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Surgery for Crohn's Disease and Ulcerative Colitis



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(Disclaimer: Surgery information is up to date at the time of printing. Due to rapid advances and new findings, there may be changes to this information over time. You should always check with your doctor to get the most current information. This information should not replace the recommendations and advice of your doctor.) Crohn's disease and ulcerative colitis are lifelong illnesses. Treatment with medication is the first therapeutic option. Eventually, some people living with Crohn's disease or ulcerative colitis may require surgery. This brochure reviews possible reasons that make surgery necessary, describes the various procedures, and helps you to learn what to expect.

About Crohn's disease and ulcerative colitis

Crohn's disease and ulcerative colitis belong to the same disease category, inflammatory bowel diseases (IBD).

IBD causes chronic inflammation in the gastrointestinal (GI) tract. Chronic inflammation impairs the ability of the affected organs to function properly, leading to symptoms such as abdominal cramping, diarrhea, rectal bleeding, and fatigue.

While both diseases share many of the same symptoms, there are some important differences. *Ulcerative colitis* is limited to the large intestine (colon) and the rectum. Inflammation occurs only on the surface layer of the intestinal lining. It generally starts in the rectum and expands up the colon in a continuous manner.

Crohn's disease most commonly affects the end of the small intestine (the ileum) and the beginning of the colon, but it can affect any part of the GI tract from the mouth to the anus. Crohn's disease may also appear in "patches," affecting some areas of the GI tract while leaving other sections in between completely untouched. (These are known as "skip" areas). In Crohn's disease, the inflammation may extend through all layers of the intestine, including the area around the anal canal (perianal area).

The medications used to treat both ulcerative colitis and Crohn's disease are prescribed to decrease intestinal inflammation. While they cannot cure the diseases, they can often bring about a state of *remission* (a period where a person is symptom free). Remissions can last for months or years, depending on the individual. Over time, adjustments in medication dose or type may be needed to maintain remission.

Medication may not adequately control symptoms for everyone with IBD, and some people with these conditions develop complications that need more aggressive treatment. In these cases, surgery may be recommended or required.

For more information about Crohn's disease and ulcerative colitis, view our brochures at www.ccfa.org or call our Information Resource Center at 888.MY.GUT.PAIN (694.8872).

When is surgery necessary?

About 23 to 45 percent of people with ulcerative colitis and up to 75 percent of people with Crohn's disease will eventually require surgery.

Some people with these conditions have the option to choose surgery, while for others, surgery is an absolute necessity due to complications of their disease.

Reasons for elective surgery

Some people with IBD decide to have surgery because they can no longer bear the symptoms of their disease or they are no longer responding to their prescribed medication. The medications used to treat Crohn's disease and ulcerative colitis are not necessarily effective for all patients all the time. Some patients do well on a particular medication for a time, and then, for unknown reasons, they stop responding. Some people experience many side effects from the medications. Surgery will be considered if a person's quality of life has been severly impacted despite medical treatment or if side effects of the medications are significant.

Colorectal cancer

Elective surgery may also be recommended for some people with IBD to eliminate the risk of colorectal cancer. Patients with ulcerative colitis and Crohn's disease have a higher risk for colorectal cancer than the general population. Colorectal cancer rarely occurs in the first eight to ten years after initial diagnosis of IBD. The risk increases the longer a person lives with the disease. People whose disease affects most of their colon are at the greatest risk for developing colorectal cancer.

In most cases, colorectal cancer starts as a *polyp* (a small lump growing from the wall of the intestine). Polyps start out benign but become cancerous over time. Patients with IBD, however, do not always form precancerous polyps. Instead, abnormal and potentially precancerous tissue (called *dysplasia*) may lay flat against the wall of the intestine. In addition, abnormal, precancerous cells can be present in an area of the intestinal wall that appears normal at the time of colonoscopy.

People who have had IBD for more than eight to ten years should have surveillance colonoscopies every one to two years (depending on other risk factors, such as family history of colorectal cancer). The standard colonoscopy is usually accompanied by a series of *biopsies* small tissue samples taken for microscopic examination. If dysplasia is found (even if it's not cancerous), surgery to remove the colon and rectum is usually recommended to eliminate the risk of developing cancer.



Conditions that require immediate surgery

Ulcerative colitis

Sudden, severe ulcerative colitis

This is the main reason for emergency surgery for ulcerative colitis. About 15 percent of people with ulcerative colitis have an attack of the disease so severe that medications, even intravenous steroids, cannot control the symptoms. Surgery may be necessary if medications are unable to bring the attack under control.

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

Perforation of the colon

Chronic inflammation of the colon may weaken the wall to such an extent that a hole occurs. This is potentially life threatening because the contents of the intestine can spill into the abdomen and cause a serious infection called *peritonitis*.

Crohn's disease

Intestinal obstruction or blockage

Chronic inflammation in the intestines can cause 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.

Excessive bleeding in the intestine

This is a rare complication of Crohn's disease. Surgery is performed only if bleeding cannot be controlled by other means.

Perforation of the bowel

As with ulcerative colitis, chronic inflammation may weaken the wall of the intestine to such an extent that a hole occurs. Occasionally, a portion of the bowel near a stricture can also expand, causing the wall to weaken and a hole to occur.

Fistula

Inflammation can cause 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 and form a tunnel to another part of the intestine, between the intestine and another organ such as the bladder or vagina, or to the skin surface. These are called *fistulas*. Fistulas can also form around the anal area, and may cause drainage of mucus or stool from an area adjacent to the anus. Repair of this connection requires surgery.

Abscess

An *abscess* is a collection of pus, which can develop in the abdomen, pelvis, or around the anal area. It can lead to symptoms of severe pain in the abdomen, painful bowel movements, discharge of pus from the anus, fever, or a lump at the edge of the anus that is swollen, red, and tender. An abscess requires not only antibiotics, but also surgical drainage of the pus cavity to allow for healing.

Toxic megacolon

As with ulcerative colitis, severe inflammation can lead to toxic megacolon and require immediate treatment and surgery.

Your health care team

Once surgery becomes necessary or is decided on as the course of treatment, a surgeon who specializes in performing surgery on the gastrointestinal tract should be consulted to perform the operation.

Your regular gastroenterologist will also play an essential role in your treatment before and after surgery.

If surgery is elective, spend some time choosing a surgeon and a hospital. In addition to being board certified in general surgery, or board certified in colon and rectal surgery, the surgeon



should have a great deal of experience performing the specific procedure you will undergo. You can ask the surgeon about his or her experience and also ask for information on how to speak with others who've had the same procedure. Some state health departments publish outcome data about certain procedures performed at specific hospitals. Your gastroenterologist or other health care provider can recommend surgeons, or you can check with the American Society of Colon & Rectal Surgeons (www.fascrs.org), the American College of Surgeons (www.facs.org), or CCFA (www.ccfa.org) for more information.

Common procedures for ulcerative colitis

The standard surgical procedure for ulcerative colitis is removal of the colon and rectum, called *proctocolectomy*.

Because ulcerative colitis affects only the colon and rectum, once these organs are removed, the person is cured. For many years, those who underwent proctocolectomy were required to wear a bag over a small hole in the abdomen to collect stool. This procedure is called *total proctocolectomy* with end *ileostomy*. While this procedure is still performed, modifications to the procedure allow many patients to undergo variations that eliminate the need to wear a permanent external bag.

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

Proctocolectomy: Surgical removal of the colon and rectum.

- **Colectomy:** Surgical removal of the colon.
- Ileum: The lower portion of the small intestine.
- Ileostomy: A surgically created hole in the abdomen for the elimination of waste.
 Ileostomy can be permanent or temporary.
- Stoma: A hole in the abdomen created during ileostomy.
- Ostomy bag: A small plastic pouch worn over the stoma to collect stool. An ostomy bag is also known as a pouching system, collection pouch, or appliance.

Proctocolectomy with ileal pouchanal anastomosis

Proctocolectomy with ileal pouch-anal anastomosis (IPAA) is the most commonly performed surgical procedure for ulcerative colitis. It is an attractive option for many people because it eliminates the need to permanently wear an ostomy bag (pouch, appliance, etc.). The nerves and muscles necessary for continence are preserved and stool is passed through the anus.

The procedure can be performed in one, two, or three stages, although it usually is performed in two. In the first surgery, the colon and the rectum are removed, but the anus and anal sphincter muscles are preserved. The ileum is then fashioned into a pouch and pulled down and connected to the anus. The pouch may be shaped like a J, S, or W.

Because the newly formed pouch needs time to heal, a temporary ileostomy is often performed to divert stool away from the pouch. In this procedure, a loop of the small intestine is pulled through an opening in the abdomen to allow for the elimination of waste. An ostomy bag is worn continuously during this time, and must be emptied several times a day. Issues related to the temporary ileostomy are similar to those experienced with a permanent ileostomy (see page 12). About 12 weeks after the initial surgery (once the pouch has healed), the temporary ileostomy is closed during a second, smaller operation. The small intestine is reconnected and the continuity of the bowel is re-established. From this point on, the internal pouch serves as a reservoir for waste, and stool is passed through the anus in a bowel movement. An external ostomy bag is no longer required.

This procedure may also be performed in one stage. In this case, the colon and rectum are removed and the pouch is created and joined to the anus without a temporary ileostomy. Due to an increased risk of infection, the procedure is performed less often than the two-stage procedure.

In some cases, IPAA may be performed in three stages. In the first surgery, the colon is removed and an ileostomy is created. In the second surgery, the rectum is removed and the ileum is formed into the pouch, which is connected to the anus. As with the two-stage procedure, this is done to allow the pouch time to heal. About eight to 12 weeks later, the third surgery is performed to close the ileostomy and reattach the small intestine to the pouch. The patient can then begin using the newly created pouch and

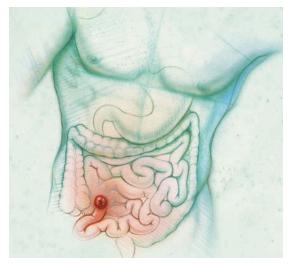


Figure 1: Site of ostomy

pass stool through the anus. A three-step procedure may be recommended for people with ulcerative colitis who are in poor physical health, on high doses of steroids, or when emergency surgery for bleeding or toxic megacolon is necessary.

Total proctocolectomy with end ileostomy

In the traditional proctocolectomy procedure, the colon, rectum, and anus are removed, and an end ileostomy is created. In this procedure, the end of the small intestine (ileum) is brought through a hole in the abdominal wall in order to create the stoma, which allows drainage of intestinal waste out of the body. The stoma, which is about the size of a quarter, will protrude slightly. It will be pinkish in color and will be moist and shiny.

After the procedure, an external ostomy bag must be worn over the stoma at all times to collect waste. The bag is a component of a pouching system that also includes a skin barrier. The bag is emptied several times a day. The usual site for an ileostomy is the lower abdomen just below the belt line, to the right of the navel (see Figure 1).

For more information, visit the United Ostomy Associations of America website at www.uoaa.org.

Living with an ileostomy

People can live long, active, and productive lives with an ileostomy. In most cases, they can engage in the same activities as before the surgery, including sports, gardening, outdoor activities, water sports, traveling, and work. An initial period of adjustment should be expected. Several pouching systems are available to choose from and it will be necessary to learn how to use the system, as well as how to care for the skin surrounding the stoma. There are no specific dietary restrictions for a person with an ileostomy, 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 to thicken your stool output and control diarrhea. These foods include applesauce, bananas, or peanut butter.

The psychological implications of a change in body image may be a problem at first. Many people initially feel self-conscious about wearing an ostomy bag. However, the pouch is fairly flat, under clothing, and is not visible. No one needs to know about it unless you decide to tell them.

Many people are concerned about how the surgery will impact their sexual activity. For most people, sexual function is not impaired. Some men may experience erectile dysfunction and some women may have pain during intercourse, but this usually is only temporary. Body contact during sex will not loosen the pouch, but there are some adjustments you'll need to make to accommodate the presence of the pouch. You and your partner are likely to have questions and concerns. The United Ostomy Associations of America, Inc. (www.uoaa.org) has information on a range of topics, including intimacy, sexuality, diet, travel tips, support, and ostomy supplies.

Post-surgical complications

Some complications may occur after the surgery, including infection from the surgery or at the site of the stoma. Additionally, the small intestine may become obstructed from food or from scar tissue. If the obstruction is from food, it should be temporary and ease when the food moves through the intestines. If no waste material exits the stoma for four to six hours, and is accompanied by symptoms of cramps and/or nausea, you may have a blockage. A physician or other health care provider should be immediately notified if you experience these symptoms.

