INTRODUCTION

This information is about the types of surgery that may be needed in the treatment of Ulcerative Colitis (UC). You may also find other Crohn’s and Colitis UK information useful, especially our booklets, Ulcerative Colitis and Living with IBD. All our publications are available from our website: www.crohnsandcolitis.org.uk

HOW THE DIGESTIVE SYSTEM WORKS

To understand the various operations, it can help to get to know the main features of the gastrointestinal (digestive) system and the way it works. As you can see from the diagram below, the gastrointestinal tract, which is also known as the gut, is like a long tube that starts at the mouth and ends at the anus.

The main purpose of the gut is to break down the food we eat so that our body can absorb its nutrients. This begins as we chew and swallow food, which then passes down the oesophagus (gullet) into the stomach where digestive juices break it down to a porridge-like consistency.

The partly digested food then moves from the stomach into the small intestine (also known as the small bowel). Here the food is broken down even further, so that useful nutrients can be absorbed into the blood stream through the wall of the intestine.

The waste products from this process, which include liquid and undigested parts of food, are then pushed from the ileum into the colon (large intestine). The colon – which together with the rectum makes up the large bowel - has four main sections: the ascending colon, the transverse colon, the descending colon, and the sigmoid colon which connects to the rectum.

The colon absorbs the liquid and the left over waste forms solid faeces (stools). These collect in the last part of the colon and the rectum and are passed out of the body in a bowel movement.
Ulcerative Colitis (UC) causes inflammation and ulceration of the mucosa (inner lining) of the large bowel. These raw areas or ulcers may bleed or produce pus. As it becomes inflamed and sore, the colon is less able to absorb water or to hold as much waste. It also tends to produce more mucus (a natural lubricant). This leads to more frequent and looser bowel actions, experienced as urgency and diarrhoea. Other common UC symptoms include crampy abdominal pain, blood and mucus in stools, fatigue, a lack of energy, and weight loss. If you lose a lot of blood you may also develop anaemia (a reduced number of red blood cells) which can also make you feel very tired.

UC sometimes affects just the rectum, in which case it is called proctitis. It may also involve part or all of the colon. When the descending or ‘distal’ colon is involved it is called distal colitis, and when it affects most of the colon or the entire colon, it is often known as extensive or pancolitis (total colitis).
SURGERY FOR ULCERATIVE COLITIS (UC)

For more details on the different types of UC and their symptoms, see our booklet: Ulcerative Colitis.

UC is sometimes described as a chronic condition. This means that it is ongoing and usually lasts throughout your life, but you may have long periods of good health when the disease is in remission, alternating with relapses or ‘flare-ups’ when the symptoms are more severe. Treatment for UC may be medical or surgical, or a combination of both.

WHEN IS SURGERY NECESSARY?

Medical treatment for IBD has improved considerably over the years, and a much wider range of drugs is now available for UC. Even so, about one in four people with UC will require surgery at some time during their illness. To some extent it may depend on the type of UC. Surgery is seldom needed for proctitis, but is much more likely to become necessary for people with extensive or total UC.

Some of the most common reasons for surgery are outlined below.

- **Poor response to long term medical treatment**
  UC is often well treated with drugs, but sometimes medical therapies fail to control the inflammation. If you experience repeated flare-ups with troublesome symptoms, and these seriously affect your quality of life, you may wish to consider surgery.

- **Emergency problems**
  Surgery may sometimes be recommended for people with serious acute symptoms, such as severe diarrhoea with bleeding, dehydration and a raised temperature, which do not respond to medical treatment even when treated in hospital. Urgent surgery may also be needed for rare complications such as toxic megacolon (very severe disease of the colon) or a perforation (a hole or tear) in the wall of the colon.

- **Cancer of the large bowel**
  Ulcerative Colitis is not a form of cancer. However, if you have had severe UC affecting all or most of the colon and this has lasted for at least 8-10 years, there is a slightly increased risk of bowel cancer. You may be offered regular colonoscopies to check for this. (A colonoscopy is an examination of the colon using a colonoscope – a long flexible tube with a camera in the tip) If cancer is found, this may require surgery. For more information see our leaflet: Bowel Cancer and IBD.

