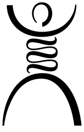


Crohn's and Colitis
Foundation of Canada

Fondation canadienne des
maladies inflammatoires
de l'intestin

Surgery and

INFLAMMATORY

BOWEL

DISEASE

What is Inflammatory Bowel Disease?

Inflammatory bowel disease (IBD) is a term used to describe two similar, yet distinct conditions: Crohn's disease and ulcerative colitis. IBD is also known by other names including: Crohn's colitis, ileitis, distal colitis and pancolitis. These diseases affect the digestive system and cause the intestines to become inflamed, form sores (ulcers), bleed easily, scar and lose the normal smoothness of their inner lining. Symptoms of IBD include abdominal pain, cramping, fatigue, diarrhea, fever and joint pain.

Crohn's disease can affect any part of the gastrointestinal tract, from the mouth to the anus. Patches of inflammation occur, with healthy tissue between diseased areas; these are called "skip lesions". The inflammation can extend through every layer of affected bowel tissue. Crohn's disease cannot be cured by drugs or surgery, although either or both can relieve the symptoms.

Ulcerative colitis affects *only* the colon (large bowel), and *only* a single layer of bowel tissue: the inner lining. The disease almost always starts in the portion of the colon called the rectum, and *may* extend as a continuous (not patchy) inflammation from there into the rest of the colon. Usually, ulcerative colitis can be controlled with medication. The disease *can* be completely eliminated by surgically removing the colon, but afterward, waste material (stool) may have to be stored and expelled through an external appliance (bag).

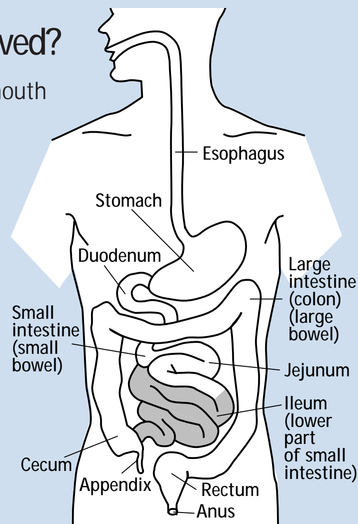
No one knows what causes IBD. It affects people regardless of race, gender or age. People are most frequently diagnosed between the ages of 15 to 25 years, or 45 to 55 years.

IBD is unpredictable. Many people experience "flare-ups" (attacks) and then the disease seemingly goes away. The quiet periods are called "remission" and can vary in length from weeks to years. Most people will "relapse" and have multiple attacks. IBD symptoms may also vary in severity. Some people have mild symptoms and can be treated with a combination of drugs and nutritional therapy, while others experience debilitating symptoms and need to take potent drugs, visit hospital frequently, and/or have surgery.

See the CCFC brochure "The Facts about Inflammatory Bowel Disease" for more information.

Which Parts of the Body are Involved?

The Digestive System: Food passes from the mouth down the **esophagus** (swallowing tube) into the **stomach**, which dilutes and mixes the food and passes it on to the **small bowel** (small intestine). The small intestine breaks down the food. Each part of the small intestine (which is some six metres long and includes the duodenum, jejunum and ileum) absorbs different nutrients. Leftover material passes into the **large intestine** (also called the **colon** and is about 1.5 metres long), which absorbs water and forms stool. Solid stool is passed to the **rectum** and eliminated through the **anus**.



This brochure is provided for information only. A doctor should always be consulted for advice and medical treatment.

OUR MISSION: FIND THE CURE. YOU CAN HELP. CALL US.
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416-920-5035 or 1-800-387-1479

Surgery and Inflammatory Bowel Disease

Many people think of surgery as the medical treatment of last resort. This is not true for inflammatory bowel disease (IBD). Surgery is very much an option for IBD, as are medication and nutritional therapy. Sometimes surgery is the *only* treatment for a particular condition.

Approximately 75 per cent of people with Crohn's disease, and 30 per cent of people with ulcerative colitis, will have surgery at some point in their lives.

