

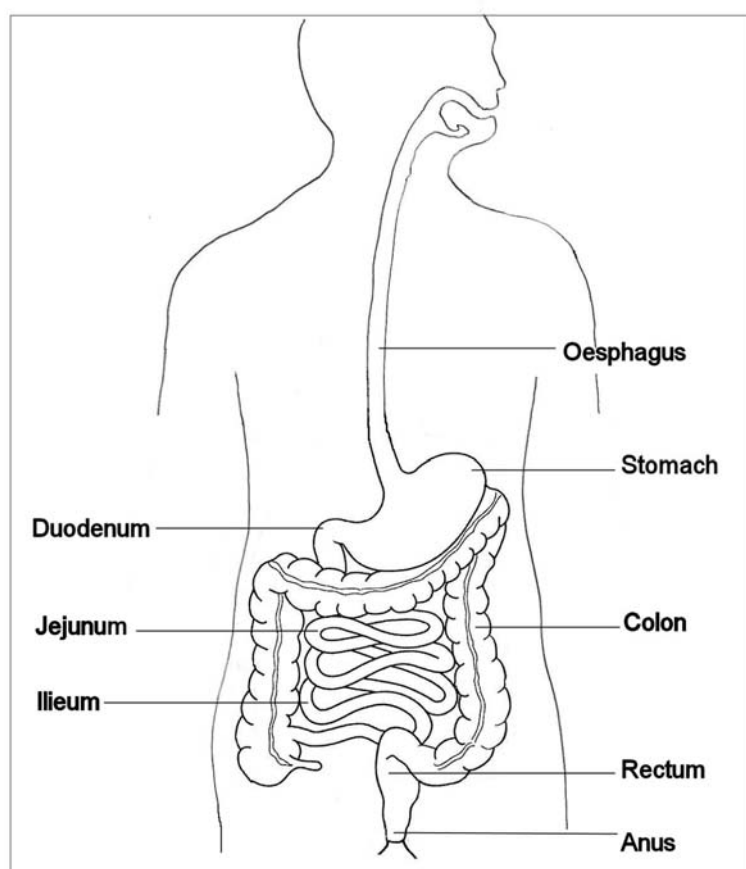
Surgery for Crohn's Disease

Introduction

This information is about the types of surgery that may be needed in the treatment of Crohn's Disease. You may also find other Crohn's and Colitis UK information useful, especially our booklets, *Crohn's Disease* 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 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). This has 3 sections: the duodenum, jejunum and ileum. 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 colon (large intestine or large bowel).

Finally, the colon absorbs the liquid and the left over waste becomes solid faeces (stools). These collect in the rectum and are passed out through the anus in a bowel movement.

How does Crohn's Disease affect the gut?

Crohn's Disease causes inflammation and can affect any part of the gut, although it is most commonly found in the ileum (the lower end of the small intestine) or in the colon. The areas of inflammation are often patchy, with sections of normal gut in between. A patch of inflammation may be small, only a few centimetres, or spread quite a distance along part

of the gut. As well as affecting the lining of the bowel, Crohn's may also go deeper into the bowel wall and cause abscesses or a fistula (see below).

The type of treatment recommended for Crohn's will depend on the part(s) of the gut affected and on the severity of the symptoms. It may be medical or surgical or a combination of both. For some people, especially children, nutritional therapy (the use of an exclusive liquid diet to treat or reduce inflammation) can be a useful option.

When is surgery necessary?

Over the last decade advances such as the development of biological drugs have produced increasingly effective medical therapies for Crohn's Disease. There have also been changes in the way surgery for Crohn's is now managed, for example extensive resections (removal of diseased sections of the intestine) are now less common. Nevertheless, surgery remains an important treatment option, often in combination with medical therapies, and it is estimated that about 70% of people with Crohn's will still need surgery at some point in their lives.

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

- **Poor response to drug or nutritional treatment**
Sometimes drug and/or nutritional therapies fail to control the inflammation and you may continue to experience symptoms such as diarrhoea, pain, poor appetite, and weight loss. Your doctor may then recommend surgery to remove any irreversibly damaged sections of intestine.
- **Strictures in the intestine**
The inflammation from Crohn's may cause scarring, and this can lead to a stricture, or narrowing of the space in the intestine, especially in the small intestine. This can make it difficult for food or waste matter to pass through and may cause a blockage. Symptoms of a stricture include cramping pains, distension or bloating, and, if there is a serious blockage, nausea, vomiting and constipation. You may need surgery to overcome the narrowing or blockage.
- **Abscesses or fistulas**
Sometimes the inflammation spreads through the full thickness of the bowel wall and forms an abscess (a collection of pus). As the abscess develops it may 'hollow out' a chamber or hole. This then becomes a fistula - a channel or passageway linking the bowel to another loop of bowel, another organ such as the bladder or vagina, or the outside skin. About a third of people with Crohn's develop fistulas (or fistulae), most commonly perianal fistulas linking the anal canal (back passage) to the skin near the anus. Fistula symptoms vary but often include leaks of faecal matter, and can be very distressing. (For more information on fistulas, see our information sheet, *Living with a Fistula*.) Abscesses can cause pain, fever and feeling generally unwell. Surgery can be used to treat both abscesses and fistulas.
- **Delayed growth in children**
Poor absorption of nutrients combined with steroid treatment can lead to delayed growth in children with Crohn's Disease. While this is most likely to be managed with nutritional treatment and drug therapy, it can also be helpful to remove any severely damaged sections of the intestine.

- **Cancer**

If you have severe Crohn's Disease 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. (For more details on this, see our information sheet, *Bowel Cancer and IBD*.) This may require surgery.

- **Emergency problems**

Emergency surgery is not often required for Crohn's Disease, but may be needed if there is severe bleeding from the bowel, a perforation (a hole or tear in the wall of the bowel), for toxic megacolon (very severe disease of the colon), or to treat a bowel obstruction.

Which are the most common operations?

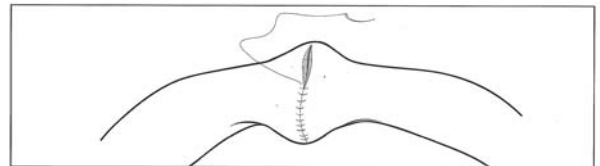
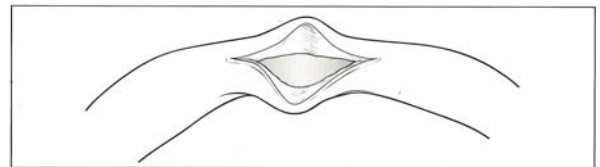
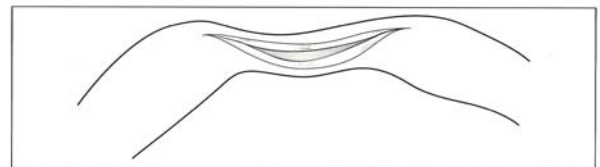
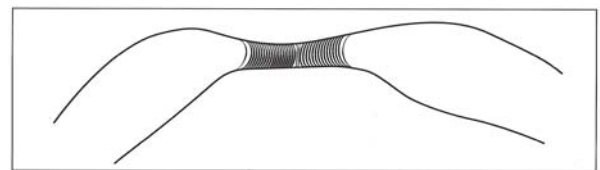
The operations most likely to be carried out for Crohn's Disease are described below.

- **Strictureplasty**

This is a way of treating strictures and blockages in the small intestine which avoids removing any gut.

The surgeon opens up the narrowed section of the intestine with a lengthwise cut, and then reshapes it by sewing it up the opposite way.

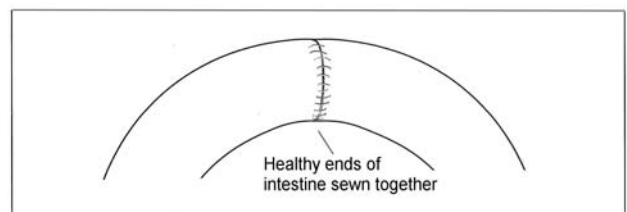
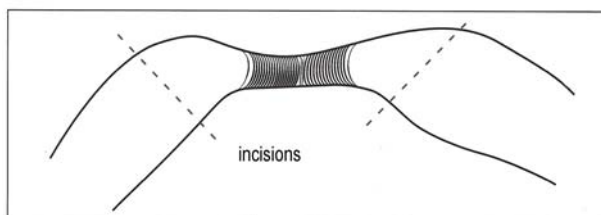
Food can then pass freely through the reshaped section.



Strictureplasty

- **Resection**

If the stricture is long, or there are several strictures close together, a resection may be preferable to a strictureplasty. In a resection the surgeon removes the damaged and diseased part of the gut, and then sews (or staples) together the ends of the remaining healthy sections. This join is called an anastomosis.

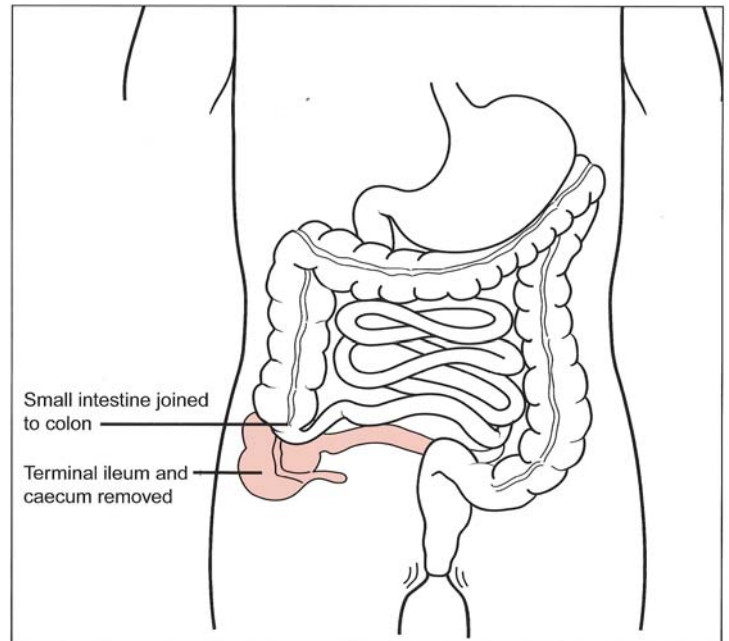


Resection

- **Ileo-caecal resection**

It is fairly common for Crohn's Disease to affect both the terminal ileum (the last part of the small intestine) and the caecum (see the diagram below). If the inflammation is severe and persistent, then it may be necessary to remove that part of the intestine. The healthy end of the small intestine is then joined directly to the large intestine (colon). This operation is known as an ileo-caecal resection (or an ileal caeectomy).

Ileo-caecal resection

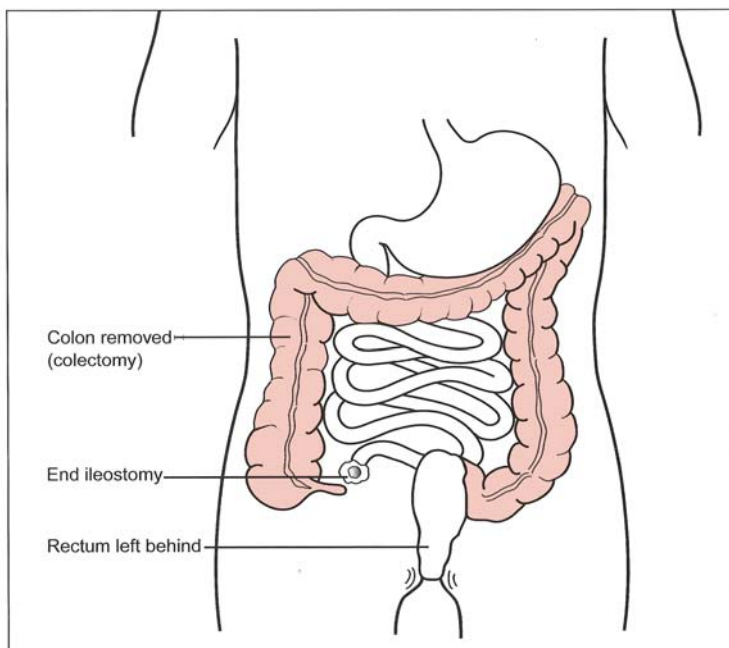


- **Limited right hemicolectomy**

If the first part of the ascending colon (the right side of the colon, on the left in the diagram above) is also affected, the surgeon may remove this as well, before joining up the rest of the colon. This is a limited right hemicolectomy.