WHICH ARE THE MOST COMMON OPERATIONS?

The operations most likely to be carried out for Ulcerative Colitis are described from the next page.
• **Proctocolectomy with ileostomy**
In this operation the entire colon is removed, together with the rectum and the anal canal. The surgeon then brings out the end of the small intestine through an opening in the wall of the abdomen. This is an ileostomy or stoma. An external bag is then fitted onto the opening to collect the waste. This can be emptied or changed as necessary. (See **Stomas** for more information.)
• Restorative Proctocolectomy with ileo-anal pouch
This procedure is commonly called pouch surgery, but may also be described as IPAA (Ileo pouch-anal anastomosis) surgery.

It generally requires two operations. In the first and main operation the surgeon removes the whole colon and the rectum, but leaves the anus. Then a pouch is made using the ileum (the lower end of the small intestine) and this is joined to the anus. Finally, a looped section of the small intestine is brought out onto the external wall of the abdomen through a temporary ileostomy. This allows the waste from digestion to be collected in a stoma bag until the newly-formed pouch has had a chance to heal – which generally takes about three months. This temporary ileostomy can then be closed in a second operation. The main advantage of a pouch is that faeces (stools) can be passed through the anus in the normal manner, although usually more frequently. Many people with a pouch have about six bowel movements a day, plus one or two more at night.
- **Colectomy with ileo-rectal anastomosis**
  This operation is much less common as it is only suitable for a small number of people with UC. In this the colon is removed, but instead of creating an ileostomy, the surgeon joins the end of the small intestine directly to the rectum. This avoids the need for an ileostomy. However, this operation will only be recommended if there is little or no inflammation in the rectum and no long-term risk of developing rectal cancer.
Colectomy with ileostomy

If you are having emergency surgery for UC you may have a colectomy with an ileostomy – which usually allows for the possibility of pouch surgery at a later date. In this operation the surgeon removes the colon but leaves the rectum. Then, as in a proctocolectomy, the end of the small intestine is brought out through an ileostomy and an external bag is fitted onto this opening to collect the waste from digestion. This ileostomy may be temporary or can become permanent.

The upper end of the rectum is either closed or brought out to the surface to another temporary stoma. This is called a mucous fistula and is needed because the rectum may produce mucus for a while.

Depending on your individual medical condition, once you have recovered from the colectomy you may be able to have pouch surgery as described earlier. In this, the rectum will be removed and a pouch made from the ileum (the last part of the small intestine) and connected to the anus. Alternatively, you may decide on a permanent ileostomy.

“Although I still suffer from fatigue and joint pain, my quality of life with an ileostomy is so much better than when I had a colon. I wish I had surgery before I did, because it has really improved my symptoms.”

Katryna, age 36 diagnosed with Ulcerative Colitis in 2005
As described above, sometimes in surgery for UC the intestine is brought to the surface of the abdomen and an opening is made so that digestive waste products (liquid or faeces) drain into a bag, rather than through the anus. Because the part of the intestine brought to the surface is the ileum (the lower end of the small intestine), this procedure, and the end of the intestine connected to the opening, is known as an ileostomy. In some operations for certain other conditions, including Crohn’s Disease, the large intestine or colon is brought to the surface and connected in a similar way, and this is known as a colostomy. Both types of opening are also called stomas.

Most stomas are about the size of a 50p piece and pinkish red in colour. Because the contents of the small bowel are liquid and might irritate the skin, an ileostomy usually has a short spout of tissue, about 2-3cm in length. Depending on the type of stoma bag used, ileostomy bags usually have to be emptied four to six times a day and changed two or three times a week.
A two-piece stoma bag (one piece stoma bags are also available)

I found it quite daunting leaving hospital after my surgery and having to change the stoma bag myself. But the stoma nurses showed me how to do it, and they were an absolute lifeline to me even after I left the hospital. I could contact them whenever I was unsure about something which was so reassuring.

Amy, age 35
diagnosed with Ulcerative Colitis in 2012

LAPAROSCOPY

Some of the operations outlined above, including pouch surgery, may now be carried out using laparoscopy (minimally invasive surgery). This is also known as ‘keyhole surgery’. Instead of making one large opening in the wall of the abdomen, the surgeon makes four or five small incisions (cuts) each only about 1cm (half an inch) long. Small tubes are passed through these incisions and a harmless gas is pumped in to inflate the abdomen slightly and give the surgeon more space. A laparoscope, a thin tube containing a light and a camera, is used to relay images of the inside of the abdomen to a video screen in the operating theatre. Small surgical instruments can also be passed through the incisions and guided to the right place using the view from the laparoscope. If a section of the intestine needs to be removed, this can be done through a separate larger incision.
Laparoscopic operations tend to take longer than ‘open’ surgery, but can have a number of advantages, such as:

- less pain after the operation
- smaller scars
- faster recovery - for example, being able to eat and drink more quickly after the operation
- reduced risk of a wound infection or a hernia,
- a shorter stay in hospital.

However, laparoscopic surgery may not be available in all centres, and may not be appropriate if you have already had abdominal surgery.

ARE THERE RISKS TO SURGERY?

Ulcerative Colitis is a very individual condition and the risks and benefits of different types of treatment will vary from person to person. Your IBD team should be able to help you weigh up what will be best for you.

Surgery for UC, like all surgery, will carry some general risks, including those linked to having a general anaesthetic. There is also a small risk that some operations may lead to complications such as infections. Particular operations may have other risks. For example, occasionally an anastomosis (join) or an ileo-anal pouch can develop a leak. Adhesions (sticky bands of scar tissue that form as part of the healing process) can twist the intestine. If you have a pouch there is also a risk that you may develop pouchitis (inflammation of the pouch), which may need treatment with antibiotics. Your surgical team will be able to tell you more about complications like these, how likely they are for the operation planned for you, and how they are usually treated.

WHAT ARE THE ADVANTAGES OF SURGERY?

Unlike Crohn’s Disease, which can recur after surgery, Ulcerative Colitis cannot recur once the colon has been removed, and so is ‘cured’ by surgery. This should mean:

- relief from pain
- relief from symptoms such as urgency or diarrhoea
- being able to stop taking drugs which may be causing side effects
- feeling able to lead a fuller life, for example being able to leave the house in a more relaxed frame of mind.

Getting used to having a stoma or a pouch will take time, and for some, can be a challenge. However, many people who have had such operations feel that, in general, they have a better quality of life than before their surgery.
WHAT CAN I EXPECT TO HAPPEN BEFORE THE OPERATION?

If the surgery is elective (planned), you will have time to talk through the options with your health care team and to discuss the best way to prepare for the operation. It is important that you are as fit as possible before having the surgery. So, if you are seriously underweight you may be advised to take extra nutrients, perhaps in the form of a special liquid feed as a supplement to your diet. If you smoke, you will be advised to stop.

Exact procedures vary from hospital to hospital, but you will probably be asked to attend a pre-admission clinic for a health check a week or two before your admission. During this appointment a doctor or nurse will examine you and ask about your general health as well as your UC symptoms. They will take a blood sample for routine tests and may send you for other tests such as a chest x-ray or ECG (a tracing of your heart rhythms). This information will help the anaesthetist plan the best anaesthetic for you.

A surgeon will meet you to discuss your operation and you may be asked to sign a consent form at this stage (or this may not happen until you are actually admitted to hospital). It is important that you fully understand what operation is planned and what are the likely benefits and side-effects. Your surgeon is also likely to explain about the complications that can happen as a result of surgery. Do ask questions if you feel you do not understand anything, or would like more information. You may also meet a colorectal nurse, and, if you are going to have a stoma, a stoma care nurse, who will also be able to help with any queries you may have about the operation or your after care.

Once in hospital you may expect something like the following to happen.

- A doctor will examine you and a nurse will check your temperature, blood pressure, pulse and weight. This information can then be compared with readings taken after the operation.

