SURGERY IN IBD

It's possible that you will face the prospect of surgery at some point during the course of your IBD. Approximately 20% of people with ulcerative colitis and 40% of people with Crohn's disease will eventually require surgery and this is often a cause for concern.

A recommendation by your clinical team to consider surgery is never made lightly. When treating IBD the top priority is always to preserve the bowel for as long as possible, but sometimes this isn't possible – the disease may be too extensive or severe and may no longer be responding to medications. It is important to understand that surgery for IBD is not simply reserved for when everything else has failed, but is a useful treatment option in some people. Surgery can offer long-term relief of symptoms and may reduce or even eliminate the need for ongoing use of medications, often vastly improving quality of life.

Sometimes surgery is needed to manage sudden or severe complications such as rupture (perforation) of the bowel, significant rectal bleeding or an acute severe attack of colitis. These can be emergency situations and the decision to have surgery needs to be made at short notice with few, if any, other options. In most cases, however, surgery is elective or planned. This means that you can choose whether or not to have surgery, after considering the reasons why a particular procedure is recommended and learning what to expect before, during and after surgery. The choice of which procedure is right for you is ultimately a mutual decision between you and your clinical team, based on individual factors such as the extent and severity of your disease as well as your age, general health and lifestyle.

Often surgery for IBD can be done with a keyhole (laparoscopic) approach, allowing you to get back to normal activity a little quicker and minimising the scars associated with surgery.

When I woke [from surgery] I had a colostomy bag. Over the next 5 weeks I learnt to cope with a bag, it took me at least 3 weeks to accept that I had one. Today I still have a few hiccups and have some inflammation, low iron, etc, but over all I am better than what I was when I started. I can control my body, I have less pain, I am not so tired, and I do have a lot of great days.

– TERESA

It can be a good idea to speak to other people who've already undergone similar procedures so that you can gain a true perspective on life before and after surgery. Quite often, people have fears about surgery and its consequences. Once they've had an operation, many people wish they hadn't put off their decision and thus avoided months or even years of needless suffering.

In this chapter of Living With IBD we present the most common surgical procedures for Crohn's disease and ulcerative colitis.

A. Surgery for Crohn's disease

Approximately 40% of people with Crohn's disease will eventually need to undergo surgery at some time in their lives. Surgery is not a cure for Crohn's disease but it can induce remission, relieve symptoms and greatly improve quality of life. Because the inflammation in Crohn's disease can reappear in previously healthy parts of the bowel after surgery, surgeons use techniques to preserve as much of the bowel as possible while dealing with the specific problem or complication.

The most common reasons for surgery in Crohn's disease are:

- To manage complications (obstruction, perforation, abscess, excessive bleeding). These may be surgical emergencies and a decision to operate may need to be taken quickly.
- To manage disease that is not responding to medications or because the person finds it difficult to tolerate the side effects of medications.
- To reverse delayed growth and pubertal development in children and adolescents with Crohn's disease.

The location and severity of the disease in the bowel, and/or the type of complication that arises, will determine the type of surgical procedure that may be performed.

Surgery for abscesses and fistulas

Abscesses and fistulas are complications that can occur when the inflammation of Crohn's disease penetrates outside the bowel wall.

Abscesses develop most frequently in the abdomen, pelvis or tissues surrounding the rectum and anus. Depending on their location, some abscesses can be drained by inserting a needle through the skin and removing its contents (percutaneous needle aspiration) or by surgical drainage. In some cases, abscesses can break open and drain into the abdominal cavity causing severe pain, fever, shock and bacteria in the bloodstream (septicaemia). This is considered to be a surgical emergency and the abdomen must be opened so that it can be cleaned, the abscess drained and, if necessary, affected parts of the bowel removed (resected).

Fistulas are abnormal channels that develop from an area of diseased bowel to other organs such as the bladder, vagina, other loops of bowel, or the skin. Surgery may be required if a fistula does not respond to medications or leads to organs such as the bladder or vagina.

• Stricturoplasty

Stricturoplasty is a procedure used to widen a narrowed area in the bowel that is causing a blockage without removing any part of the bowel. A lengthwise cut is made across the stricture and it is then sewn up crossways. This opens up the stricture and relieves the blockage. Several stricturoplasties may be done in a single operation or may be combined with

other procedures such as a resection and anastomosis.

Resection and Anastomosis

Although every effort is made to preserve the bowel in patients with Crohn's disease, sometimes removal of a part of the bowel surgically may be the best option, e.g. in the case of a perforation of the small bowel, a fistula to the bladder, or, in people with disease not responding to medical treatment. The surgical procedure involves removing the diseased section of bowel (resection) and joining together the cut ends of healthy bowel (anastomosis). Depending on which parts of the bowel are removed and which parts are joined together, the procedure may have different names. As an example, the procedure called 'ileocaecal resection with anastomosis' refers to removal of the junction of the small bowel (ileum) and beginning of the large bowel (caecum) and joining the two ends back together. Some people with Crohn's disease have segments of large bowel involved. Surgery to remove an affected section is called a 'segmental colectomy'.

Surgery to remove the entire colon is known as 'colectomy'. If the rectum is not affected by disease, it is possible to join the end of the small bowel (ileum) to the rectum (ileorectal anastomosis) which keeps the bowel all connected up. If the rectum and anus are also affected by disease, a 'panproctocolectomy' may be required which involves removing the colon, rectum and anus. This necessitates the formation of an ileostomy.

Ileostomy

Sometimes in Crohn's disease a 'bag' (ileostomy) is necessary. This can be either temporary or in a few cases permanent. An ileostomy is when the end of the small bowel (ileum) is brought outside the body through a hole (stoma) that is usually created in the lower right abdomen near the belt line. After the procedure, a stoma bag (appliance) is worn over the opening at all times to collect the bowel content. This bag needs to be emptied several times a day.

An ileostomy is done infrequently when a join has been done, unless the bowel is severely diseased or there is associated severe infection. In these cases the ileostomy is generally temporary. When a panproctocolectomy is done the ileostomy is permanent.

Implications of having an ileostomy

Immediately after surgery the stoma may be red and swollen but this will subside within a few weeks. You'll need to use a skin barrier which is a doughnut-like wafer designed to fit snugly around the stoma and protect the skin from any irritation caused by drainage of the bowel content. It normally takes a day or so before any drainage begins to accumulate in the bag. There is an initial learning curve to adjusting to an ileostomy; however, specialty nurses and/or stoma therapists are available to provide support both in hospital and at home. Importantly, no one ever needs to know you have an ileostomy unless you tell them. Normal clothing can be worn with only minimal adjustments and odour isn't a problem. Changing a bag soon becomes a simple and discreet process.

Recurrence of disease after surgery

About 25% of adult patients with Crohn's disease will experience a recurrence of active disease within five years of having had a resection. This most commonly occurs at or near the site of a join (anastomosis) or ileostomy. Although disease recurrences can sometimes be treated successfully with medications, about half the people with recurrent symptoms will need to undergo further surgery.

B. Surgery for ulcerative colitis

About 20% of people with ulcerative colitis eventually require surgery. This generally involves removal of the colon and rectum (proctocolectomy).

The most common reasons for surgery in ulcerative colitis are:

- To manage complications (eg perforation, massive bleeding, sudden severe ulcerative colitis or over-distension of the colon). These may be surgical emergencies and a decision to operate may need to be made quickly.
- To manage disease that is not responding to medications or because the person finds it difficult to tolerate the side effects of medications.
- To reduce the risk of colorectal cancer in people with precancerous changes in colon tissue.

Because the symptoms of ulcerative colitis don't recur once the colon is removed, surgery is often regarded as a cure. However, the lasting effects of surgery (e.g. an ileostomy to collect bowel content) and the possibility of complications related to the surgery mean that it is not a cure in the true sense of the word.