Just as people who have had a limb removed sometimes feel as if the limb is still there, some people who have their rectum removed still feel as if they need to have a bowel movement. This is called *phantom rectum*. It is normal to feel this after surgery and does not require any treatment. It often subsides over time.

Life after surgery

Most people do very well post-surgery, and after recovery are able to return to work and normal activity. An adjustment period of up to one year should be expected after surgery. Initially, there may be up to 12 bowel movements a day. Stool may be soft or liquid, and there may be urgency and leakage of stool. As the pouch gradually increases in size and anal sphincter muscles strengthen, stools will become thicker and less frequent. 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.

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. (see chart on pages 14-15.) It's also important to drink plenty of fluids—six to eight glasses a day, preferably between meals.

After the surgery, normal sexual activity can be resumed. In fact, some people find their sex life improves because the pain, inflammation, and other symptoms of ulcerative colitis are gone. Prior to surgery, patients should speak with their health care provider about any concerns, such as erectile dysfunction, retrograde ejaculation, or decreased fertility.

Potential long-term complications

The most common complication of IPAA surgery is *pouchitis*. Inflammation of the pouch occurs in up to 50 percent of patients, usually within the first two years after surgery. Symptoms are diarrhea, crampy abdominal pain, increased frequency of stool, fever, dehydration, and joint pain. The condition is treated with an antibiotic prescribed by a physician.

Ostomates Food Reference

Gas Producing	Odor Producing
Alcoholic beverages Beans Soy Cabbage Carbonated beverages Cauliflower Cucumbers Dairy products Chewing gum Milk Nuts Onions Radishes	Asparagus Baked beans Broccoli Cabbage Cod liver oil Eggs Fish Garlic Onions Peanut butter Strong cheese
Color Changes	Odor Control

Source: United Ostomy Associations of America.

Listed below are some general effects that foods may have on you after ostomy surgery. Use trial and error to determine your individual tolerance. Do not be afraid to try foods that you like; start with small amounts.

Increased Stools	Stoma Obstructive
Alcoholic beverages Whole grains Bran cereals Cooked cabbage Fresh fruits Leafy greens Milk Prunes Raisins Raw vegetables Spices	Apple peels Raw cabbage Celery Chinese vegetables Whole kernel corn Coconuts Dried fruit Mushrooms Nuts Oranges Pineapple Popcorn Seeds
Constipation Relief	Diarrhea Control
Coffee Cooked fruits Cooked vegetables Fresh fruits Fruit juices Water Any warm or hot beverage	Applesauce Bananas Boiled rice Peanut butter Pectin supplement (fiber) Tapioca Toast

Small bowel obstruction is another potential, but less common, complication of IPAA surgery. It may develop due to adhesions from the surgery. Bowel obstruction causes crampy abdominal pain with nausea and vomiting. In about two-thirds of people who have this complication, it can be managed with bowel rest (not eating for a few days) and intravenous fluids during a short stay in the hospital. The other one-third of people will require surgery to remove the blockage.

Other possible complications include pelvic abscess and pouch fistulas, which may require additional treatment. Pouch failure, which requires removal of the pouch and conversion to a permanent ileostomy, occurs in a small percentage of patients.

Minimally invasive approaches to surgery

In recent years, surgeons have developed methods to perform some of the above surgeries with minimally invasive techniques. In the traditional open surgical method, a long incision is made in the abdomen allowing the surgeon direct access to the organs. With minimally invasive surgery—also called laparoscopic sur*gery*—small openings are made in the abdomen through which specialized instruments are inserted. One of these instruments, called a laparoscope, has a tiny camera at the tip. The image from this camera is displayed on a monitor, allowing the surgical team to see inside the body. Instruments for performing the surgery are inserted through four or more additional short incisions.

Minimally invasive surgery for ulcerative colitis generally takes longer to perform and the outcomes and possible complications are the same as with traditional open surgery. However, recovery time in the hospital after the surgery often is shorter.

Common procedures for Crohn's disease

Different types of surgical procedures may be performed for Crohn's disease, depending on the complication, severity of the illness, and location of the disease in the intestines.

