 a.m. to 5 p.m. EST, or by emailing info@crohnscolitisfoundation.org.

• Crohn's & Colitis Foundation Online Community

The Foundation hosts a free website where patients can get the support they need in managing their condition. They'll participate in discussion boards, share or read personal stories, and much more. The Crohn's & Colitis Community is waiting for people just like you. Join today at www.crohnscolitiscommunity.org.



• Camp Oasis

The Crohn's & Colitis Foundation's Camp Oasis is a summer camp program. Its mission is to enrich the lives of children with IBD by providing a safe and supportive camp community. For more information, visit www.crohnscolitis-foundation.org or call the IBD Help Center.

• Membership

By joining the Crohn's & Colitis Foundation, you'll get:

- » News, educational programs, and supportive services from your local chapter
- » An "I Can't Wait" card (may provide help when asking to use a public restroom)
- » A chance to contribute to research to find a cure for these challenging diseases

The Crohn's & Colitis Foundation sponsors events to increase awareness and raise funds to find cures for Crohn's disease and ulcerative colitis. Contact your local chapter or visit www.crohnscolitisfoundation.org to find an event nearest you.



• spin4 crohn's & colitis cures

Participate in a high-energy spin4 crohn's & colitis cures event near you! With inspirational instructors and fun playlists to keep you motivated, these indoor cycling relays are truly a #partyonabike. Teams of up to four people each ride for a 30-minute session, and every teammate receives plenty of swag! The events generate awareness of Crohn's disease and ulcerative colitis, and raise funds to support groundbreaking IBD research and patient services. Learn more at www.spin4.org.



• **Take Steps** is the Crohn's & Colitis Foundation's national walk program. Take Steps enables patients and families to raise money for crucial research and to build awareness about Crohn's disease and ulcerative colitis. Visit www.cctakesteps.org for more information.



• Team Challenge

We challenge you to achieve more than you ever thought possible. Team Challenge combines fitness and fundraising, empowering you to help find a cure for Crohn's disease and ulcerative colitis while also being part of a supportive community. Whether you train & travel to a destination event with our teams, participate in one of our virtual options, or create your own event, there are plenty of ways to get active and raise funds! Learn more: www.ccteamchallenge.org.

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About the Crohn's & Colitis Foundation

The Crohn's & Colitis Foundation is the leading nonprofit organization focused on both research and patient support for inflammatory bowel disease (IBD). The Foundation's mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life for the more than 3 million Americans living with IBD. Our work is dramatically accelerating the research process through investment initiatives; we also provide extensive educational resources for patients and their families, medical professionals, and the public.

We can help! Contact us at:

888-MY-GUT-PAIN
(888-694-8872)
info@crohnscolitisfoundation.org
www.crohnscolitisfoundation.org

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The Crohn's & Colitis Foundation is a nonprofit organization that relies on the generosity of private contributions to advance its mission to cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases.