



INFORMATION SHEET

SURGERY FOR ULCERATIVE COLITIS

INTRODUCTION

This information sheet 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**, and our information sheet **Living With a Stoma**. All our publications are available from our website: www.crohnsandcolitis.org.uk

HOW THE DIGESTIVE SYSTEM WORKS

To understand the various operations, it is helpful to know about the gastrointestinal system and the way it works. As you can see from the diagram on the next page, the gastrointestinal tract, which is also known as the gut, is 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 passes down the oesophagus into the stomach, where digestive juices break it down to a porridge-like consistency.

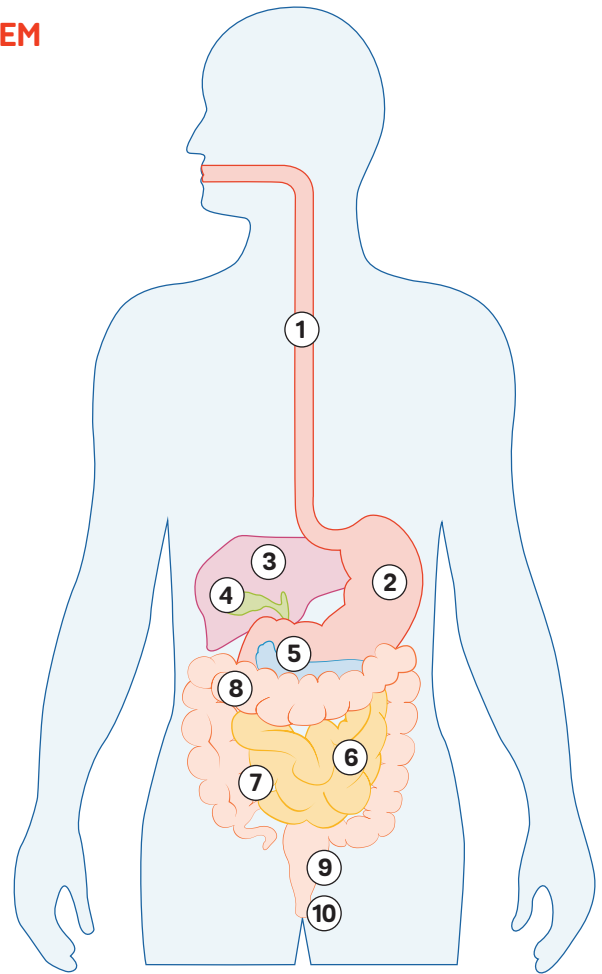
The partly digested food then moves from the stomach into the small intestine (also known as the small bowel). Here the food is broken down even further, so that nutrients can be absorbed into the bloodstream through the wall of the intestine.

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 leftover 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.

THE DIGESTIVE SYSTEM

- 1 OESOPHAGUS**
- 2 STOMACH**
- 3 LIVER**
- 4 GALL BLADDER**
- 5 PANCREAS**
- 6 SMALL INTESTINE**
- 7 ILEUM**
- 8 LARGE INTESTINE (COLON)**
- 9 RECTUM**
- 10 ANUS**



HOW DOES ULCERATIVE COLITIS AFFECT THE GUT?

Ulcerative Colitis causes inflammation and ulceration of the mucosa (inner lining) of the large bowel. These raw areas or ulcers may bleed or produce mucus, a natural lubricant. As it becomes inflamed and sore, the colon is less able to absorb water or to hold as much waste. This leads to more frequent and looser bowel actions, experienced as urgency and diarrhoea. Other common UC symptoms include cramping abdominal pain, blood and mucus in stools, fatigue, a lack of energy, and weight loss.

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 colon is involved it is called distal or left-sided colitis. When it affects most of the colon or the entire colon, it is known as extensive or pancolitis (total colitis) respectively. Treatment for UC may be with medicine or surgery.

WHEN IS SURGERY NECESSARY?

Medical treatment for Inflammatory Bowel Disease (IBD) has improved considerably, and a much wider range of drugs is now available for Ulcerative Colitis. Even so, up to one in four people with UC may require surgery at some time. To some extent this may depend on the type of UC a person has. Surgery is not often needed for proctitis, but is more likely to become necessary for people with left-sided, extensive or total UC.

