

THE CUTTING EDGE

Surgery for Crohn's
Disease & Ulcerative Colitis



**CROHN'S
& COLITIS**

Make it stop. For life.



www.crohnsandcolitis.ca

If you have picked up this booklet it is a safe bet that you, or someone you know, has inflammatory bowel disease (IBD). Whether IBD takes the form of Crohn's disease or ulcerative colitis, there are many treatments that will help you manage your chronic (lifelong) illness.

Crohn's and Colitis Canada urges you to become knowledgeable about these treatments. By being informed, you will become your own health advocate and in conjunction with your health care team, map out a treatment approach that helps you attain a high quality of life.

Crohn's and Colitis Canada wants to help you on your journey of discovery. Our promise reflects our determination to cure Crohn's disease and ulcerative colitis and improve the lives of children and adults affected by these chronic diseases.



We are committed to helping you learn more about Crohn's and colitis. Our patient education booklets are an element of that commitment. Please go to **www.crohnsandcolitis.ca** for the complete list. You can download them at your convenience or contact your local Crohn's and Colitis Canada chapter and a free copy will be mailed out to you!

This particular booklet addresses the topic of surgery. If you will excuse the pun, surgery "opens up" a whole range of treatment options that help individuals in the management of their disease. In order to understand the need and objectives for different types of surgery, we will also explore the anatomy and function of different parts of the gut.



SURGERY AS A TREATMENT OPTION

Surgery is an approach used by your doctors to help you control your disease. It is generally accepted that 47% of people with Crohn's disease and up to 16% of those with ulcerative colitis will have surgery in their lifetime.

Furthermore, 33% of Crohn's disease patients who had surgery will experience some recurrence of their disease within five years and may require additional surgery. Ulcerative colitis patients on the other hand, are "cured" of their disease once the affected portion of their gut is removed (more about this later.)

When do physicians consider surgery? Obviously this is not a recommendation that is made lightly and there are a number of questions that have to be addressed such as:

- Are drug therapies adequately managing your symptoms?
- Are drug therapies likely to be of benefit?
- Are the side effects of your drugs causing you serious and intolerable side effects?
- Did your symptoms come on quickly and are they so severe and unrelenting that your health is in serious jeopardy?
- Are there additional complications that cannot be addressed in any other way?
- Are there any other health risks that might affect the outcome of the surgery (for example, is there a pre-existing heart condition or a history of blood clots)?

These questions will be considered by your surgeon in consultation with your gastroenterologist (GI). Your GI and your surgeon are usually not the same person and each physician has expertise in different aspects of your care. Their combined thoughts on surgery as an option will be invaluable to you in your own decision-making process.

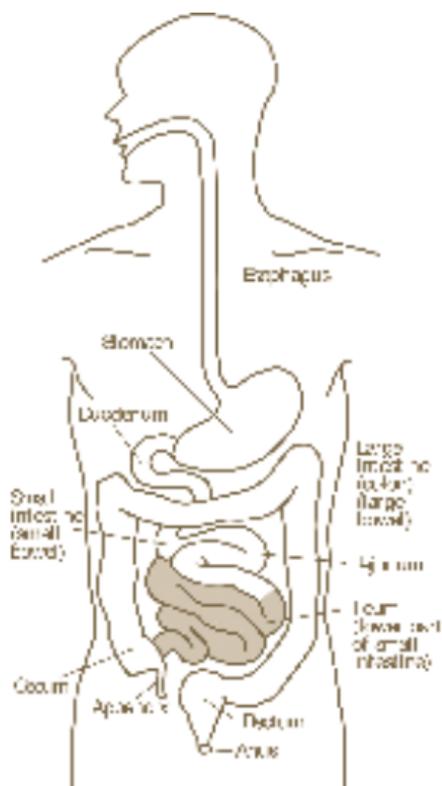


THE GEOGRAPHY OF YOUR GUT

Before you can fully appreciate the pros and cons of surgery, you need to have an understanding of the parts (anatomy) and functions of your gut and the effects of Crohn's or colitis on those areas.

The digestive tract or gastrointestinal (GI) tract is a

hollow tube that starts at your mouth and ends at your anus. When you eat and drink, food navigates from your mouth to your esophagus (the tube that connects to your stomach), then to your stomach, small intestine (or small bowel), large intestine (also known as the large bowel or colon), moving finally to your rectum and then out of your body via your anus.