- **Colectomy with ileostomy**

For those with severe Crohn's Disease in the large intestine or colon, it may sometimes be necessary to remove most or all of the colon. This operation is called a colectomy.

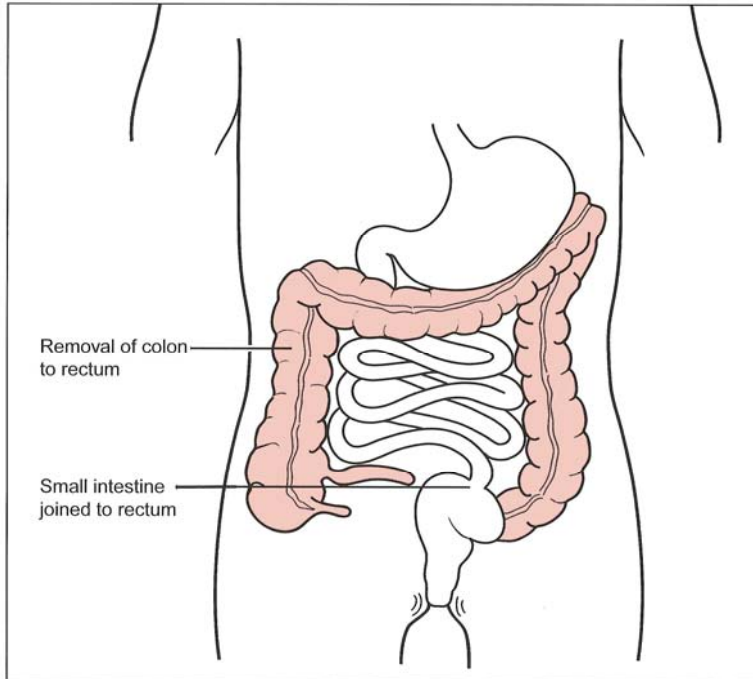


The surgeon then brings the end of the small intestine out through an opening in the wall of the abdomen. This is an ileostomy or stoma. An external bag is fitted onto the opening to collect the waste. This can be emptied or changed as necessary. (See below for more details on stomas).

Colectomy with ileostomy

- **Colectomy with ileo-rectal anastomosis**

Sometimes when the rectum has remained healthy it may be possible to have a colectomy with ileo-rectal anastomosis. In this the colon is removed but, instead of creating an ileostomy, the surgeon joins the end of the ileum (small intestine) directly to the rectum. This operation is not advisable if the rectum is severely inflamed or scarred, or if the anal muscles have been damaged. Without a colon the faeces tend to be very liquid and people with this type of anastomosis may need to empty their bowels several times a day.