Some of the most common reasons for surgery are:

- **Poor response to long-term medical treatment**

UC is often well-treated with drugs, but sometimes medical therapies fail to control the inflammation. If people experience repeated flare-ups or have ongoing active disease with troublesome symptoms that seriously affect quality of life, they may wish to consider surgery.

- **Emergency problems**

Surgery may sometimes be recommended for people with serious acute symptoms that do not settle with medical treatment, even when treated in hospital. These include severe diarrhoea with bleeding, dehydration and a fever.

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**

If a person has left-sided, extensive or total UC for at least 8-10 years, there is a slightly increased risk of developing bowel cancer. These people may be offered regular colonoscopies - an examination of the colon using a long tube with a camera in the tip.

Colonoscopies can also detect precancerous changes in the bowel, which if found may require surgery. For more information see our leaflet **Bowel Cancer and IBD**.

“

My surgery was an emergency and I was initially devastated that I needed a stoma. However, having the ‘bag’ really wasn’t what I expected – it improved my quality of life hugely and was very manageable.

”

Ellie, age 22

diagnosed with Ulcerative Colitis in 2013

WHICH OPERATIONS ARE THE MOST COMMON?

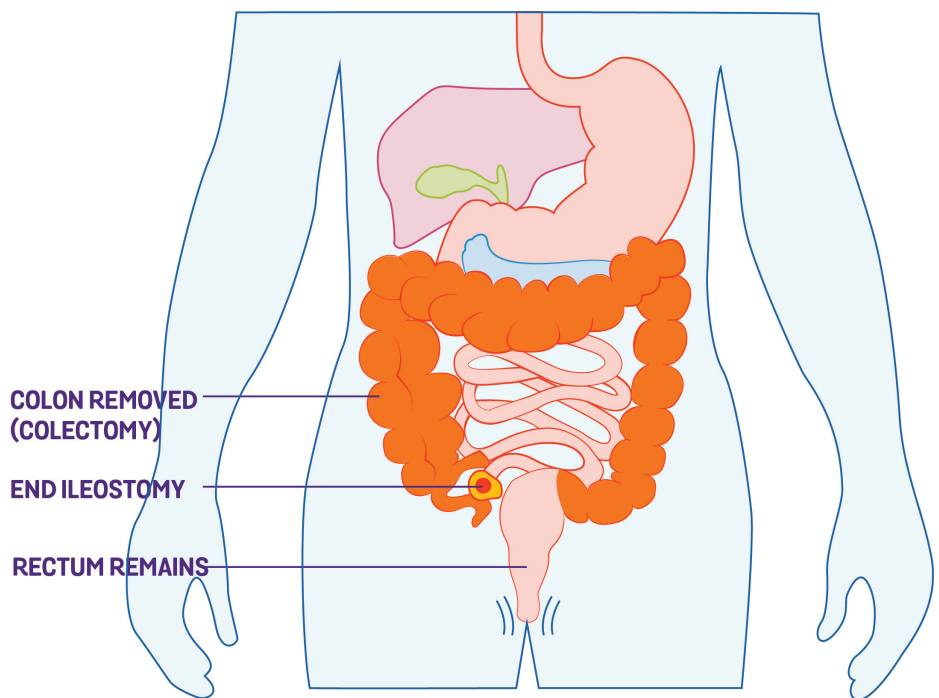
The operations most likely to be carried out for Ulcerative Colitis are described starting on the next page.

- **Colectomy with ileostomy (subtotal)**

Subtotal colectomies are the most common type of surgery for UC, and usually allow for the possibility of pouch surgery to be carried out at a later date. During this operation the surgeon removes the colon but leaves the rectum. Then the end of the small intestine is brought out through an opening in the wall of the abdomen. This is called an ileostomy or stoma. An external bag is fitted onto the opening to collect the waste from the small intestine that would previously have gone into the colon. This ileostomy may be temporary or can become permanent.

The upper end of the rectum is either closed or also brought out to the surface as a temporary stoma. This 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 below. In this procedure, the rectum will be removed and a pouch made from the ileum (the last part of the small intestine) to connect to the anus. Alternatively, you may decide on living with a permanent ileostomy.