As you can see from the diagram, the small and large intestines are sub-divided into smaller geographic areas. The small bowel consists of (in order from beginning to end) the:

- **Duodenum (around 8 cm long)**
- **Jejunum (can be up to 3 metres long!)**
- **Ileum (can also be up to 3 metres long!)**

Resection:
The cutting away or removal of all or part of an organ

Each section of the small bowel contributes to the breakdown and absorption of the food we eat, thus sustaining our health and our life. When parts of the small bowel are resected, your ability to absorb nutrients can be affected.

The large intestine or large bowel is also known as the colon. As food passes from the ileum to the colon, it travels through the ileocecal valve. This valve enables the small bowel to pass its contents into the colon on an intermittent basis, rather than all at once.

The function of the colon is to absorb salt and water from the material that has entered it, and to store it until it is passed out of your body as feces (or stool). When food first enters the colon, it is very watery; by the time it leaves your body, the stool has firmed up because water has been extracted.

Like the small bowel, the colon (which can be as long as 1.5 metres) is divided into smaller sections (from top to bottom):

- **Cecum**
- **Ascending colon**
- **Transverse colon**
- **Descending colon**
- **Sigmoid colon**
- **Rectum**
- **Anus**



ULCERATIVE COLITIS OR CROHN'S DISEASE

Ulcerative colitis only affects portions of the large intestine, including the rectum and anus and typically only inflames the innermost lining of bowel tissue.

It almost always starts at the rectum, extending upwards in a continuous manner through the colon. ulcerative colitis can be controlled with medication and can even be cured by surgically removing the entire large intestine.

Crohn's disease on the other hand, can affect any part of the GI tract from mouth to anus, but is quite common in the small bowel and the first part of the colon. Patches of inflammation occur between healthy portions of the gut and can penetrate the intestinal lining from inner to outer layers. Unlike ulcerative colitis, resection of the section of bowel involved with Crohn's disease does not guarantee that the inflammation will not recur in other parts of the bowel.

Most people do not have both ulcerative colitis and Crohn's disease; they have one or the other. In a very small percentage of individuals it proves to be difficult to establish which disease is present. In these cases, the disease is called "Indeterminate Colitis" until such time as a more definitive diagnosis can be made.

In either event, when your gut is not functioning properly because of Crohn's disease or ulcerative colitis, the result can be diarrhea (possibly bloody), abdominal pain, cramping, gas, bloating, fatigue and/or loss of appetite.

When people complain of a "pain in their gut", they are often describing pain that originates from their small bowel or their colon, not their stomach as is so often thought. Pain derived from an inflamed intestinal tract can be excruciating.

Remission vs. Acute Episode:
Periods of time when your symptoms are under control vs. occasions when your symptoms are active

Both Crohn's disease and ulcerative colitis can flare-up

at unpredictable times. In fact, doctors and researchers are not sure what causes a remission and what launches an acute episode. We do know that contrary to what you might think, diet and stress do not precipitate a recurrence of your disease. While both may aggravate your gut and any symptoms that you are experiencing, they are not thought to CAUSE a relapse of your disease.

MINIMALLY INVASIVE SURGERY

Laparoscopic Surgery: Involves the use of a camera mounted on the end of a flexible optical scope (the laparoscope) and the use of specialized instruments that permit “minimally invasive” surgery in the abdomen

We would be remiss if we did not talk a little bit about laparoscopic surgery. You probably have heard about it, and if so, wonder how applicable it may be to your situation. The advantages of “MIS surgery” include smaller, fewer incisions and therefore less post-operative pain, as well as faster recovery and quicker return to normal activity. This type of surgery is performed for many

kinds of abdominal surgery, such as the removal of a gall bladder.

Laparoscopic surgery potentially offers many benefits for patients with Crohn’s disease or ulcerative colitis. First, many patients are young and post-operative scarring is a real concern for them after open surgery. For youth, avoiding a large incision is very important to their self-image. Second, surgery performed laparoscopically seems to decrease the risk of adhesions (internal scar tissue) and that is important for Crohn’s disease and ulcerative colitis patients who will often require multiple operations. Finally, wound healing is sometimes difficult for patients with Crohn’s disease or ulcerative colitis because of their poor nutritional status and the effects of the drugs that they must take. With fewer and smaller incisions, laparoscopic surgery can be advantageous.