In many cases, surgery is performed to remove a diseased portion of the gastrointestinal tract. This surgery may involve removal of a section of an intestine, or it may mean removing an entire organ (such as the colon and/or rectum).

Unlike ulcerative colitis, Crohn's disease cannot be cured with surgery, except in some instances where only the colon, rectum, and anus are affected. If the diseased portion of the intestine is removed, the inflammation can reappear adjacent to the site of the surgery, even if that part of the intestine was normal prior to the surgery. The primary goals of surgery for Crohn's disease are to conserve as much bowel as possible, alleviate complications, and to help the patient achieve the best possible quality of life.

Small bowel disease

When Crohn's disease affects the small intestine, areas of diseased bowel 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 crampy pain. There are two surgical procedures for strictures: strictureplasty and small bowel resection.

Strictureplasty

In a *strictureplasty*, the narrowed area of intestine is widened without removing any portion of the small intestine. The surgeon makes a lengthwise incision along the narrowed area and then sews it up crosswise. This shortens and widens the segment of bowel. Several strictures may be treated in one surgical procedure. Strictureplasty is most effective in the lower sections of the small intestine (*ileum* and *jejunum*), and is less effective in the upper section (*duodenum*).

Performing strictureplasty avoids the need to remove a section of the small intestine, which can sometimes lead to a condition called *short bowel syndrome* (described on page 19). Strictureplasty is generally safe and effective, but about half of the people who have this procedure will require subsequent surgery.

Small bowel resection

Strictures may also be treated with a *small bowel resection*. In this procedure, a segment of the small intestine is removed and the two ends of healthy intestine are joined together (*anastomosis*). Small bowel resection may also be required if a hole develops in the wall of the small intestine.

A bowel resection may offer patients many years of symptom relief. However, about 50 percent of adult patients will have a recurrence of symptomatic Crohn's disease within five years after having a resection. The disease usually recurs at the site of the anastomosis. Recurrent Crohn's disease often can be successfully treated with medications, such as immunomodulators or biologics. However, about one-half of people with recurrent symptoms will need a second surgery.

Another possible complication of bowel resection is a condition called *short bowel syndrome*. The small intestine serves the essential function of absorbing nutrients from digested food into the bloodstream, where they travel to nourish the body. If too much of the small intestine is removed, nutritional deficiencies may occur.

Colonic disease

Some people have severe Crohn's disease that affects the colon and/or rectum. Surgery may be needed to remove the entire colon (*colectomy*), the colon and rectum (*proctocolectomy*), or a portion of the colon (*resection*).

Large bowel resection

In a *large bowel resection*, the diseased portion of the colon is removed and the healthy intestine on either side of the removed area is sewn together. This is similar to a small bowel resection (described above). As with that procedure, Crohn's disease recurs about 50 percent of the time, usually at the site where the intestine was connected.

Colectomy and proctocolectomy

If the colon must be removed entirely but the rectum is unaffected by the disease, a *colectomy* will be performed. Once the colon is taken out, the ileum will be joined to the rectum. This allows the person to continue to pass stool through the anus.

If the rectum is affected and must be removed along with the colon, the surgeon will perform a *proctocolectomy with end ileostomy*. This procedure is the same as the one described on page 9 for people with ulcerative colitis. Unlike ulcerative colitis patients, Crohn's disease patients generally do not undergo the variation of the procedure that eliminates the need to wear an external ostomy bag (proctocolectomy with ileal pouch-anal anastosis). This is because the disease frequently recurs in the internal pouch, making pouch excision more common.

Perianal disease and intestinal fistulas

About 35 to 50 percent of adults with Crohn's disease will develop a *fistula* (see page 6) during their lifetime. A fistula usually starts as an

infection. A collection of pus, intestinal bacteria, and fluids penetrates through the wall of an intestinal organ, and a channel forms to another loop of intestine or organ (bladder, vagina, or skin). Because they contain infected material, fistulas may initially be treated with antibiotics. Surgery for a fistula may be necessary if its symptoms do not respond to medications. 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. In a surgical procedure called *fistulotomy*, the goal is to cure the fistula without damaging the anal sphincter muscles, which are necessary for fecal continence. For these fistulas, the recurrence rate is fairly low following surgery and there is little impact on continence. Complications from this procedure are rare. If a fistulotomy cannot be performed, other surgical techniques may be required.