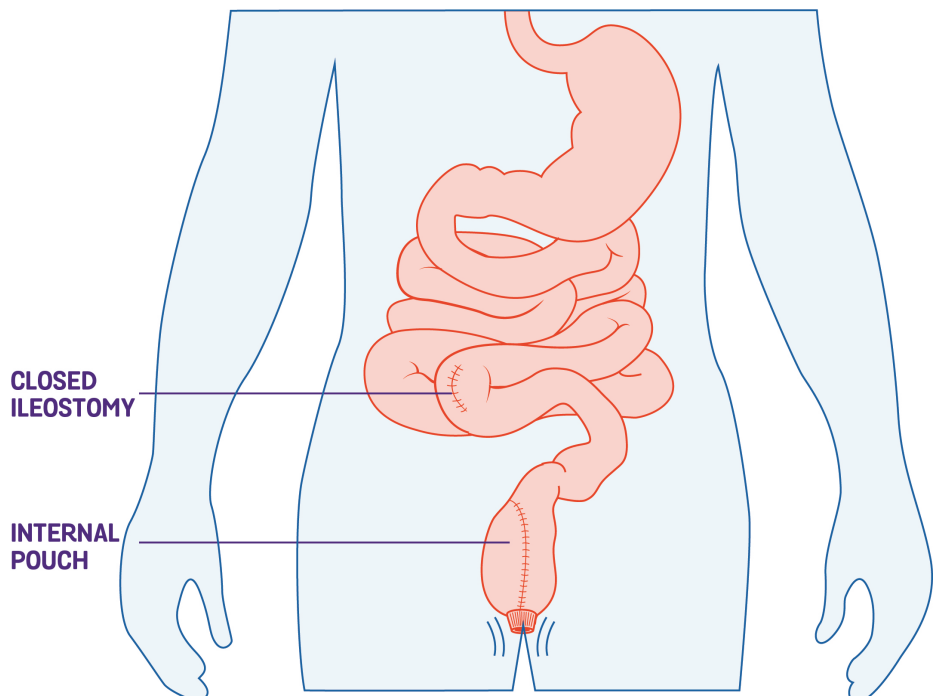
- **Restorative Proctocolectomy with ileo-anal pouch**

This procedure is commonly called pouch surgery, but may also be described as IPAA (ileo pouch-anal anastomosis) surgery. It generally requires two or three operations, but in rare circumstances may be done as a single stage. Your IBD team will discuss which option is best for you.

In the first operation, the surgeon removes the whole colon, but leaves the rectum and the anus. As with the subtotal colectomy described above, a temporary ileostomy is then formed to collect waste from digestion. At this stage, patients are generally able to stop taking medications for their UC.

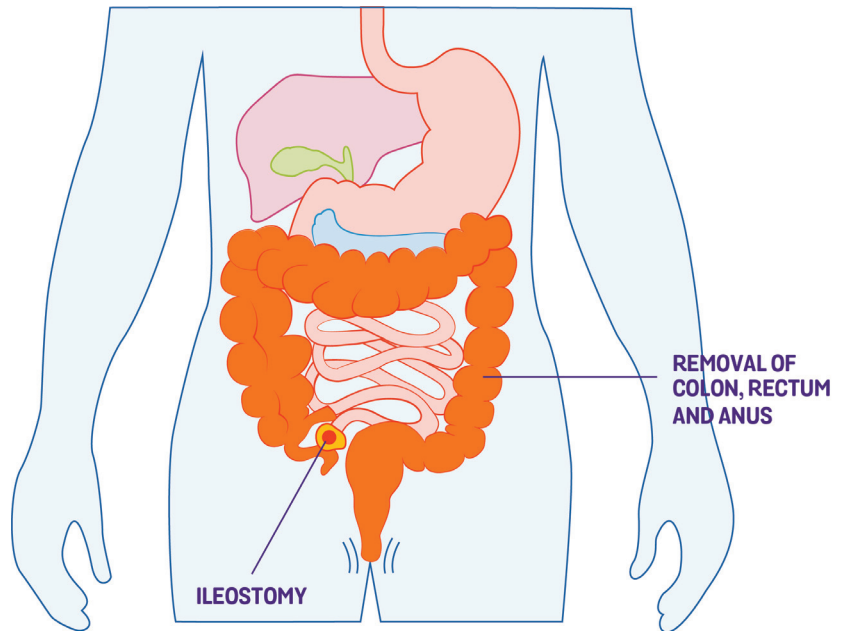
During the second operation, a pouch is made using the ileum (the lower end of the small intestine), which is joined to the anus. The pouch aims to replace the function of the rectum, and stores stool until it can be passed out of the body in a bowel movement. For patients having a two-stage procedure, the pouch is created in the first operation. A looped section of the small intestine is then brought out through an opening in the external wall of the abdomen to create a temporary ileostomy. The ileostomy gives the newly formed pouch a chance to heal, which generally takes about three months. This temporary ileostomy can then be closed in the second or third operation so the pouch can be used.