Restorative Proctocolectomy

Restorative proctocolectomy – also known as ileal pouch anal anastomosis (IPAA) – is now the most common surgery performed in people with ulcerative colitis. Its main advantage is that it allows the bowel to be connected up so that stool can be passed through the anus as normal. This can often be done with keyhole (laparoscopic) surgery allowing you to get back to normal activity a little quicker and minimising the scars associated with surgery.

A restorative proctocolectomy consists of three stages:

Stage 1

The colon is removed.

Stage 2

The rectum is removed but the anus and anal sphincter muscles are preserved. About 40cms of the end of the small bowel (ileum) is doubled back on itself to create a 20 cm pouch of the small bowel which is then connected directly to the anus. The pouch acts as a reservoir for the stool to be passed through the anus in the usual manner. The newly-formed pouch needs time to heal so a temporary ileostomy is generally performed.

Stage 3

A few months after the initial surgery and once the pouch has healed, the temporary ileostomy is closed. The internal

pouch now serves as a reservoir for intestinal waste. Stool is passed through the anus in the normal manner.

In people who have a planned operation on lower doses of steroids the procedure can be done in 2 operations combining the first and second stage at the first operation.

In people with acute severe disease or those who are taking high doses of steroids, the procedure is done as three operations a minimum of 6 weeks apart. This allows them to come off their medications between the first and second operation.

Restorative proctocolectomy is a good option for many people with ulcerative colitis but it doesn't suit everyone. After the surgery, most people have several soft bowel movements per day plus some during the night; some seepage of mucus through the anus may also occur. Over time the number of bowel movements decreases. After about 6 months or so, most people will have about six semi-formed bowel movements during the day and another at night.

Although most people do well after restorative proctocolectomy there's a possibility that complications may arise:

Inflammation of the pouch or 'pouchitis' occurs in about 30% of people after surgery. Symptoms include diarrhoea, crampy abdominal pain, increased frequency of stools, fever, dehydration and joint pain. Pouchitis is usually treated with antibiotics.

About 10% of patients will experience pouch failure, which requires removal of the pouch and conversion to a permanent ileostomy.

About 5% of people who undergo IPAA surgery develop infection at the site where the ileum is attached to the anus. This can cause abscesses and/or a narrowing (stricture) of the anal canal.

Although less common, bowel obstruction can occur because of adhesions or scar tissue forming after surgery. Symptoms include crampy abdominal pain with nausea and vomiting. In most people, bowel obstruction can be managed with bowel rest (not eating for a few days) and intravenous fluids. Others may need additional surgery to remove the blockage.

Women who've undergone restorative proctocolectomy may experience difficulties falling pregnant and caesarean section is recommended for delivery.

Men who've had restorative proctocolectomy have a small chance of having difficulties achieving or sustaining an erection as a direct result of the surgery.

Anyone wishing to have children should discuss these issues with their gastroenterologist and gynaecologist before making a decision to have the surgery.

Pan-proctocolectomy and ileostomy

An alternative procedure for ulcerative colitis is panproctocolectomy (removal of the colon, rectum and anus). Whilst still a major operation this is more straightforward, but necessitates a permanent ileostomy. The ileostomy is performed after the colon, rectum and anus have been removed. This involves bringing the ileum outside the body through an opening (stoma) that is usually created in the lower right abdomen near the belt line. After the procedure, a stoma appliance (bag) is worn over the opening at all times to collect intestinal waste. This bag needs to be emptied several times a day.

Which is the best option for me?

In the event that surgery is recommended to manage your ulcerative colitis, the choice about whether to have restorative proctocolectomy or panproctocolectomy with ileostomy is highly personal and will depend on your age, general health and lifestyle. For example, some people may have a strong wish to avoid an ileostomy and are prepared to put up with more frequent bowel movements and the occasional leakage that can occur with IPAA surgery. On the other hand, people who don't have good bowel control before surgery or are older may prefer to have an ileostomy where the risk of soiling is less or even non-existent.

Crohn's & Colitis™ NEW ZEALAND
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