Women with Crohn's disease can develop a fistula between the rectum and vagina, which may be difficult to treat. The procedure that is performed will depend on the individual circumstances.

Minimally invasive approaches to surgery

Many of the surgical procedures described above can be performed using a minimally invasive technique (described on page 16). The advantages of a minimally invasive approach for Crohn's disease surgery include less pain after the operation, less chance of infection, and a shorter hospital stay. The ideal candidates for laparoscopic surgery are nonobese patients who have had no prior operations, are undergoing elective procedures, and have few, if any, other health problems. During emergency surgery for life-threatening complications, it is not always possible to perform surgery with minimally invasive techniques.

Intestinal transplant

In a small number of people with severe Crohn's disease, most of the small intestine must be removed. Without this organ, the body is no longer able to absorb nutrients from digested food, and the person must receive nutrition through intravenous feeding. Over the long term, intravenous feeding can have life-threatening complications, such as infection or liver failure.

People with these complications are potential candidates for intestinal transplant. In this rare procedure, the small intestine from a deceased donor is transplanted into a person with Crohn's disease. In some cases, just the small intestine is transplanted, while in other cases the liver and possibly other digestive organs are also transplanted.

The success rate with this procedure has been improving over the years, but it remains difficult and risky, and is generally a last resort. There is a high risk for death during or following the surgery. There also is a chance that the body will reject the transplanted organ. People who have organ transplants must take medication for the rest of their lives to prevent organ rejection.

Making the decision to have surgery

Some people with IBD suffer needlessly because they try to avoid surgery.

If medical therapy no longer keeps the disease under control, surgery should be seriously considered. Surgery is a treatment option, the goals of which are to relieve ongoing symptoms, reduce the risk of cancer, and improve quality of life.



The decision to undergo surgery will be a collaboration among yourself, your health care providers (gastroenterologist, surgeon, nurse practitioner, and others), and close family members. When parents are considering surgery for a child with IBD, it will be important to decide how and when to involve them in the discussion. Involving and educating children will help to reduce their concern and possible anxiety about surgery.

When making the decision to have surgery, it's helpful to understand why you may need surgery, to educate yourself about the different surgical options, and to ask questions of your health care team. You also may want to speak with patients who have undergone the procedure you are considering.

All surgery carries some risks. Some are common to all surgeries and some are specific to the individual procedures. Risks with any surgery include bleeding, infection, and issues associated with general anesthesia. These can generally be managed by the surgical team if they occur. Ask your surgeon to explain all of the relevant risks associated with the procedure as they pertain to you and your individual condition.

Preparing for surgery

In some cases, surgery will be an emergency procedure and there will be little time to prepare.

However, if possible, it is important to prepare yourself for the surgery.

- Try to be in the best possible physical and mental shape prior to the procedure. Nutrition is extremely important because when you are well nourished, your immune system is strong, which lessens the likelihood of surgical complications such as infection.
- Prepare yourself mentally for surgery and recovery. If the procedure will result in an ostomy, there will be much to learn. It's best to start preparing in advance by consulting with a wound-ostomy care nurse (a health care provider who specializes in ostomies).
- Build a support team of family, friends, and others who can assist you before and after surgery with transportation, meal preparation, and other daily tasks.
- Try to resolve work, family, and school obligations in advance. Speak with your employer about taking time off from work or ask about the company's Family Medical Leave policy. Check into temporary disability, social security, or other appropriate programs. 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.

After surgery

You will receive specific instructions for postoperative care after surgery.

You may be given drugs, such as pain medication or antibiotics, and there will likely be specific instructions regarding diet, physical activity, and other lifestyle issues. These may apply temporarily or permanently.

Because of the possibility for complications from surgery or recurrence of disease (for Crohn's disease patients), it will be necessary to continue to follow up with your gastroenterologist and your surgeon after recovering from surgery.

Several organizations, including CCFA, offer support and advice for people undergoing surgery for IBD. You can visit CCFA's website (www.ccfa.org), call the Information Resource Center at 888.MY.GUT.PAIN (888.694.8872), or join a 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.fascrs.org). The United Ostomy Associations of America, Inc. (www.uoaa.org) has patient guides and support groups to help provide information to patients before and after surgery.