On the other hand, removing large segments of the bowel (especially the colon) may be more difficult laparoscopically. Patients who have had previous surgery may have a lot of adhesions which obscure the surgical view. As well, it may not be possible if there are fistulas and abscesses present or if surgery is being performed as an emergency. Sometimes the surgeon may begin the operation laparoscopically, but convert to an “open” approach. In other words, your surgeon will proceed with your operation with the typical abdominal incision(s) and “open” up your abdomen using the conventional approach. When undergoing surgery for Crohn’s disease or ulcerative colitis you need a safe operation that takes care of the disease process. Sometimes this can be done laparoscopically, but in some patients the laparoscopic approach may not be feasible.

Laparoscopic surgery may be an option for you; discuss it with your surgeon so the best choice can be made for your individual circumstance.

SURGERY FOR ULCERATIVE COLITIS

Indications for surgery

The most common reason for patients to have surgery for ulcerative colitis is for “failure of medical therapy.” Some of the considerations are: how long the patient has been on medication,

Failure of medical therapy means that the non-surgical approach has not adequately controlled your symptoms. This occurs for a variety of different reasons.

(especially prednisone), without improvement in symptoms; whether the symptoms recur as soon as the medication is decreased; in children, whether there is growth retardation and whether there are side effects from the medication. As well, the quality of life and the preferences of patients must be considered. Other indications for surgery include a stricture in the bowel, presence of pre-cancerous or even cancerous changes and infrequently severe bleeding, perforation of the bowel or toxic megacolon (severe colitis). The decision to remove sections of your gut is not to be taken lightly and your surgeon and GI will be invaluable in helping you make up your mind. As the patient, you definitely have a role in determining the course of action.

Types of Surgery for Ulcerative Colitis

After weighing the pros and cons of surgery, the next decision to be made is what type of procedure is the most appropriate. As mentioned previously, once the large bowel and rectum are removed, ulcerative colitis does not recur; this is effectively a "cure" for the disease. There are several options available. The most common are:

1. Subtotal colectomy and ileostomy
2. Total proctocolectomy and ileostomy
3. Ileal Pouch with Anal Anastomosis (IPAA) which is also known as restorative proctocolectomy or pelvic pouch procedure

The Kock pouch is also an option but has largely been abandoned because of the high complication rate associated with this procedure.

1. Subtotal colectomy and ileostomy

Ectomy: Words ending in "ectomy" indicate that there will be a resection of all or part of an organ

This procedure is sometimes performed on patients who are very sick and require surgery on an urgent or even emergent (emergency) basis. It also is used in patients on multiple medications that may impair healing, such as high doses of prednisone, or biologic therapy. In this operation, only

the colon is removed, an ileostomy is created and the rectum is left intact with the result that most people regain their health and can get off all medications. In the future, when they are fully recovered, a second operation can be performed to remove the rectum, or an IPAA (see below) is constructed. Generally, it is not advisable to leave the rectum in place since the disease may flare-up later on or cancer may develop.

Ostomy: Words ending in "ostomy" indicate a procedure that brings the cut end of the small or large intestine out to the surface of the abdomen, allowing the exit of feces from the body via an opening known as a stoma.

2. Total Proctocolectomy and Ileostomy

In this procedure, all of the colon and rectum are removed and an ileostomy is constructed. The ileostomy is usually fashioned on the outside of the abdomen, on the right side. People who have an ileostomy will need to wear a specially designed bag (otherwise known as an appliance) over the stoma, to collect feces. This bag will need to be emptied throughout the day.

The necessity of wearing an appliance for the collection of feces is, for many people, a very daunting thought prior to surgery. However, once patients have a stoma, they realize that they can lead a normal life with virtually no restrictions. Indeed, many studies show that the quality of life for individuals with an ileostomy can be the same as that for the average population.

Although a permanent ileostomy is perceived as a major disadvantage of this operation, there are many advantages: often it can be performed in one operation; it eliminates the disease completely; there is no future risk of colorectal cancer and no need for medications. As well, although it is a major operation, it has fewer complications than other procedures.

3. Ileal Pouch with Anal Anastomosis (IPAA)

Anastomosis is a surgically created joining of two resected areas

If a surgeon is performing an IPAA procedure he or she will remove all of the colon and rectum and leave the anus and sphincter in place. A pouch is made using about a foot of small bowel which is then joined to the anus (creating an anastomosis). The procedure can be done in different ways. The pouch can be made as a J pouch or an S pouch. The pouch can be joined to the anus by sewing it or stapling it. All of these details will be considered by your surgeon but in most cases do not affect the outcome or function of the pouch.