- If there is a possibility that you may need a stoma, a stoma care nurse will visit you to talk through what this may mean for you, and to make sure you have all the information you need. She should be able to tell you, for example, where (if you are going to have one) the stoma is likely to be, and may make a mark on your abdomen to show this.

- If you have not already done so, you will be asked to sign a consent form to confirm that you agree to the operation. If anything is unclear, ask for it to be explained. If you don’t want the surgery to happen you have a right not to sign the form.

- An anaesthetist will visit you to talk about how you will be given the anaesthetic and how your pain will be controlled after the operation. Good pain relief helps recovery, so this will be an important part of your post-operative (after the operation) care.

- You may need to take a ‘bowel preparation’ (a strong laxative) the day before the operation. This is to make sure that the bowel is completely empty. Or, you may be asked to have an enema to clear the last part of the bowel.

- You will usually be given a pair of support stockings to wear during and after the operation, and you may be given a small injection as well. Both these measures help prevent blood clots in the legs.
WHAT CAN I EXPECT TO HAPPEN AFTER THE OPERATION?

Immediately after the operation you will be moved into the recovery room, where your condition can be closely monitored. Once you have fully regained consciousness you will be moved to a ward.

You will be given pain relief, perhaps through an epidural (a fine tube attached to your back) or intravenously (through a drip in your arm, into a vein). The delivery of the pain-killing drugs may be automatic, or you may be able to control it by pressing a hand-held button. You may also be given medication to control anaesthetic side effects such as nausea and vomiting.

There may be several other tubes coming out of your body, including a drip to provide fluids, a catheter to drain and measure urine, and a drain tube near the operation wound. Some people will also have a nasogastric tube (a tube in your nose to keep your stomach empty). These tubes will be removed over the next few days and you should be able to start taking painkillers by mouth if you need them. You may find your throat feels sore from the breathing tube used during the operation. Gargles can usually help ease this.

Depending on the operation you have had, you may be encouraged to get out of bed and into a chair the day after, or in some cases, the same day as your surgery. This is to help get your circulation moving. As you continue to recover, a physiotherapist may visit you to show you some simple leg and chest exercises.

Also depending on the type of surgery performed, some people will be allowed to start drinking water within hours of their operation. Others may be asked to wait until bowel sounds are heard and they have begun to pass wind. So, it may be a few days before you can start taking fluids and you may need to build up from small sips to drinking normally. You will then be encouraged to start eating a light diet.

If you have a stoma, the stoma care nurse will show you how to look after it and how to manage your stoma bag. If you have any problems, don’t hesitate to ask for help.

Some people have found that a few days after the surgery they do not feel as well as they did immediately after the operation and can feel quite depressed. This may be partly a reaction to the ‘shock’ of the operation, and this experience usually passes.

HOW LONG WILL I NEED TO STAY IN HOSPITAL?

This can vary quite a lot according to the type of operation needed and also from individual to individual. Most people stay in hospital for about a week, although if you have had a laparoscopic (keyhole) operation you may be allowed to go home earlier. If you have had open surgery you may need to stay a few days longer. In general, hospital stays for planned or elective surgery tend to be shorter than for emergency surgery, as people who need emergency surgery are usually more unwell and may have a more complicated recovery.

HOW LONG WILL IT TAKE TO RECOVER?

When you first go home you will probably find that you feel weak and tire easily. You may not feel like doing much. On the other hand, you should no longer have the symptoms from your UC, and, as you recover, should begin to feel a lot better than before the operation.
As time passes you will regain your strength and stamina, and will probably be able to return to your normal daily activities including sports and hobbies. Everyone is different, however, and how long this takes can depend not on only the type of operation you have had, but also on your age and your general state of health. During your recovery it is important to strike a balance between trying to do more each day and over-doing things. Listen to your body and only do as much as feels comfortable.

A gentle exercise program may help speed up your recovery and you will probably be given some advice on this by the hospital or your IBD team.