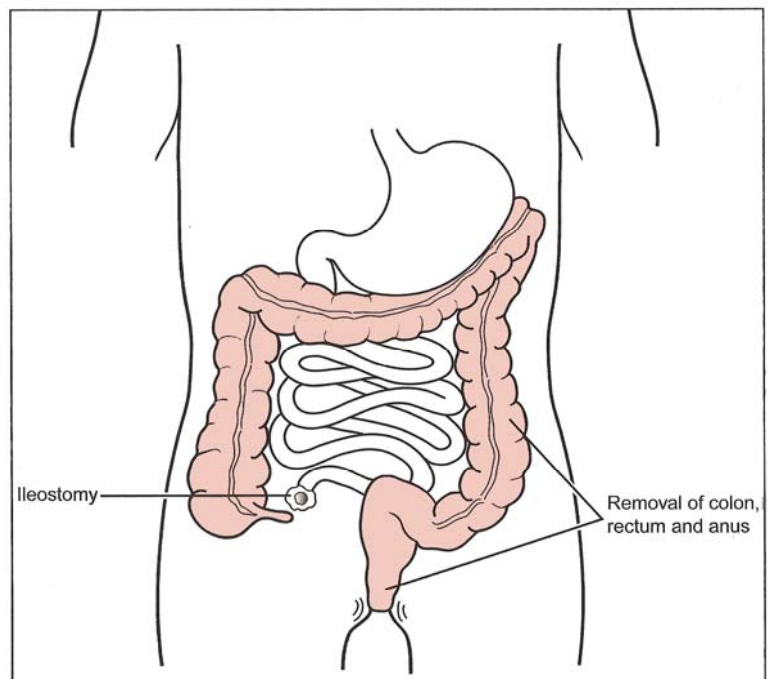


Colectomy with ileo-rectal anastomosis

- **Proctocolectomy and ileostomy**

If the rectum is also affected by the inflammation it may have to be removed along with the colon and the anal canal, in an operation known as a proctocolectomy.

The surgeon will then create an ileostomy in the same way as for a colectomy.



Proctocolectomy with ileostomy

- **Surgery for abscesses and fistulas**

Abscesses may need to be lanced (opened surgically) and drained. Fistulas linking a diseased part of the small intestine with the colon are usually removed with a resection. Some perianal fistulas can be managed with an operation known as a fistulotomy, in which the fistula is opened and cleaned and left to heal up gradually. Another operation that may help a fistula to heal is the insertion of a Seton Stitch. For more information on these see our information sheet, *Living with a Fistula*.

Laparoscopy

Some of the operations outlined above, for example ileo-caecal resections, 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:

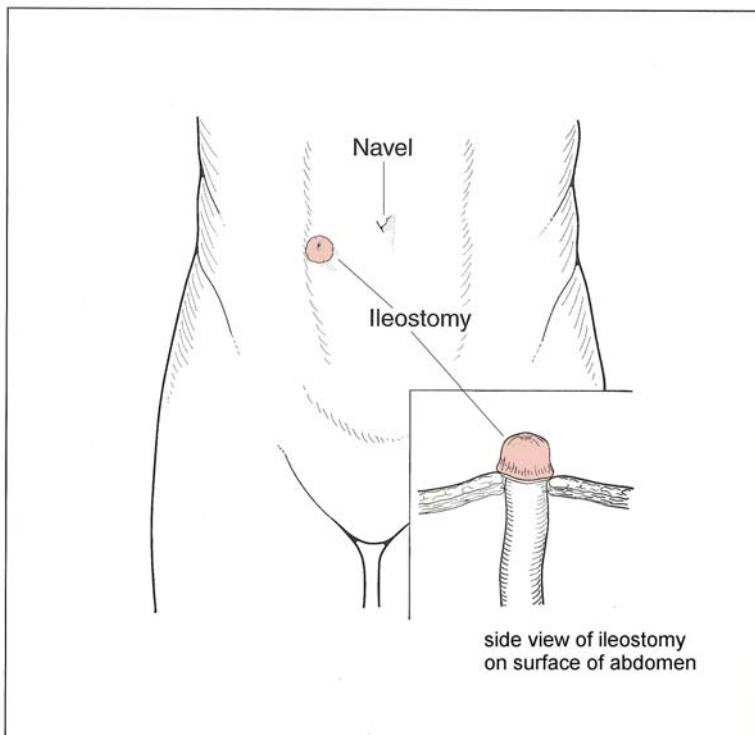
- less pain after the operation
- smaller scars
- faster recovery for example, being able to eat and drink more quickly after the operation
- reduced risk of a wound infection
- a shorter stay in hospital.