Generally the IPAA is performed in two but often three operations. During that time, a temporary ileostomy is required for several months to allow the pouch to heal.

The advantage of the IPAA is once the ileostomy is closed, patients are once again able to expel feces from the anus and they do not have the inconvenience of an ileostomy. Most patients have more frequent bowel movements than previously because the colon is no longer present to extract water from feces. This may cause some irritation to the skin. However, most individuals do not have any feelings of urgency (needing to go to the bathroom) and are fully continent (no leakage) of stool, so they are extremely happy with their outcome. As well, like the total proctocolectomy, they are free of the disease so they feel well and do not require medication. The disadvantage of this operation is that it is more difficult to perform and therefore could lead to more complications.

The IPAA is now considered the procedure of choice for patients requiring surgery for ulcerative colitis. However some patients may not be candidates for an IPAA. If you are over 60 years of age or have damage to your anal sphincter, the possibility of fecal leakage after the IPAA might be a major deterrent in the selection of this surgery.

SURGERY FOR CROHN'S DISEASE

Indications for Surgery

Unlike ulcerative colitis, where the most common indication for surgery is failure of medical management, surgery for Crohn's disease is usually performed because of the occurrence of complications. Narrowing of the bowel and possibly blockages may occur due to scarring so patients experience pain when they eat; this results in hospitalization. Crohn's disease can also erode through the bowel wall and cause a perforation resulting in an abscess or fistula.

Short Bowel Syndrome:
When too much short bowel is resected, patients are unable to adequately absorb nutrients and maintain fluid and electrolytes.

Because Crohn's disease can occur anywhere in the GI tract from mouth to anus, it may recur after surgery. Since Crohn's disease seems to affect the small bowel frequently and this portion of your gut is responsible for nutrient absorption, it is important to minimize the areas resected. If too much is removed, patients can develop Short Bowel Syndrome.

Types of Surgery for Crohn's Disease

The most common types of surgery include:

1. Small Bowel Resection
2. Strictureplasty
3. Large Bowel Resection
4. Total proctocolectomy with ileostomy
5. Perianal Surgeries

1. Small Bowel Resection

Depending upon the location of Crohn's disease, the surgeon may remove parts of the small bowel. Most commonly, the ileum along with the ileocecal valve and the cecum are sites of Crohn's disease; thus the most common type of resection is an ileocolic resection. During surgery, the affected part of the bowel is removed along with a few centimeters of normal gut.

The cut ends of the intestine are joined together (anastomosed) to re-create a continuous GI tract. Sometimes a temporary ileostomy is required above the anastomosis if there is infection present or if the surgery is performed as an emergency. The stoma can be closed several months later.

2. Strictureplasty

In some patients, there may be multiple areas of small bowel that have narrowed due to Crohn's disease. If all of these small areas are removed, then the patient might not have enough small bowel left to absorb nutrients. As well, some of these patients may have had previous resections so much of their small bowel has already been removed. In order to preserve as much bowel as possible, surgeons may perform a procedure known as a strictureplasty. The strictureplasty opens up the narrowed bowel so food can once again pass freely. Often these areas completely heal so the patient does not experience a recurrence of blockage in the same place and the bowel can once again absorb nutrients.

Plasty:

Words ending in "plasty" denote a procedure where a constricted tubular area is surgically opened up



3. Large Bowel Resections

Because the colon is affected less often in patients with Crohn's disease, large bowel resections are not as commonly performed as they are with patients having ulcerative colitis. The type of procedure that is performed may vary depending on the site and extent of the Crohn's disease as well as whether there is perianal disease. The Crohn's disease affects all or most of the colon, then a total proctocolectomy and ileostomy may be required as described previously. However, often the rectum is not affected in Crohn's disease so patients may avoid having a permanent ileostomy. In that instance, part of the colon may be removed and joined to the remaining colon or rectum as described under small bowel resection.

4. Ileal Pouch with Anal Anastomosis (IPAA)

The IPAA is generally not recommended for patients with Crohn's disease because of the risk of recurrence of the disease in another location, including the pouch and perianal area. The risk of recurrence means a high degree of possibility that the pouch will have to be removed.