The main advantage of a pouch is that faeces (stools) can be passed through the anus in the normal manner, although more frequently than normal. As a pouch cannot fully replace the function of a healthy colon, many people have about six bowel movements a day, plus one or two more at night. Some people also experience incontinence after pouch surgery. For more details see our information sheet **Managing Bowel Incontinence in IBD**.



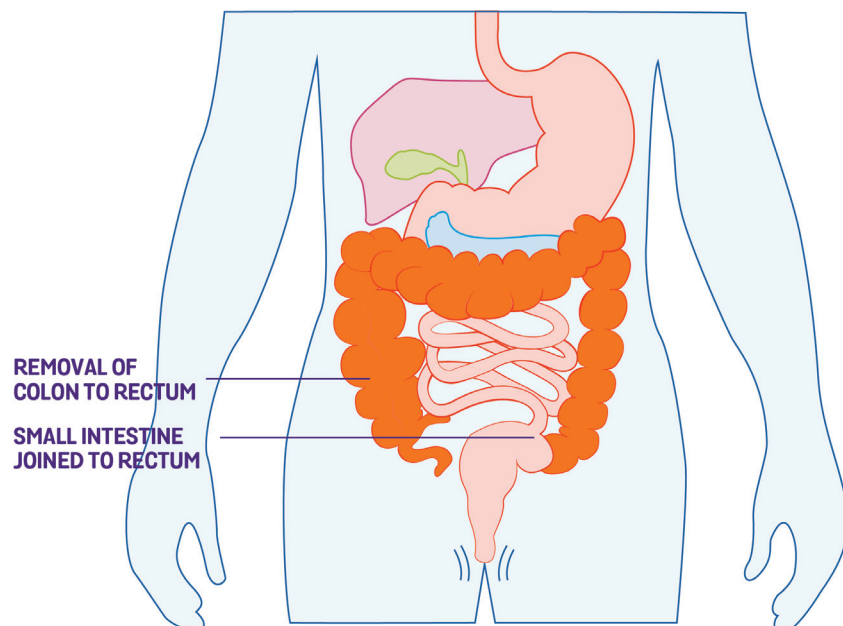
- **Proctocolectomy with ileostomy**

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 a permanent ileostomy in the wall of the abdomen. A bag is fitted onto the opening to collect the waste from the small intestine. This can be emptied or changed as necessary (see **Stomas** below). This surgery is irreversible, but means that you no longer have a colon to become inflamed or develop bowel cancer.



- **Colectomy with ileo-rectal anastomosis**

This operation is rarely performed as it is only suitable for a small number of people with UC. The colon is removed and the surgeon joins the end of the small intestine directly to the rectum. This avoids the need for an ileostomy, so it may be useful for people who could not cope with a stoma or who are unsuitable for pouch surgery. This operation will only be recommended if there is little or no inflammation in the rectum and low long-term risk of developing rectal cancer.



LAPAROSCOPY

Some of the above operations, including pouch surgery, may be carried out using laparoscopy or single-port 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. In single-port laparoscopy, only one incision is made.

Small tubes are passed through the incision(s) and a harmless gas is used 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 incision(s) and guided to the right place using the view from the laparoscope.

Laparoscopic operations tend to take longer than 'open' surgery, but 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.

Laparoscopic surgery may not be available in all centres and may not be appropriate for some procedures, particularly if you have already had abdominal surgery.