Crohn's disease cannot be cured by surgery. Surgery is done to relieve the distressing symptoms, treat complications such as fistulas or narrowing of the bowel and improve quality of life. Symptoms may subside – perhaps for quite some time – and medication may be stopped, but the disease may manifest itself again.

Approximately 75 per cent of people with Crohn's disease, and 30 per cent of people with ulcerative colitis, will have surgery at some point in their lives.

Surgery for Crohn's disease may repair damage such as abscesses and fistulas; remove an obstruction or blockage of the bowel; or remove (resection) an entire section of diseased (inflamed) tissue.

Ulcerative colitis can be "cured" by surgery which removes the diseased tissue. Depending on the type and extent of surgery performed, the person may have to rely afterwards on alternative means of collecting and eliminating feces (stool).

People with ulcerative colitis are much less likely to require surgery than those with Crohn's disease. Usually, the initial course of treatment is to control ulcerative colitis with medication and nutritional therapy. Surgery becomes an option when massive bleeding or toxic megacolon (described on page 5) occurs, when medication doesn't work, or when the intestinal lining becomes pre-cancerous or cancerous.

A Guide to Surgical Terms

The name of a procedure ending in "-ectomy" means "removal."

- A **total colectomy** or **proctocolectomy** means the entire colon (large bowel, rectum and anus) is removed.
- A **subtotal colectomy** means removal of the colon, but not the rectum or anus.
- A **proctectomy** means *only* the rectum is removed.

A procedure ending in "-ostomy" refers to surgery that connects a hollow organ to the outside of the body. When part of the bowel is removed and the ends are joined together, the surgically created connection is called an "anastomosis".

After most ostomy operations (except the Kock ileostomy) the person is required to wear an external appliance to collect and eliminate stool. The appliance is usually a special plastic bag which is positioned over the new surgical opening (the stoma) and attached to a plastic ring that is held to the skin with an adhesive paste.

> After most ostomy operations the person is required to wear an external appliance to collect and eliminate stool.

In an **ileostomy**, the ileum (the lowermost part of the small bowel, which leads into the colon) is rerouted on the right lower side of the abdomen, directly to the skin's surface. An appliance is then placed over the stoma to collect liquid stool. The person can't control the timing of elimination, but can control the emptying of the appliance - as infrequently as three or four times a day.

In a **colostomy**, part of the colon is removed and the remainder re-routed to the lower left side of the abdomen, directly to the skin's surface. An appliance is fitted over the stoma to collect solid stool; it is emptied as necessary. Some people are able to irrigate (wash out) their colostomies and to regulate the emptying of stool to a point where an appliance is not required.

More recent variations in surgical procedures - such as pelvic pouch procedures - eliminate the need for external appliances.

Surgery for Crohn's Disease

The most common forms of **Crohn's disease** are ileitis (small-bowel Crohn's disease) and ileo-colitis (Crohn's disease affecting the ileum and colon).

Surgery for Abscesses and Fistulas: In approximately one in four people with Crohn's disease, the disease affects the anus. This is called perianal disease and includes abscesses and fistulas. Abscesses and fistulas do *not* occur in ulcerative colitis.

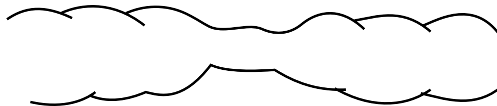
Abscesses and fistulas develop when there is a microscopic break in the intestinal lining which allows infections to develop. An abscess may begin as a pimple-like boil that may enlarge and become quite painful. Surgery for an abscess involves an "incision" or surgical cut in the abscess which allows the liquid inside to drain away. A rectal fistula is an abnormal opening, or channel, that directly connects the rectum to the skin (an external fistula), or connects the rectum to an organ, such as the bladder or the vagina (an internal fistula). Surgery may be needed to drain away infected fluid and close the opening.

Surgery for Small-Bowel Obstruction: The most common surgical procedure for Crohn's disease involves removing a blockage or obstruction in the small bowel. Obstructions happen because, as the disease progresses, inflammation causes the wall of the small bowel to thicken. Eventually, the bowel becomes so narrow that food materials can no longer pass through it. This narrowing is called a "stricture". A stricture may be corrected by either "strictureplasty" or "resection."