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

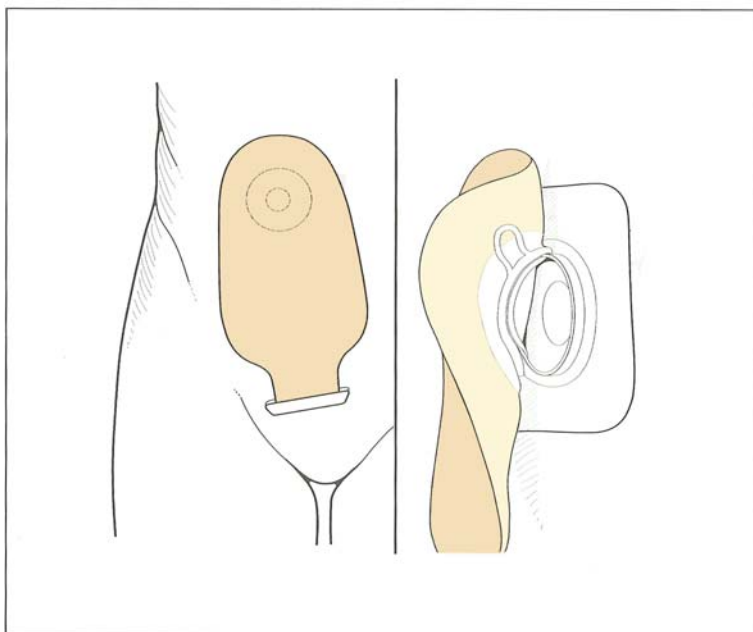
Stomas

As described above, sometimes in surgery for Crohn's 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, 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 stool, so colostomy bags are usually emptied slightly less frequently, (about one to three times a day), and may need to be changed each time.



An ileostomy showing the stoma opening



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

Are there risks to surgery?

Crohn’s Disease 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 Crohn’s, like all surgery, will carry some general risks, such as 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) leaks or the small bowel becomes obstructed. 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.

Your surgical team will be able to tell you more about complications like these, and how they are usually treated.

Because Crohn's Disease can develop anywhere in the gut, including in previously healthy sections of the small intestine or colon, surgery cannot 'cure' it. So, there is always a chance that symptoms will reoccur after the operation, either close to the operation site or in another part of the gut. It may be possible to treat these symptoms with medication, but it could mean that another operation is necessary. There is some research to show that about half of those who have an ileo-colonic resection need another operation within 10 years. However, recent studies have suggested that the newer biological medical therapies may help to prevent Crohn's recurring following surgery.

What are the advantages of surgery?

Depending on the operation, surgery can bring real benefits such as:

- relief from pain
- relief from symptoms such as diarrhoea or vomiting
- being able to reduce or even stop taking drugs which may be causing side effects
- the ability to eat a more varied diet and to gain weight more easily
- feeling able to lead a fuller life, for example being able to leave the house in a more relaxed frame of mind.

Many people have found that once they have recovered from their operation their quality of life is much improved. In one study looking at resection surgery from the patient's point of view a majority of those interviewed said they wish they had had their operation earlier.

What can I expect to happen before the operation?

If the surgery is planned or elective, 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. Smoking has been shown to be one factor that increases the risk of needing surgery again.

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 Crohn's 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 the likely benefits and side-effects are. Your surgeon is also likely to explain to you 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 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.
- 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.
- In some cases 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. In other cases, you will not need a laxative but may be asked to have an enema to empty the last part of the bowel.
- You will usually be given a pair of white 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 regained consciousness you will be returned to the 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. 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. This is to help get your circulation moving. A physiotherapist may visit you to show you some simple leg and chest exercises.

Also depending on the type of surgery performed, some people are allowed to start drinking water within 12 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 type of operation and also from individual to individual. Most people stay in hospital for between one and two weeks. The average stay is about 7 – 10 days after the operation, although you may be allowed to go home earlier, and have any stitches or clips taken out at home. In general, hospital stays for elective or 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 pain from your Crohn's, 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 on not only the type of operation you have had, but also 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 colostomy or ileostomy and 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. You may also find patient associations like the Ileostomy and Internal Pouch Support Group, or the Colostomy Association helpful. (See Useful Organisations below.)

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, 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 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, following a resection you may expect to be off work for about four-six weeks; after an ileostomy, for about two months.

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 recovery, and is particularly important if you have had sections of your small intestine removed. Some people with Crohn's have difficulty in absorbing fat from their food, especially after resections, and if you have had your terminal ileum removed you may need to have vitamin B12 injections. People with a stoma do not generally need a special diet, although it can help to take extra fluids and salt, and you may 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 Crohn's Disease.

- **Sex and Pregnancy**

Most people are able to resume sexual activity after surgery for Crohn's Disease, 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 no reason for women not to consider pregnancy after having surgery for Crohn's, although if you have a stoma a caesarean section may be recommended.

- **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 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, which is 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)

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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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.