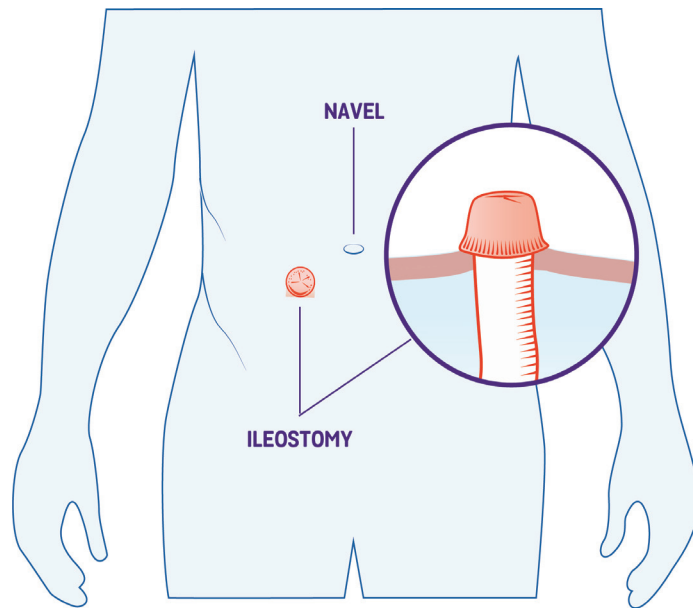
STOMAS

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 (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 is known as an ileostomy, or stoma.

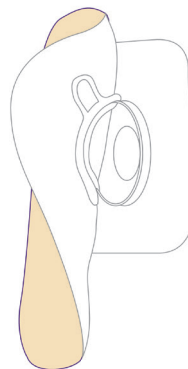
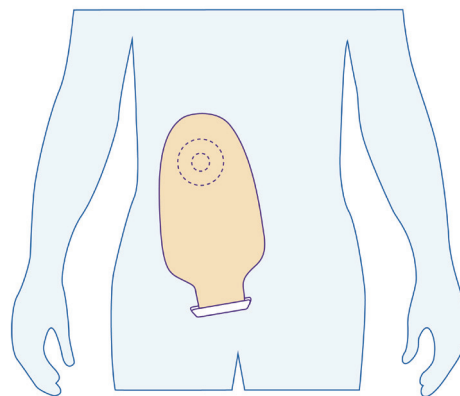
Most stomas are about the size of a 50p piece and pinkish red in colour. Because the contents of the small bowel are liquid and might irritate the skin, an ileostomy usually has a short spout of tissue, about 2-3cm in length. Ileostomy bags usually have to be emptied four to six times a day, and changed two to five times a week. This will depend on the type of stoma bag used, and also the type of ileostomy. Bags for loop ileostomies tend to need changing more than those for end ileostomies.

Our information sheet **Living With a Stoma** has more details about different types of stomas, and how to manage them in your everyday life.

An ileostomy showing the stoma opening



A two-piece stoma bag. One-piece stoma bags are also available



“

I am amazed how many people are surprised to hear I have a bag. Obviously it's not 'obvious'!

”

Annie, age 54
diagnosed with Ulcerative Colitis in 2011

A specialist nurse can help you choose the most suitable stoma bag. They can be easily drained through an opening in the bottom of the bag, and can be concealed under everyday clothes.

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. Like all surgery, operations for UC 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, and adhesions (sticky bands of scar tissue that form as part of the healing process) can twist the intestine.

If you have an ileo-anal pouch there is also a risk that you may develop pouchitis, an inflammation of the pouch that may need treatment with antibiotics. A small proportion of patients with a pouch can also develop a fistula - a channel or passageway linking the pouch to the bowel, bladder, vagina or the outside skin. These are often successfully treated with drugs, but may occasionally need surgery. For more information on fistulas, see our information sheet **Living With a Fistula**.

In rare circumstances, people who have had IPAA surgery may later develop Crohn's Disease of the pouch, symptoms of which include urgency, incontinence and abdominal pain.

While very unlikely, these complications mean a small number of people must have their pouches removed. Your surgical team will be able to tell you more about complications like these, how common they are, and how they are usually treated.

WHAT ARE THE ADVANTAGES OF SURGERY?

Unlike Crohn's Disease, which can recur after surgery, Ulcerative Colitis cannot come back once the colon has been removed. For most people this should mean:

- relief from pain
- lessening of symptoms such as urgency and diarrhoea
- being able to stop taking drugs that may be causing side effects

For procedures in which the entire large intestine is removed, the risk of colon cancer is also eliminated.

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. For example, people find they are able to leave the house in a more relaxed frame of mind and that IBD symptoms are much improved after recovery from surgery.

“

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

PREPARING FOR SURGERY

If the surgery is elective (planned), you will have time to talk through the options with your healthcare team and to discuss the best way to prepare.

What can I expect to happen before the operation?