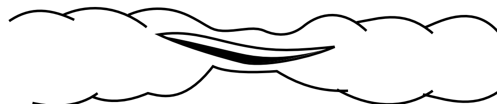
In **strictureplasty**, the narrowed area of intestine is opened and the intestine is widened. The stricture doesn't usually re-form in the same place. Strictureplasty is a favoured procedure because it doesn't involve removing part of the small bowel.

STRICTUREPLASTY

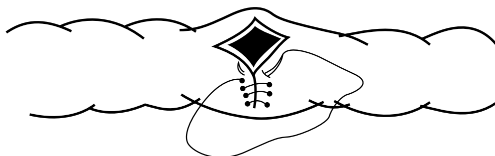
1. Narrowed bowel



2. Stricture opened



3. Pulled together and stitched



In a **resection**, the diseased area is removed and the remaining sections of healthy tissue are joined.

Surgeons try to avoid procedures that could shorten the ileum, because they can lead to **short-bowel syndrome**. The ileum digests and absorbs fat. Any resection involving the ileum removes a little more absorptive surface. When there is not enough tissue to absorb the nutrients in food, this is called short bowel syndrome, one symptom of which is chronic diarrhea. The person must compensate for the removed ileum by eating less fat and taking medication.

As for the other parts of the small bowel: the usual procedure for the jejunum is a resection; the ileum can take over the jejunum's nutrient-absorbing functions, even if extensive resections have been done. The duodenum is only a few centimetres long, which makes it difficult to do either a resection or strictureplasty. Surgeons prefer a bypass operation called a gastrojejunostomy, in which the upper jejunum is connected to the stomach.

Surgery for Crohn's Colitis and Ulcerative Colitis (IBD involving the colon)

Since food and other nutrients are absorbed in the small intestine, people can live without the colon.

When surgery involves removing the colon, stool storage and elimination are changed. Sometimes internal or external devices are needed. Here are the most common procedures:

TOTAL PROCTOCOLECTOMY AND ILEOSTOMY

This is the standard and most long-standing procedure — really two procedures. In the **total proctocolectomy**, the entire large intestine — including the colon, rectum and anus — is removed. (Sometimes this is done in two stages - first the colon is removed and later, the rectum is removed.) The small intestine adjusts over time to take over most of the functions of the large intestine. An **ileostomy** is done to allow the elimination of waste through the ileum. A "conventional end ileostomy," is accomplished by bringing the end of the ileum to the outside of the body and forming a stoma. An appliance is fitted over the opening to collect waste material. The person can't control the passing of stool. However, he or she can empty the appliance when convenient - usually three or four times a day.

When surgery involves removing the colon, stool storage and elimination are changed.

COLECTOMY WITH ILEORECTAL ANASTOMOSIS

If the rectum is still reasonably healthy, a total proctocolectomy – which removes the colon, rectum and anus – may not be necessary. The alternative is the colectomy with ileorectal anastomosis, in which only the diseased colon (but not the rectum or anus) is removed, and the ileum is joined directly to the rectum. Waste can be eliminated through normal bowel movements. About five per cent of cases are eligible for this procedure. There is a chance that the disease will flare-up in the rectum. If the rectum becomes badly diseased later, a conventional ileostomy may be needed.

Surgery Specifically for Ulcerative Colitis

SURGERY FOR TOXIC MEGACOLON AND PERFORATIONS

While toxic megacolon can develop in Crohn's disease, it is more common in ulcerative colitis. Toxic megacolon in ulcerative colitis can sometimes be fatal if it occurs at the same time as another condition: a perforation. In **toxic megacolon**, the muscle wall of the colon dilates or becomes almost paralyzed. Bacteria and gases build up inside the colon. A **perforation** is a hole that develops in the colon and is one of the serious complications of toxic megacolon. The bowel's contents – which, in a paralyzed colon, include built-up bacteria, feces and gases – escape into the abdominal cavity, causing peritonitis (inflammation of the abdominal wall).

Toxic megacolon in ulcerative colitis can sometimes be fatal if it occurs at the same time as another condition: a perforation.