If you have a stoma bag, it will take time to learn how to manage it. Talk to the stoma care nurses if you have a problem or need more information. Many hospitals have ongoing stoma clinics or offer a stoma care advice line run by the stoma care nurses, to help with any problems that develop once you are home. Specialist stoma or IBD nurses should also be able to help with advice about living with an ileo-anal pouch. You may also find patient associations helpful. (For more details, see Other Organisations.)

Most people are advised not to do any heavy lifting or housework such as ironing or vacuuming for a period of time following their operation. You should not start to drive again until you are able to control a car properly, including making an emergency stop if you need to, and this may take several months. Your car insurance may not cover you if you drive before you are fully recovered.

When you can return to work will depend on the operation you have had and the type of work you do. People with jobs that involve a lot of physical effort may need more time off than those with less active jobs, although even sitting at a desk all day can be very tiring after surgery. In general, it usually takes about two to three months before most people feel able to return to work.

HOW MIGHT AN OPERATION AFFECT MY EVERYDAY LIFE?

- **Diet**
  Immediately after your operation you may need to eat an easy to digest ‘low residue’ diet. Your hospital will give you details of this. Once you have recovered you may find that you can eat larger meals and a wider range of foods. Eating a balanced and nutritious diet should help you recover and then keep up your general health.

  Many people with a stoma do not need to stay on a special diet, but you may find it helpful to take extra fluids (including an electrolyte mix), and you may prefer to avoid certain foods. High fibre and spicy foods can be a particular problem for people with an ileostomy. Eating starchy foods such as white bread and rice can sometimes help improve stoma or pouch function. Your stoma care nurse or the hospital dietitian should be able to advise you.

  Our booklet, Food and IBD, has further information on diet and Ulcerative Colitis.

- **Sex and Pregnancy**
  Most people are able to resume sexual activity after surgery for Ulcerative Colitis, although it may take a little time, perhaps several months, to recover fully. In men, operations on the rectum can occasionally lead to impotence. This may resolve itself – if not there are several aids and medicines which can help. There is some research to show that both of the main operations most commonly carried out for UC, but especially IPAA surgery, can affect fertility in women. Couples who may want to have a family after UC surgery should discuss this with their consultant. Doctors also usually recommend that a woman with a stoma or pouch gives birth by caesarean section. For more details see our information sheets, Fertility and IBD and Pregnancy and IBD.
**Emotional reactions**
Everyone reacts to surgery in their own way and some people experience a range of emotions, both before and then after an operation. You may feel apprehension, doubt, acceptance, relief, confidence, a sense of wellbeing and perhaps even some disappointment. It is not uncommon for people with an operation scar or a stoma to feel depressed about their changed body image. This can be a time of worry for family members as well.

You may find it helpful to talk to someone about these feelings. Stoma care and IBD nurses can be an excellent source of support. If you would like to speak to a professional counsellor, check whether your GP has a counselling service. There may also be a counsellor attached to your IBD team or hospital. Our information sheet, *Counselling for IBD*, has more details on how to find a counsellor. We also provide a confidential supportive listening service, as well as an information line. See below for details of these services.

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**HELP AND SUPPORT FROM CROHN’S AND COLITIS UK**

All our information sheets and booklets are available to download from our website: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk). If you would like a printed copy, please contact our information line – details below.

**Crohn’s and Colitis UK Information Line:** 0300 222 5700. Open Monday to Friday, 9 am to 5 pm, except Thursday open 9 am to 1 pm, and excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email [info@crohnsandcolitis.org.uk](mailto:info@crohnsandcolitis.org.uk) or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

**Crohn’s and Colitis Support:** 0121 7379 931: Open Monday to Friday, 1 pm to 3.30 pm and 6.30 pm to 9 pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD.

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**OTHER ORGANISATIONS**

- **IA – The Ileostomy and Internal Pouch Support Group:** 0800 018 4724  
  Website: [www.iasupport.org](http://www.iasupport.org)

- **Colostomy Association:** 0800 328 4257  
  Website: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

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ABOUT CROHN’S & COLITIS UK

We are a national charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 28,000 members and 50 local groups throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn’s and Colitis UK. To find out how call 01727 734465 or visit www.crohnsandcolitis.org.uk.