

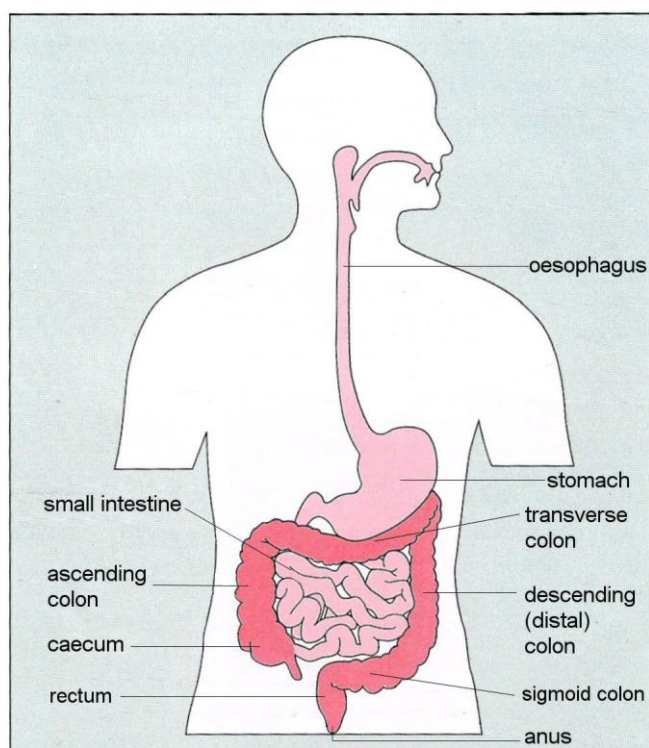
Surgery for Ulcerative Colitis (UC)

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*. Most of 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, and it passes down the oesophagus (gullet) into the stomach where digestive juices break it down further over 2-4 hours.

The stomach then empties the food into the small intestine (also known as the small bowel). Here the food is broken down into even smaller particles and the useful nutrients are absorbed through the wall of the intestine into the blood stream.

The waste products from this process, which include liquid and undigested parts of food, are then pushed into the large intestine or large bowel. The

colon – which together with the rectum makes up the large bowel - has four main sections: the ascending colon, the transverse colon, the descending or distal colon, and the sigmoid colon which connects to the rectum.

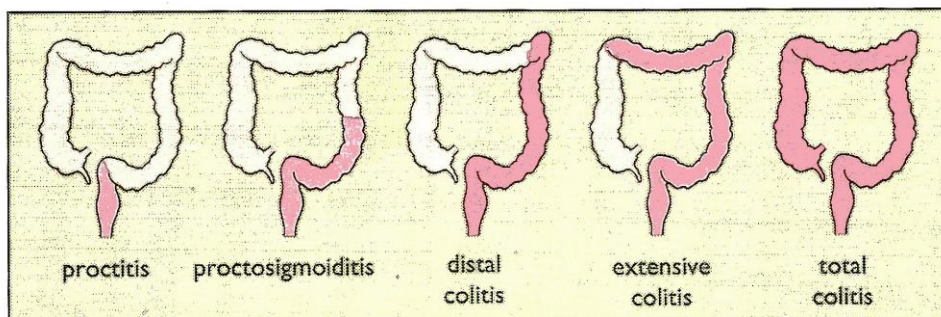
The colon absorbs some vitamins and minerals and the water from the liquid waste. The left over waste becomes solid faeces (stools). These collect in the rectum and are passed out of the body through the anus in a bowel movement.

How does Ulcerative Colitis affect the gut?

Ulcerative Colitis (UC) causes inflammation and ulceration of the mucosa (inner lining) of the large bowel. Raw areas or ulcers develop on the surface of the lining, and these may bleed and produce pus. The colon is less able to absorb water or hold as much waste and 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, a lack of energy, and weight loss. If you lose a lot of blood you may 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, as shown below. UC affecting the rectum and the sigmoid colon is known as proctosigmoiditis. When the descending colon is involved it is called distal colitis, and when it affects most of the colon or the entire colon, extensive or pancolitis (total colitis).



Exact symptoms tend to vary with the extent of the disease. For more details 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 flare ups when the symptoms are much more severe. Treatment for UC may be medical or surgical, or a combination of both.

When is surgery necessary?

About one in four people with UC will require surgery at some time during their illness. Surgery is seldom necessary for people with proctitis, but if you have extensive or total colitis it becomes more likely that you might need to have an operation to remove all or part of your colon. 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 have repeated flare ups with symptoms such as urgency and diarrhoea that seriously affect your quality of life, you may wish to consider surgery.

- **Emergency problems**

Surgery may also be recommended for people with acute symptoms, for example, severe diarrhoea with bleeding, dehydration and a raised temperature, if they do not respond to intensive medical treatment once admitted to hospital. Rare complications such as acute toxic dilation (distension) of the colon, or a perforated colon also require urgent surgery.

- **Cancer of the large bowel**

UC is not a form of cancer. However, if you have had severe Ulcerative Colitis 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, which may require surgery. For more information on this see our leaflet *Bowel Cancer and IBD*.

- **Involvement of other organs**

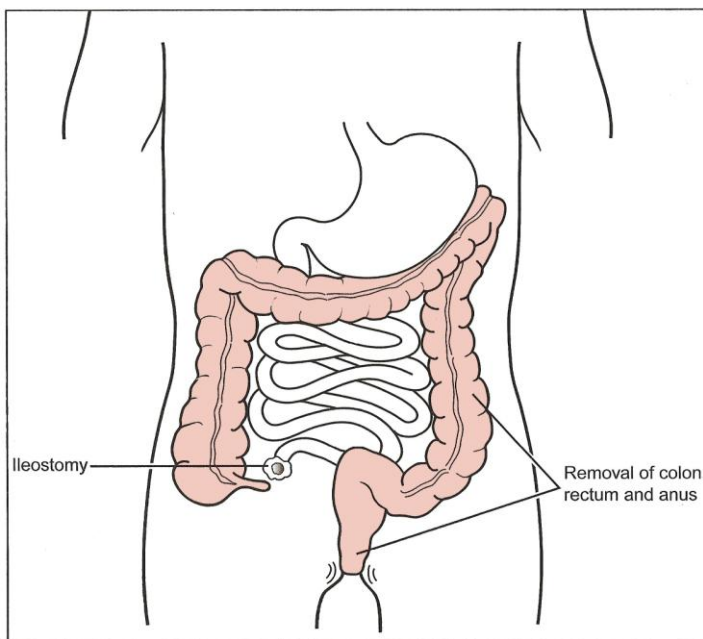
Inflammation in other parts of the body, such as the eyes, skin, or joints, can sometimes be associated with extensive or total UC. Rarely, surgery may be suggested if medication fails to control these symptoms

Which are the most common operations?

The operations most likely to be carried out for Ulcerative Colitis are described below.

- **Proctocolectomy with ileostomy**

In this operation the whole 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 stoma to collect digestive waste. The bag is emptied or changed when necessary. (See below for more detail on stomas.)



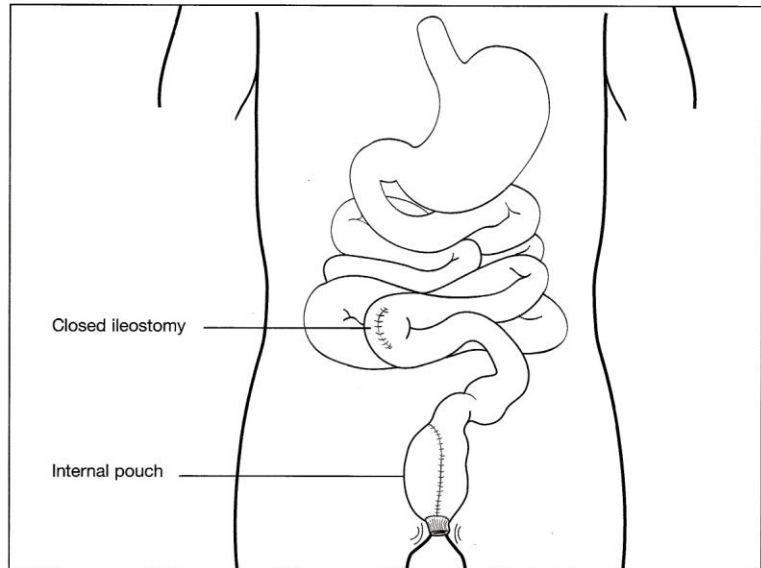
Proctocolectomy with ileostomy

- **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.

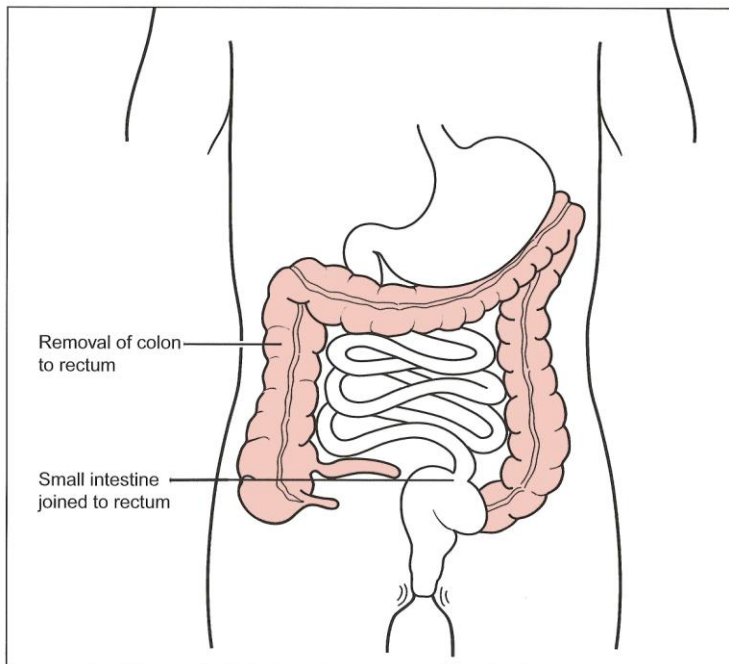
It generally requires two operations. In the first and main operation the surgeon removes the whole colon and the rectum, but leaves the anus. Then a pouch is made using the ileum (the lower end of the small intestine) and this is joined to the anus. Finally, a looped section of the small intestine is 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. A second operation will then go ahead to close the temporary ileostomy. The main advantage of a pouch is that faeces (stools) can be passed through the anus in the normal manner, although probably more frequently. Many people with a pouch have about 6 bowel movements a day, plus one or two more at night.

Illeal pouch following closure of loop ileostomy



- **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 so may be helpful for people who do not want or could not cope with a stoma. It may also be an option for people unsuitable for pouch surgery. However, this operation is only recommended if there is little or no inflammation in the rectum and if there is no long-term risk of developing rectal cancer.



Colectomy with ileo-rectal anastomosis

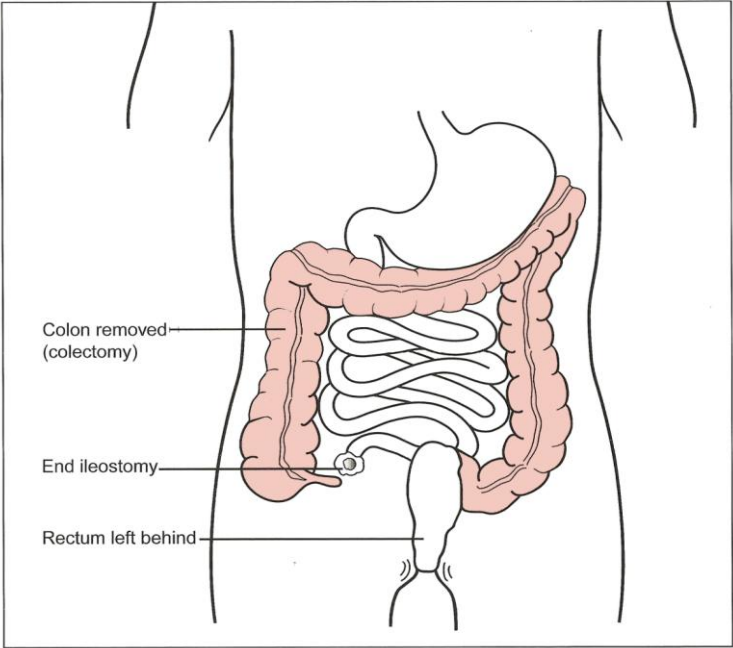
- **Colectomy with ileostomy**

If you are having emergency surgery for Ulcerative Colitis 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. Alternatively, you may decide on a permanent ileostomy.