Toxic megacolon can sometimes respond to medical therapies, however surgery is often required if patients do not respond quickly to medications or if there is a suspected perforation. In those cases, surgery - subtotal colectomy and ileostomy - is performed.

- In the subtotal colectomy, the colon (but not the rectum) is removed.
- In the ileostomy, the ileum is connected through the abdominal wall to form a stoma. Waste no longer passes from the ileum into the colon, but is directed through the end of the ileum to the outside of the body. Waste is collected in an appliance.
- Sometimes, a mucous fistula - an opening created between the rectum and the skin - is created. This allows potentially harmful leaks of mucous and blood from the rectum to empty into a bag rather than into the abdomen.

CONTINENT RESERVOIR (KOCK) ILEOSTOMY

The most common procedures for ulcerative colitis have been a total proctocolectomy and ileostomy. This involves removing the colon – including the rectum – and routing waste through the ileum and the abdominal wall. This procedure has its drawbacks. The person has to wear an artificial, external bag to collect stool. In addition, the passage of stool out of the body cannot be controlled (though the bag can be emptied when convenient).

The Kock ileostomy solves both problems. Instead of an external appliance, the surgeon creates an internal "pouch," or reservoir, made from the person's own ileum. The person is then able to control the emptying of the reservoir. A one-way, non-leaking "nipple valve" is fitted at an opening made from the pouch to the outside of the abdomen. To empty the pouch, the person simply inserts a tube through the nipple valve into the pouch, leans over a toilet, and drains the pouch through the tube.

> The Kock ileostomy has generally been replaced by newer procedures that eliminate the need for external appli-ances and allow "normal" bowel movements.

Although the Kock ileostomy is still performed in patients who have had a total proctocolectomy and ileostomy, or have damage to their anal muscles, it has generally been replaced by newer procedures which eliminate the need for appliances and allow "normal" bowel movements.

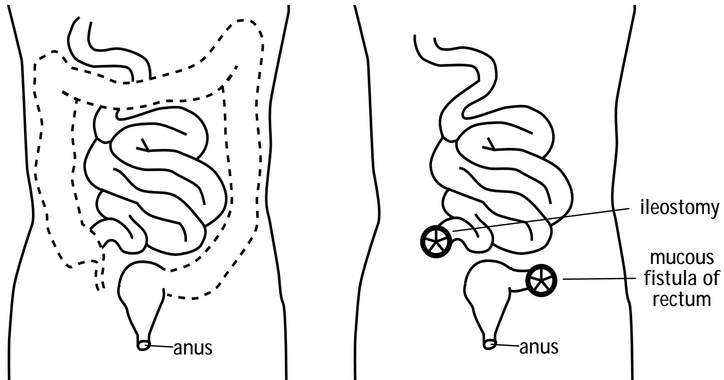
The Kock ileostomy and other "pouch" procedures which create a "substitute rectum" from the ileum, are *not* used for those with Crohn's disease. This is because it's important to preserve as much of the nutrient-absorbing ileum as possible. When people with Crohn's disease have operations that leave them with less than 60 centimetres of ileum, they are at risk of developing short bowel syndrome (inability to derive enough nutrition from food without resorting to supplements).

PELVIC POUCH (RESTORATIVE PROCTOCOLECTOMY WITH ILEO-ANAL ANASTOMOSIS)

The pelvic pouch evolved from the Kock ileostomy and is the procedure of choice for many people facing surgery for ulcerative colitis. In this procedure, all of the colon and rectum is removed except for the last 1-2 centimetres (so that the anal muscles are preserved). A reservoir or pouch is created in the pelvis, with the end of the ileum attached to the anus. This completely avoids the need for any external appliances, and the person can have "normal", though frequent, bowel movements.

