

It's possible that you will face the prospect of surgery at some point during the course of your inflammatory bowel disease (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 doctors 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. It can sometimes be a useful treatment option if the amount of bowel involvement is very limited but causing a lot of symptoms. 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 vou and vour 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 activities quickly and minimising the scars associated with surgery.

It can be a good idea to speak to other people who have 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 section of living with IBD, we present the most common surgical procedures for Crohn's disease and ulcerative colitis.



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 made quickly.
- manage disease that is not responding to medications or because the person finds it difficult to tolerate the side effects of medications
- 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 fistulae

Abscesses and fistulae occur when the inflammation of Crohn's disease penetrates outside the bowel wall.

Abscesses are pockets of infection or pus that 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).

Fistulae 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 (called a stricture). Strictures usually result from scarring in an area of the bowel that was previously inflamed.

Strictures can cause blockages and a stricturoplasty is a procedure that widens the stricture 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 (see below).

#### 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. 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 'ileocecal 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 a 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 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.

#### lleostomy

Sometimes in Crohn's disease a 'bag' (ileostomy) is necessary. This can be either temporary or, occasionally, 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 contents. A temporary ileostomy is often done to allow the bowel 'downstream' and the area around the anus a chance to heal. After



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there is improvement, the ileostomy is 'taken down' and the bowel reconnected.

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

Many 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.

These disease recurrences can often be treated successfully with medications, although some patients with recurrent symptoms will need to undergo further surgery.

# Surgery for ulcerative colitis

Some 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 (e.g. 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.



- manage disease that is not responding to medications or because the person finds it difficult to tolerate the side effects of medications.
- reduce the risk of colorectal cancer in people with pre-cancerous 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.

# Proctocolectomy (with an ileostomy or a 'J-pouch')

If surgery is needed for the reasons above, it is best to remove the entire colon. Removing the entire colon means there will be no more colitis (since there will be no colon) and it removes the small risk of developing colon cancer in the future.

#### Two types of surgeries can be performed:

 The entire colon and anus can be removed, and the person is given an ileostomy. This is called a panproctocolectomy. During the operation the ileostomy is performed after the colon, rectum and anus have been removed. This involves bringing the ileum (the end of the small

- intestine) outside the body through an opening (stoma) that is usually created in the lower right abdomen. After the procedure, a stoma appliance (bag) is worn over the opening
- 2. The entire colon can be removed as above, but with formation of a J-pouch. The pouch is created by taking the end 40cms of the ileum and doubling it back on itself to create a 20cm pouch, shaped like a J. This procedure is sometimes called a 'restorative proctocolectomy' because the J-pouch is connected directly above the anus, so people pass stool normally through the anus, rather than through an ileostomy. The pouch acts as a reservoir for the stool to give people control. However, there can be problems associated with the surgery. Some people get recurrent inflammation in the pouch, called 'pouchitis', which is usually treated with antibiotics. Also, following the surgery people usually have frequent bowel motions with an average of six semi-formed stools per day and one at night. The surgery can also make it more difficult for a woman to become pregnant (although in vitro fertilisation, IVF, is an option if this is the case).

# 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 proctocolectomy with a J-pouch or a panproctocolectomy with ileostomy is highly personal and will depend on your age, general health and lifestyle.

For example, some people may wish to avoid an ileostomy and are prepared to put up with more frequent bowel movements and the risk of getting pouchitis. 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.

Prior to the surgery, your surgeon will go over the different options in detail and spend a lot of time talking about the benefits and risks of each procedure.