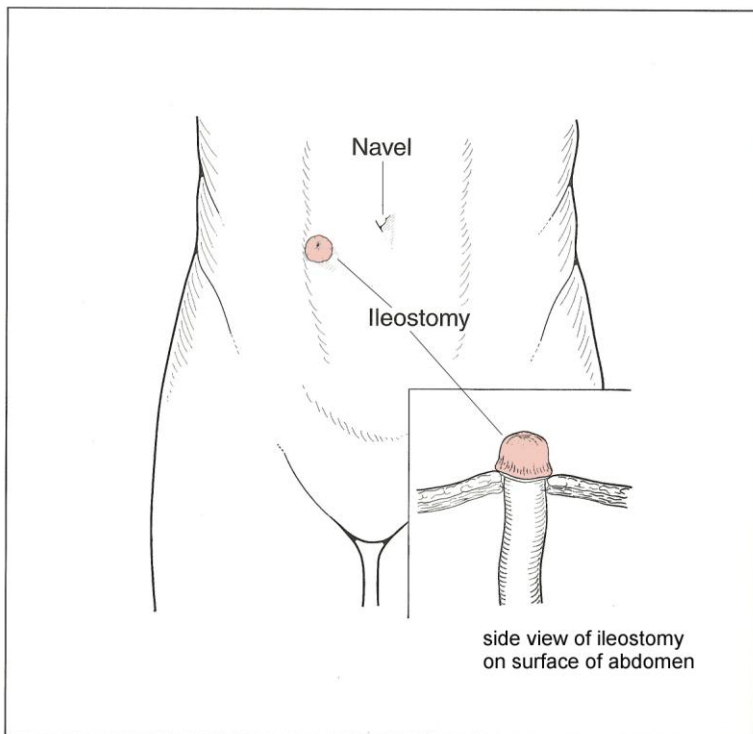
Colectomy with ileostomy



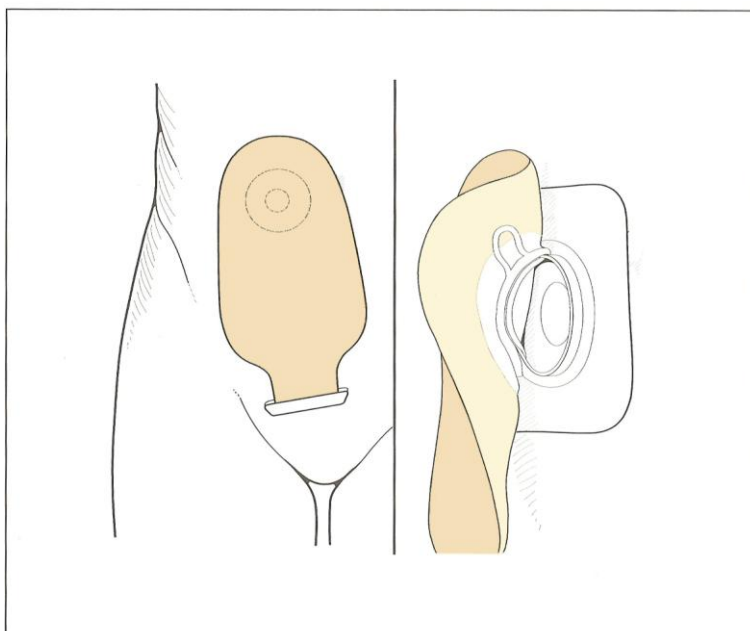
Stomas

As described above, sometimes in surgery for Ulcerative Colitis 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. If 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. If the large intestine or colon is brought to the surface and connected in a similar way, it is 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 about twice a week. Colostomies pass firmer stools, so colostomy bags are usually emptied slightly less frequently (about one to three times a day), and usually need to be changed each time.



An Ileostomy showing the stoma opening



A two-piece stoma bag – one piece stoma bags are also available.

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 television monitor 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
- a shorter stay in hospital.

However, 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.

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 and will need further surgery. Adhesions (sticky bands of material that form as part of the healing process) can twist the intestine. These usually settle down by themselves, but sometimes need dietary treatment. 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.¹ Your surgical team will be able to tell you more about any possible complications, 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 and 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.

However, as above, complications do sometimes develop, and it will take time to get used to having a pouch or an ileostomy.

