



Surgery

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This booklet sets out to answer the questions most commonly asked about the surgical options available in NZ for people with inflammatory bowel disease (IBD).

There are distinct differences in the surgical treatment of Crohn's disease and ulcerative colitis and therefore this booklet has been divided into two sections. The purpose of this booklet is to explain these surgical procedures, some of which can be very complicated. If you are thinking about having surgery then use the information to help formulate questions to ask your surgeon before you have surgery so you understand exactly what is going to be done.

Surgery in Crohn's disease

When does surgery become necessary in Crohn's disease?

Because about two-thirds to three-quarters of patients with Crohn's disease will need surgery at some time during their lives, it is important to understand why an operation might be needed. First, an operation may be needed to correct a complication such as excessive bleeding, perforation of the bowel, intestinal obstruction, abscess formation, or toxic megacolon (dilation and loss of muscle tone in the colon). These conditions are almost always surgical emergencies, and a decision to operate must be made quickly.

On the other hand, you might choose to have surgery because medical treatments have failed to control symptoms such as pain, weight loss, fever or extreme fatigue, or because the side effects of these treatments are intolerable. In any elective surgery, it is essential to consult with your gastroenterologist and surgeon about whether surgery at this time will change the course of your disease, which operations are available to you, and what you can expect after surgery. Because surgery does not cure

Crohn's disease, surgeons have adopted a "conservative" strategy aimed at solving the immediate problem or complication that necessitated the surgery and returning you to the best possible quality of life while preserving as much bowel as possible.

When properly timed, surgery also can reverse delayed growth and development experienced by children and adolescents with Crohn's disease. Poor growth in IBD is largely the result of increased nutritional needs with active disease combined with inadequate caloric intake. Nutritional therapies, such as special supplements, enteral (tube) feedings at night, or total parenteral nutrition (TPN), are usually attempted before surgery is considered for delayed growth.

What is the most commonly performed operation in CD?

When a diseased segment of intestine is causing severe problems or is not responding to medical therapy, it can be removed surgically. The cut ends of healthy bowel are then sewn together, restoring intestinal continuity. This operation is called a *resection and anastomosis*. The surgeon generally removes only the diseased segment or segments, leaving behind as much healthy bowel as possible, in case there is a later recurrence of disease.

You may hear your surgeon refer to a resection and anastomosis by various names, depending on which part of the intestine was resected and which parts were rejoined. For example, when a portion of the ileum and the caecum are removed, the procedure is called an *ileocaecal resection with anastomosis*, indicating the two structures that have been joined together - in this case, the remaining ileum and the ascending colon.

When is proctocolectomy (removal of colon and rectum) with ileostomy advisable?

More than half of all people with Crohn's disease have ileocolitis (disease in the ileum and colon), and another 15 percent have disease only in the colon. When colonic disease does not involve the lower (sigmoid) colon and/or the rectum, the surgeon may decide to resect the diseased part of the ileum and colon as described above, and rejoin the healthy ends of bowel (ileosigmoid or an ileorectal anastomosis). This operation, however, may be followed by recurrence of disease usually at or above but occasionally below the anastomosis. When this happens, the surgeon may perform a subtotal colectomy and a *temporary* ileostomy (bringing the cut end of ileum through the abdominal wall and creating a stoma), leaving the rectum intact in the hope of rejoining it to the remaining ileum at a later date. In some cases, the rectum is so diseased and its sphincter muscles so damaged that it cannot be saved. The surgeon then constructs a *permanent* ileostomy, which is essentially the same operation that is sometimes performed for ulcerative colitis.

Unlike the situation in ulcerative colitis, proctocolectomy and ileostomy may not prevent a recurrence of Crohn's disease. Many people, however, choose life with an ostomy rather than endure repeated frustrations with medical treatments, intolerable side effects, and less definitive surgeries. (The question of recurrence after operation is covered below.)

What happens when there are multiple strictures in the intestine?

Strictures (narrowed areas) present a special problem in Crohn's disease, especially when they occur in the small intestine. While strictures may lead eventually to partial or complete bowel obstruction, if extensive and multiple, their surgical removal may leave an insufficient length of intestine to absorb an adequate amount of food.

Recently, surgical experience has shown that it is possible to operate through diseased bowel and still achieve a good result. Thus, surgeons have developed a new operation called strictureplasty, in which strictures are

widened without resecting any bowel. In performing a strictureplasty (literally, "repair of a stricture"), the surgeon cuts the strictured area of intestine in the line of the intestine and sews it together crossways, thus widening the narrowed area. Numerous strictureplasties can be done during a single operation, or can be combined with a resection and anastomosis, if necessary. "Single" obstructing strictures are best treated with resection. Although strictureplasty is a fairly new operation, results reported in recent studies have been very favourable.

What can be done to treat abscesses and fistulas?

Abscesses and fistulas are called perforating complications of Crohn's disease. Abscesses are localised collections of pus, intestinal fluids, and bacteria, which can develop in the abdomen, the pelvis, or in the tissues surrounding the rectum. Fistulas are channels or tracts that develop between the diseased bowel and other organs, such as the bladder, the vagina, other loops of bowel, or even the skin.

An abscess may perforate directly into the abdominal cavity, causing severe pain, fever, shock, and generalised sepsis (bacteria in the bloodstream). This situation warrants immediate surgery to explore the abdomen, drain the abscess, and/or resect the area of diseased bowel giving rise to the abscess. If an abscess is contained (walled-off) within the abdomen, infection may progress more slowly. Symptoms may include intermittent fever, localised tenderness, and a tender abdominal mass felt on examination.

Abscesses of this nature usually are drained through an abdominal incision, and the diseased bowel segment is removed. Drainage also can be accomplished by passing a long needle through the skin and into the abscess (percutaneous needle aspiration). Pelvic and perirectal abscesses often can be drained through the rectum to avoid contaminating the abdominal cavity. Great care must be taken by the surgeon to avoid incisions in the external sphincter muscles, which may lead to incontinence of faeces.

Many types of fistulas, such as anal fistulas, respond to treatment with metronidazole or 6-mercaptopurine (6-MP);

other fistulas may require surgery. These include a fistula from the ileum to the bladder (ileovesical fistula) and a fistula from the rectum to the vagina (rectovaginal fistula). The ileovesical fistula often can be repaired by resecting the diseased bowel and allowing the bladder to heal spontaneously and the rectovaginal fistula can be treated by an operation via the anus which has a fair chance of success.

Can surgery be avoided by using nutritional treatments or special diets?

In some cases, yes. When there is partial obstruction due to narrowing plus inflammation of the intestine, switching to a liquid or blenderised diet, or even to one of the many available liquid supplements, may help to prevent mechanical obstruction of the narrowed channel by food particles, and may help to avoid a surgical emergency.

An elemental diet with free amino acids is generally low in fat and contains other nutrients in easily digested forms. This diet may help reduce the symptoms of Crohn's disease and thus also delay surgery. Elemental diets may also be useful for pre-operative preparation of patients and post-operative recovery.

In addition, several studies have suggested that total parenteral nutrition (TPN) in patients with Crohn's disease awaiting surgery can help to reverse malnutrition and may even reduce the number of post-operative complications and the amount of bowel removed. TPN combined with bowel rest (taking nothing by mouth) may delay surgery and can close some fistulas, at least temporarily.

What are the chances that Crohn's disease will recur after surgery?

If we define a recurrence after surgery as a return of symptoms such as pain, fever, diarrhoea, weight loss, about 20 percent of people will have a recurrence by two years, 30 percent by three years, and about 50 percent by five years. It is important to remember that these are just averages, since each case of Crohn's disease behaves differently, these rates should not be seen as predictions for individual patients.

In most studies, recurrence rates are only about one-third as high after proctocolectomy and ileostomy as after resection and

anastomosis. When they do occur, most recurrences are found at or near the site of the anastomosis. After ileostomy, recurrences nearly always occur adjacent to, and including the ileostomy site. There also is a tendency for recurrent disease to behave in the same way as the original disease, before surgery. For example, if your disease caused intestinal obstruction before surgery, recurrence is likely to result in another bout of obstruction.

If there is a recurrence will I need a second or third operation?

Most recurrent Crohn's disease responds favourably to medical treatment. In fact, only about 40 to 50 percent of those with recurrent symptoms after their first operation will need a second operation. According to one study, only 11 percent of those operated on once will ever require three or more operations in their lifetime. It is important to remember that, at the present time, the successful treatment of Crohn's disease involves *both* medical and surgical treatments. The objective of treating Crohn's disease, therefore, should not be for you to avoid surgery at all costs, but to feel well, function better, and get on with life. In many cases, surgery can help you achieve these goals.

Surgery in Ulcerative Colitis

When does surgery become necessary in ulcerative colitis?

As in Crohn's disease, surgery may be performed in an emergency or as an elective procedure. Estimates are that only about 20 to 25 percent of patients with ulcerative colitis will require surgery.

Emergency indications for surgery include perforation of the colon, massive rectal bleeding, fulminant (sudden, severe) ulcerative colitis, and toxic megacolon. The presence of any of these conditions usually means having to make a decision to have surgery on very short notice and with relatively few options. Removal of the colon (colectomy), however, also removes the emergency and may allow you to choose, at a later time one of the newer alternatives to the standard ileostomy (see below).

Even if no emergency exists elective surgery may still be needed. People with ulcerative colitis will often tolerate chronic severe symptoms which do not respond to medications, because they unrealistically fear surgery, especially ileostomy. Often these individuals do not realise just how ill they have become and how much the quality of their lives has deteriorated. Only after surgery do they appreciate how sick they were and how much the operation has improved their lives.

The other elective indication for surgery is the risk of colon cancer, a concern of ulcerative colitis patients with disease involving the colon for ten or more years. The more extensive the colitis, the greater the risk is for developing cancer. If a biopsy taken during routine colonoscopic examination reveals dysplasia (specific cell changes that usually precede the development of cancer), colectomy is generally recommended. To verify the presence of dysplasia, the slides are usually reviewed by another pathologist, and a repeat confirmatory colonoscopy with biopsy is often performed. Again, removing the colon obviously removes the risk of cancer as well as colitis.

What is the operation most commonly performed in ulcerative colitis?

Previously, the operation of choice is total proctocolectomy (removal of the entire colon and rectum) with ileostomy (creation of an external opening on the abdomen to allow drainage of intestinal waste). The reason for removing the entire colon is that ulcerative colitis will almost invariably recur in an unresected segment of colon. In some cases however, when the rectal disease is not severe, the rectum can be retained and used later as part of one of the alternative operations.

Proctocolectomy with ileostomy is a permanent cure for ulcerative colitis. This operation has been performed safely and with few complications for many decades and is the “gold standard” against which the newer operations are measured. It is also the best operation when colitis is extremely severe, when a patient is weak or nutritionally debilitated and in emergency situations.

How is this operation performed?

Proctocolectomy is performed in three main steps: 1) removal of the abdominal portion of the colon through an abdominal incisions; 2) construction of an ileostomy allowing the cut end of ileum to protrude through the skin of the lower abdomen; and 3) removal of the rectum, usually with a separate incision in the anal area. When the rectum is left in to be removed later or used for an alternative operation, the operation is called a *subtotal colectomy*.

Where is the ileostomy located?

Before the operation, the surgeon and/or the ostomy nurse will select a proper site on your abdomen for placement of the ileostomy. The ileostomy is usually placed in the lower right quadrant of the abdomen because this is where the ileum is located, and because this site does not interfere with the “belly button” or the hip bones. This location also makes the ileostomy appliance (pouch), which attaches over the new opening (stoma), inconspicuous under clothing.

What can I expect after ileostomy surgery?

After the operation, you will be wearing a skin barrier (a wafer designed to fit snugly around the stoma) and a drainable bag to collect intestinal waste. It is normal for a few days to pass before any drainage begins to accumulate in the bag. The skin barrier is essential to protect the skin around the stoma from potential irritation by faecal drainage. Your new stoma will appear red and quite swollen immediately after surgery, but it will shrink somewhat and lighten in colour within a few weeks.

When you are feeling well enough, your ostomy nurse will begin to teach you how to empty and change your bag. You may feel awkward, unwilling, frustrated, or even disgusted at first. But with practice and the support of your ostomy, surgeon, and family members, you will become more expert. With expertise and the realisation that you are healthy will come acceptance. When you are ready to go home, your ostomy nurse will provide helpful written instructions about caring for your ileostomy at home.

What is an ileoanal anastomosis (“pouch operation”) and how is it performed?

This operation removes the diseased colon, retains the anal canal, and allows faecal elimination to occur through the anus in the usual way. In most cases, the surgeon fashions an internal pouch or reservoir using about 30-40 cm of ileum, this reservoir is then pulled down through the rectal “sleeve” and stitched directly to the interior wall of the anus, where it imitates the storage function of the absent colon. Because this operation preserves intestinal continuity, no permanent external ileostomy is required.

The ileoanal anastomosis is usually performed in two stages. First, the diseased colon and rectum are removed, and the ileal reservoir is constructed and joined to the anus. To allow the sutures in the newly constructed reservoir to heal, the surgeon usually fashions a temporary loop ileostomy to divert faecal flow. The ileostomy is closed at a second operation several months later. Between the two operations it is not unusual to pass faecal-stained mucous and fluid through the rectum. In a few cases, the straight ileum is joined directly to the anus without constructing a reservoir, but this often results in very frequent, watery stools.

After the operation, most people experience frequent soft stools and some bowel movements at night. There is also frequent seepage of mucous over a 24-hour period. The stool frequency usually decreases with time, and after six months most people can expect about have to six semiformal movements during the day and one at night.

Who should have this operation?

This question is best answered in the negative. The ileoanal anastomosis is not generally performed in older persons, since the competence of the anal sphincter muscles decreases with age. Likewise, individuals who are obese, have rectal strictures, or who have developed a rectal cancer are poor candidates for the operation. In addition, since this operation usually results in increased stool frequency, it may not be suitable for those ulcerative colitis patients who experienced severe diarrhoea or even incontinence before surgery. The ileoanal anastomosis is not initially performed in those patients suffering from severe, acute

attacks of ulcerative colitis, or in those who are extremely debilitated, malnourished, or experiencing severe steroid side effects.

What are the complications of the ileoanal anastomosis?

Severe infection at the site of the stitches is an early major complication and can result in an abscess and/or narrowing of the anal canal. This occurs in 5 percent of cases. Post-operative obstruction of the intestine, often due to adhesions, occurs in about 10 percent of cases but usually does not require surgical correction,

Aside from the increased stool frequency mentioned earlier, another significant complication is an inflammation of the reservoir called *pouchitis*. Symptoms of pouchitis include diarrhoea, blood in the stool, fever, nausea, and a general feeling of malaise. While pouchitis is not a recurrence of ulcerative colitis, its exact cause is not known. Pouchitis is usually treated with antibiotics such as metronidazole (Flagyl®).

What other surgical options are available?

Another operation, the ileorectal anastomosis, consists of removing only the diseased colon and attaching the intact ileum to the upper end of the rectum. For this operation to be successful, the surgeon must consider several key factors in selecting patients. These include age of the patient, activity and distensibility of the rectum, condition of the anal sphincters, and pre-existing perianal disease or cancer. Inflammation may increase in the rectum in some patients, requiring treatment with cortisone and/or 5-aminosalicylic acid enemas and occasionally necessitating proctectomy (removal of the rectum) and ileostomy. Moreover, the frequency of loose stools, while controllable with antidiarrhoeal agents such as Imodium® (loperamide) or Lomotil®, can be bothersome to many people already troubled by years of diarrhoea. Most important, the retained rectum remains at risk for the development of cancer, although this risk can be monitored easily by screening for dysplasia with sigmoidoscopy and biopsy. If dysplasia or cancer is found, conversion to a standard ileostomy is always possible.

How can I decide which surgical option is best for me?

Obviously, consideration of an operation for ulcerative colitis is made more complex by the number of choices now available to you. Each operation has advantages and disadvantages, and your choice of one or another will depend as much on the quality of life you desire as on the extent and severity of your disease. A young college student may be motivated enough by a desire not to wear an ileostomy appliance that he or she will endure the frequent stools and occasional night time soiling that may occur with the ileoanal anastomosis. On the other hand, a taxi driver, or anyone who must be away from a bathroom for long periods of time, will probably be most comfortable with a standard ileostomy, where the risk of soiling is minimal or nonexistent.

Discussing the “pros and cons” of each operation, as well as sharing your own needs and concerns with your gastroenterologist and surgeon, will provide you with enough information to make an informed decision. Keep in mind, also, that the results of a particular operation are best when a surgeon has had a great deal of experience performing it. This is particularly true of the ileoanal anastomosis. Your gastroenterologist will be able to refer you to the surgeon best able to perform the operation of your choice.