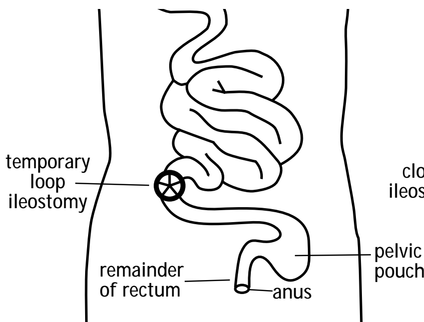
The procedure is usually done in three operations, with several months of healing allowed between them to improve the final results:

First Stage

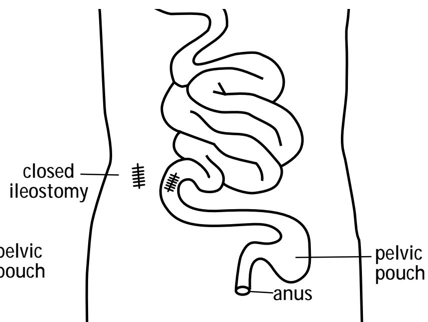


- In the first stage, the colon — but not the rectum or anus — is removed. A temporary ileostomy is done in which the ileum is connected to the outside of the body and an external artificial appliance is attached to collect and store stool. The rectum is also connected separately to the outside of the body (mucous fistula), so that potentially harmful gases can escape.
- In the second stage, most of the rectum is removed and the pelvic pouch constructed (of ileum tissue). The end of the ileum is connected to the anus. To allow the pouch and connection to heal, another temporary ileostomy, (a "loop" ileostomy), is created so that waste doesn't reach the newly-constructed pouch yet.
- The third stage is a simple procedure which closes off the loop ileostomy. The person can then begin having bowel movements the "normal" way.

Second Stage



Third Stage



Sometimes, depending on the surgeon and the status of the patient (how sick the patient is, what medication he or she is on, and his or her nutritional status), the procedure may be done in two stages. In the first, the colon and rectum are removed, the pouch constructed and a loop ileostomy are all peformed. Then a second operation is needed to close the ileostomy.

A person who has had this procedure may have eight to 10 bowel movements per day, although this can settle down to four or five per day, with good control and almost no urgency.

The pelvic pouch procedure is not usually performed in people over 60 years of age because the anal muscles are not as strong as in younger patients.

The pelvic pouch works best in people age 20 to 40, whose anal sphincter muscle (which controls continence) is strong.

The pouch procedure is unlikely to be performed on people who are very ill or debilitated; who are on very high doses of medication; who are nutritionally unfit; or who are known to have had extensive infections around the anus.

The pouch procedure and the Kock ileostomy are *not* done for Crohn's disease, because the pouch is fashioned from about 30 centimetres of ileum. If Crohn's disease should happen to develop in the new pouch, the entire pouch (not just the portion of tissue which is diseased, but also the healthy tissue) would have to be removed. No one with Crohn's disease should be put in the position of having to sacrifice normal small bowel tissue.

The pelvic pouch procedure is delicate, difficult and intricate, and more likely to develop complications than the other, conventional ileostomies.

Pouchitis and Other Complications of the Pelvic Pouch: In some cases, the pouch can become inflamed and the patient develops symptoms of diarrhea, fever and abdominal pain. This is called pouchitis. Antibiotics and other treatments usually clear it up. Patients can have chronic pouchitis but this is uncommon.

Other side effects or complications may include frequent bowel movements, obstruction with abdominal bloating, incontinence, leaking or perianal infection.

Frequent episodes of pouchitis and other complications may have to be resolved by removing the pouch and having a conventional end ileostomy or a continent reservoir ileostomy.

The Risk of Cancer

There are no exact statistics to predict the likelihood of people with IBD also developing cancer. There appears to be a slightly increased risk of colon cancer in those who have **Crohn's disease**. People who have had **ulcerative colitis** for more than 10 years have a slightly increased risk of developing colon cancer. After that time, the risk increases further each year.

The Risk of Recurring IBD

Removal of all of the colon and rectum (total proctocolectomy) cures ulcerative colitis by removing all the diseased tissue. Surgery for Crohn's disease relieves symptoms. The recurrence rate for Crohn's disease varies, depending on which part of the intestine was affected, but approximately 50 per cent of patients will have a recurrence within five years. If the disease involved the small bowel and colon or was limited to the small bowel alone, the recurrence rate is higher than if the disease was limited to the colon. The risk of recurring IBD may be lessened by medical therapy.