What can I expect to happen before the operation?

If the surgery is elective (planned), you should 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 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 should also explain the complications that can happen as a result of your surgery. Do take this opportunity to talk through the details of your operation and to 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 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
- If you are going to have a stoma, the stoma care nurse will visit you again to talk through what this may mean for you and to make sure you have all the information you need. She may make a mark on your stomach where the surgeon will create the stoma.
- 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.
- 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 clean.
- You will usually be given a pair of white support stockings to wear during and after the operation; 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, or, in some hospitals, into the HDU (high dependency unit) so that your condition can be closely monitored. Once you begin to recover you will be moved back to a general surgery ward.

You will be given some sort of 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 or from your back passage. Some people will also have a nasogastric tube (a tube passed down through the nose into the stomach), which is used to remove secretions (fluids) or gas that may collect in your stomach after surgery. 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.

To help get your circulation moving, you will be encouraged to get out of bed and into a chair as soon as you are able – probably within a day or so. As you continue to recover, a physiotherapist may visit you to show you some simple leg and chest exercises.

Depending on the type of surgery performed, some people are allowed to start drinking water within hours of their operation; others, however, will 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 is probably 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 between one and two weeks, although you may be allowed to go home earlier and have any stitches or clips taken out at home or in an outpatients clinic. In general, hospital stays for elective (planned) surgery tend to be shorter than for emergency surgery, as people having 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.

If you have a stoma bag, it may take time to learn how to manage it. Talk to the stoma care nurses if you have a problem or need more information. Specialist nurses should also be able to help with advice about living with an ileo-anal pouch. Patient associations such as the Ileostomy and Internal Pouch Support Group, or the Colostomy Association, can also be helpful. (See Useful Organisations below.)

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 only on 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.

Most people are advised not to do any heavy lifting or housework like ironing or vacuuming for a period of time following their operation. You should not start to drive again until you feel strong enough and comfortable enough to control a car properly, including making an emergency stop if you need to. 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 also depend on the operation you have had, your general health, 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. On average, it probably takes about 2-3 months before most people feel able to return to work. Working part-time for a while, or only taking on lighter duties, can often help the recovery process.

How might an operation affect my everyday life?

- **Diet**

You may find that once you have recovered from the surgery you are able to eat larger meals and a wider range of foods. Eating a balanced and nutritious diet should help your recovery. You may be advised to follow a low residue diet for a while: the hospital will give you details of this. People with a stoma or pouch do not generally need a special diet, although it can help to make a point of eating regular meals, and to take extra fluids and salt. You may also prefer to avoid certain foods. The hospital dietitian should be able to advise you. Our booklet *Food and IBD* also 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 women with a stoma or pouch give birth by caesarean section. (For more information 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. (See our information sheet *Counselling for IBD* for more details on how to find a counsellor.)

At Crohn's and Colitis UK we have a confidential supportive listening service, Crohn's and Colitis Support, staffed by trained volunteers with personal experience of IBD. Trained staff on our general Information Line can answer queries on any aspect of IBD. (See below for contact details.)

We also have available a list of *10 questions to ask your surgeon* based on those recommended by the American College of Surgery.

Useful organisations

- IA – The Ileostomy and Internal Pouch Support Group: 0800 018 4724
www.iasupport.org
- Colostomy Association: 0800 328 4257 <http://www.colostomyassociation.org.uk/>
- Ostomy Lifestyle: 0800 7314264 www.ostomylifestyle.org.uk

Crohn's and Colitis UK Information Line: 0845 130 2233, open Monday to Friday 10am – 1pm. There is an answerphone service outside these hours, or you may email info@crohnsandcolitis.org.uk.

Crohn's and Colitis Support: 0845 130 3344, open Monday to Friday 1pm – 3.30pm and 6.30pm-9pm.

Crohn's and Colitis UK produces a comprehensive range of information sheets and booklets. You can get a copy of any these from our Information Line. Most are also downloadable from our website: www.crohnsandcolitis.org.uk

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Surgery for Ulcerative Colitis - Edition 2

Last review August 2011; Next review 2013

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We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based, and details of any conflicts of interest, can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, Sutton Road, St Albans, Herts AL1 5HH, or email h.terry@crohnsandcolitis.org.uk

Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom. Membership of the Association costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help our work are always welcomed.