5. Perianal Surgeries

Perianal:

The prefix "peri" means "around". So "perianal" means the area around the anus.

Many Crohn's disease patients develop disease around the anus. Some of the manifestations do not require treatment other than sitz baths or ointments (for perianal irritation and skin tags). Some conditions (such as hemorrhoids

and fissures) can be treated with medication. However, abscesses and fistulas occur frequently and often require surgery.

Approximately one quarter of people with Crohn's disease develop abscesses and fistulas. They usually arise from little glands inside the anus which become infected and painful.

Abscess: Is a bag of pus created inside the body as a result of an infection.

Abscesses often require drainage either under local or general anaesthetic. Afterwards the wound will have to be packed by a nurse for several weeks. Sometimes abscesses burst and drain on their own without requiring a doctor; sometimes antibiotics can be used.

Fistulas also arise from infected glands within the anus. As the infection grows, it tunnels from the inside of the anus to the perianal surface. Sometimes there is just one opening; other times there are multiple openings on the skin. If there is just one opening, the fistula can often be removed with surgery. If there are multiple openings, that may not be possible. If so, a combination of surgery and medication may be required.

Fistula:

The infection has tunneled its way from the abscess to hollow organ(s) inside the body, such as the rectum and vagina

Procedures can include:

- Incisions to open up an abscess or fistula so that the pus can drain out
- The insertion of an object such as a plastic "string" or "Seton" up into one end of the fistula and out the other, in order to keep the tract open and permit the pus to drain completely out

Occasionally a fistula occurs between the rectum and vagina which can be difficult to treat. A flap of rectal tissue is sometimes used to close off the opening between the rectum and vagina, but only if the rectum is otherwise normal.

Ileostomies, both temporary and permanent, may also be done if fistulas prove to be severe and persistent. By bypassing stool away from the rectum and anus, the infection eventually subsides. Even after healing occurs, the ileostomy is usually left in place because if the bowel is reconnected and stool is passed, the infection has a tendency to flare up again.

If an ileostomy is permanent, physicians will probably recommend that the rectum be removed. Evidence shows that when a rectum is not used for long periods of time, the risk of rectal cancer increases. For preventative reasons, it is therefore best to resect it before the possibility of cancer evolves into a reality.

WHAT TO EXPECT AFTER YOUR SURGERY

If you have had open surgery, you can expect to be in the hospital for up to a week before being discharged. However this can be quite variable depending on your medical status before surgery, whether the surgery was performed electively or emergently, the type of procedure that was performed and whether you developed any complications. Your recovery period at home will span three to six weeks, depending upon a number of factors such as the kind of surgery you had, your overall health prior to the operation and the complications (if any) that arose afterwards.

If you have an ostomy, you will be referred to someone who can give you advice and support. There are enterostomal therapists available to help you understand how to properly care for your stoma, as well as help you adjust to living with an appliance.

Be aware that your digestion will be altered after surgery, particularly if you have had portions of your small bowel removed. If more than one metre of the end of your ileum has been resected, then your body's ability to absorb vitamin B12 and bile salts might be impaired. This may mean that regular injections of B12 are required and that a low-fat diet is recommended because you have a decreased ability to digest fat.

For more information on your nutritional needs, please see our booklet titled, "Food for Thought".



Kidney Stones:

There are different types of stones. For people with CD or UC, the calcium oxalate type and the uric acid type are the main concerns after bowel surgery.

The reduced ability to absorb bile salts may also set the stage for the development of calcium oxalate kidney stones. To minimize the possibility of developing this painful condition, you may be advised to avoid foods that contain high amounts of oxalate such as beans, beer, beets,

chocolate, coffee, cola, tea, cranberry juice, ketchup, rhubarb, spinach and parsley.

You may also be advised to drink ten full glasses of fluid (of which half should be plain water) every day to avoid the development of uric acid stones.

ABOUT CROHN'S & COLITIS CANADA

Crohn's and Colitis Canada is a volunteer-based charity dedicated to finding the cures for Crohn's disease and ulcerative colitis and to improving the lives of children and adults affected by these chronic diseases. As Canada's leading non-governmental funder of inflammatory bowel disease (IBD) research, we have invested over \$88 million to foster advances in research, education, awareness and advocacy. By working together we can help advance the understanding of Crohn's and colitis; fund the programs that result in a better life for those living with these diseases and ultimately find the cures.

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