Dietary recommendations

Depending on the type of surgery you have, you may need to make some adjustments to your diet. These may be temporary or permanent. 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. The exact nature of the surgery, the health of the remaining bowel, and the overall health of the patient may have an impact on the need for dietary modifications following surgery.

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, and meat and beans). Following ostomy surgery, a low-fiber diet may be recommended for the first six to eight weeks. The United Ostomy Associations of America (UOAA—www.uoaa.org) has other specific recommendations for people who have undergone ostomy surgery (colostomy, ileostomy, or IPAA) (see pages 14-15).

Because some surgeries impact the ability of the body to properly absorb nutrients from food, many people need to take nutritional supplements post-surgery. Your physician or dietitian can make recommendations for specific supplements, or a multivitamin may be taken.

For patients who have undergone IPAA surgery, the UOAA offers the following tips:

- Eat regularly—don't skip meals. Empty bowels produce gas.
- When adding new foods to your diet, try a little bit with other foods you know will be easy to digest.
- Small, frequent meals are best—always chew thoroughly.
- Rice, potatoes, or pasta once daily may reduce bowel frequency and irritation.
- High potassium foods will help offset the side effects of diarrhea.
- Limit foods containing simple sugars—they aggravate diarrhea.



The following are potential anal irritants:

- Coconut
- Dried fruits (raisins, figs)
- Foods with seeds or nuts
- Raw fruits (oranges, apples)
- Raw vegetables (celery, corn, coleslaw)
- Spicy foods

In addition to eating the right foods, be sure to also drink plenty of water, as well as beverages such as milk and juice. Limit your amount of carbonated and caffeinated liquids. Try to drink eight to ten glasses of liquid each day, but not with meals. Review the ostomates food reference chart on pages 14-15 for more information.

Tools and resources

You and your doctor share one important goal: to get your IBD under control and keep it that way. To help you do that, we have provided a surgery log.

To use the log, fill in information about your surgery under each category. You may want to leave blank lines under each surgery to enable you to record "pre-" and "post-surgery" recommendations or instructions.

We suggest you keep it somewhere handy so you can access it easily. The tracker also serves as a convenient reference for when you meet with or speak to your health care providers.



Improving quality of life

The Crohn's & Colitis Foundation of America has established a range of educational brochures, fact sheets, and programs designed to increase knowledge about these digestive diseases.

Living with Crohn's or colitis can be difficult, but the right resources and support can make day-to-day living less challenging. That's why CCFA has also developed a comprehensive free online community (www.ccfacommunity.org) to provide the support individuals need in managing their condition.

We recognize the importance of distributing unbiased, accurate, and authoritative information in order to provide education of the finest quality. One avenue used to accomplish this is the Information Resource Center (IRC). Through a toll-free number (888-MY-GUT-PAIN or 888.694.8872), e-mail (info@ccfa.org), or live chat on our website (www.ccfa.org), master's degree-level health education professionals answer questions and direct people to resources that could improve their quality of life. The IRC has truly become an important lifeline for patients, families, friends, health care professionals, and the media.

About CCFA

Established in 1967, the Crohn's & Colitis Foundation of America (CCFA) is the largest national nonprofit organization dedicated to finding the cure for IBD. Our mission is to fund research; provide educational resources for patients and their families, medical professionals, and the public; and to furnish supportive services for people with Crohn's disease or ulcerative colitis.

Advocacy is also a major component of CCFA's mission. CCFA has played a crucial role in obtaining increased funding for IBD research at the National Institutes of Health, and in advancing legislation that will improve the lives of patients nationwide.

Contact CCFA to get the latest information on disease management, research findings, to learn more about our advocacy efforts, or to join us and become a member. When you become a member, you help support vital research that will one day lead to a cure.

We can help! Contact us at:

888.MY.GUT.PAIN (888.694.8872) info@ccfa.org www.ccfa.org

Crohn's & Colitis Foundation of America 386 Park Avenue South 17th Floor New York, NY 10016-8804 This brochure is supported by an unrestricted educational grant from ConvaTec.



CROHN'S & COLITIS

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The Crohn's & Colitis Foundation of America is a nonprofit organization that relies on the generosity of private contributions to advance its mission to find a cure for Crohn's disease and ulcerative colitis.

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