Surgery cures ulcerative colitis by removing all the diseased tissue. Surgery for Crohn's disease relieves symptoms.

Life Before and After Surgery

Counselling and Support: Each member of the health-care team (including surgeon, gastroenterologist, nurse, dietitian, therapist and others) has a role in supporting individuals facing surgery. The enterostomal therapist plays a vital role in educating and counselling individuals both prior to and following ostomy surgery. This specialist shows the person how to use and care for any appliance that will be inserted or attached, and provides counselling on how to adjust to living with an ostomy.

Digestion: Surgery may impose some dietary adjustments. In Crohn's disease, inflamed portions of the ileum may be removed. If more than one metre of ileum is removed, there is significantly less absorptive tissue working to take in nutrients. It may be difficult for the body to absorb Vitamin B_{12} and bile salts. To compensate, some people will be prescribed regular injections of Vitamin B_{12}.

People who have had their colons removed and have an ileostomy or pouch may have to avoid certain "indigestibles" such as seeds. People who have had their ileum removed may need to follow a lower-fat diet and may need to take nutritional supplements and vitamins. *See the CCFC brochures "Medication for Inflammatory Bowel Disease" and "Nutrition, Diet and Inflammatory Bowel Disease" for detailed information.*

Kidney Stones: It is not unusual for kidney stones to develop after surgical removal of one metre or more of the ileum. Bile salts are produced by the liver and help the intestine to digest fat; they are then re-absorbed by the ileum. When surgery removes the ileum, the liver still manufactures bile salts – but there is less absorptive tissue to "take up" the bile salts and therefore the fat. This excess fat causes an increased absorption of oxalates (a substance in many foods) and allows kidney stones (calcium oxalate) to form.

It is not unusual for kidney stones to develop after surgical removal of one metre or more of the ileum.

A low-oxalate diet may be prescribed for those who have had extensive ileal surgery. Foods high in oxalates such as beans, beer, beets, chocolate, cocoa, cola drinks, instant coffee, cranberry juice, ketchup, rhubarb, parsley, spinach and tea may have to be avoided.

An ileostomy causes a person to release more water than would be in "normal" stool. If a person with an ileostomy doesn't consume enough fluids, he or she will produce less urine, and uric acid stones can develop. It's important that a person with an ileostomy avoid dehydration. They should drink plenty of water or other fluids (two to three litres a day).

Medication can be prescribed to prevent kidney stones.

Sexuality and Pregnancy: As with any major surgery, people who have had surgery for ulcerative colitis or Crohn's disease should avoid strenuous activity, including sex, for several weeks after surgery.

Surgery can involve supplementing or replacing the diseased bowel with artificial "appliances" to collect and eliminate waste. These appliances are linked to the bowel by a surgically-created stoma (opening) onto the skin of the abdomen. They do not affect sexual function or limit sexual activities, but may be initially embarrassing. An enterostomal therapist can assist and counsel patients about their appliances.

> People who have had surgery involving the rectum or anus could, in very rare instances, have sexual problems.

People who have had surgery involving the rectum or anus could, in very rare instances, have sexual problems. Men may become impotent, or have problems with ejaculation, while women may experience painful intercourse. Women who have had surgery can become pregnant and have normal deliveries. Some women have scarring of the fallopian tubes and ovaries following surgery. This makes it more difficult - but not impossible - to conceive. Otherwise there are no increased risks.

For more information, see the CCFC brochure "Sexuality, Fertility, Pregnancy and Inflammatory Bowel Disease."

Notes:

Together, We Can Find the Cure

The Crohn's and Colitis Foundation of Canada (CCFC) is a not-for-profit voluntary medical research foundation. Our mission: To find the cure for Crohn's disease and ulcerative colitis. To realize this, the CCFC is committed, first and foremost, to raising funds for medical research. The CCFC also believes it is important to make all people with inflammatory bowel disease aware of the Foundation, and to educate these individuals, their families, health professionals and the public about these diseases.

YES! I support the search for the cure for IBD.
Here is my tax-deductible donation right now for:

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Please send me details about:

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