It is important that you are as fit as possible before having the surgery. 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. It is very important to stop smoking prior to surgery, so if you are a smoker you will be strongly 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. You may be asked to sign a consent form at this stage, or this may not happen until you are admitted to hospital. It is important that you fully understand what operation is planned and what the likely benefits and risks are. Your surgeon will probably 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. They will also be able to help with any queries you have about the operation or your aftercare.

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. They should be able to tell you, for example, where the stoma is likely to be, and 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 care after the operation.
- You may need to take a strong laxative called a 'bowel preparation' the day before the operation. This is to make sure that the bowel is completely empty. In other cases, you will not need a laxative but 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. You are also likely to be given a heparin injection, which thins the blood. Both 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.

Your abdomen will feel sore at first, but this will eventually settle down. 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 painkilling 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 that 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.

You may find that it takes some time for your appetite to return, especially if you were unwell before surgery. 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 performed and also from individual to individual. Most people stay in hospital for about a week. Generally, people who have had laparoscopic operations are able to leave hospital sooner than people who have had open surgery. 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. Many surgical units use Enhanced Recovery After Surgery (ERAS) techniques, which aim to reduce complications after surgery and get patients safely home more quickly.

HOW LONG WILL IT TAKE TO RECOVER?

When you first go home you will probably find that you feel weak and tire easily, and so may not feel like doing much. However you should no longer have the symptoms from your UC, and should begin to feel a lot better than before the operation.

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. Many people also struggle with climbing stairs for a short period after their operation. A gentle exercise program may help speed up your recovery, and you will probably be given advice on this by the hospital or your IBD team.

You should not drive again until you are able to control a car properly, including making an emergency stop if needed. This may take several months. Your insurance may not cover you if you drive before you are fully recovered.

As time passes you will regain strength and stamina, and will probably be able to return to your normal daily activities including sports and hobbies. The length of time this takes can depend not only on the type of operation you have had, but also on your age and general state of health. During your recovery it is important to strike a balance between trying to do more each day and not overdoing things. Listen to your body and only do as much as feels comfortable.

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 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 ileoanal pouch. You may also find patient associations helpful. For more details, see **Other Organisations** below.

The timing of returning 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. It usually takes about two to three months before most people feel able to return to work.

“ 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

HOW MIGHT AN OPERATION AFFECT MY EVERYDAY LIFE?

• Diet

Immediately after your operation you may need to eat a low-fibre diet to make it easier for you to digest food. Your hospital will give you details. 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.

Initially you may be at an increased risk of dehydration, as the large intestine plays an important role in helping absorb water from food waste. You may find it helpful to take extra fluids, including an electrolyte mix. Our **Dehydration** information sheet has more information on staying hydrated with IBD and after surgery.

Most people with a stoma do not need to stay on a special diet, but 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 **Food and IBD** booklet 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, but if not there are several aids and medicines that can help. Our **Sexual Relationships and IBD** information sheet has more guidance on how surgery may affect sexual activity.

There is some evidence that both of the main operations most commonly carried out for UC, but especially IPAA surgery, can affect fertility in women. Some studies have found that the risk may be lower in people who undergo laparoscopic surgery.

Couples who may want to have a baby after UC surgery should discuss this with their consultant. Doctors often 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 after an operation. You may feel anxiety, fear, 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, especially if the surgery was an emergency and came as a shock. 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. Issues with body image and confidence can sometimes persist long after the operation, in which case you may like to speak to a professional counsellor. There may be a counsellor attached to your IBD team or hospital, or you can check whether your GP has a counselling service. Our information sheet **Counselling for IBD** has more details on how to find a counsellor.

It can be helpful to talk to other people who have had IBD surgery or who use a stoma bag. Your IBD team or hospital, your GP, or Crohn's and Colitis UK may be able to provide information about local support groups.

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**. If you would like a printed copy, please contact our helpline.

Our helpline is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD).

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

Call us on **0300 222 5700** or email **info@crohnsandcolitis.org.uk**

See our website for WebChat (Live Online):

www.crohnsandcolitis.org.uk/support/information-service

OTHER ORGANISATIONS

- **IA - The Ileostomy and Internal Pouch Support Group**
0800 018 4724
Website: **www.iasupport.org**
- **Colostomy Association**
0800 328 4257
Website: **www.colostomyassociation.org.uk**
- **Stomawise**
0779 630 2853
Website: **www.stomawise.co.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 33,000 members and 50 Local Networks throughout the UK. Membership starts 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

