



INFORMATION SHEET

SURGERY FOR CROHN'S DISEASE

INTRODUCTION

This information sheet is about the types of surgery that may be recommended 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**, 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 can be helpful to know about the gastrointestinal (digestive) 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.

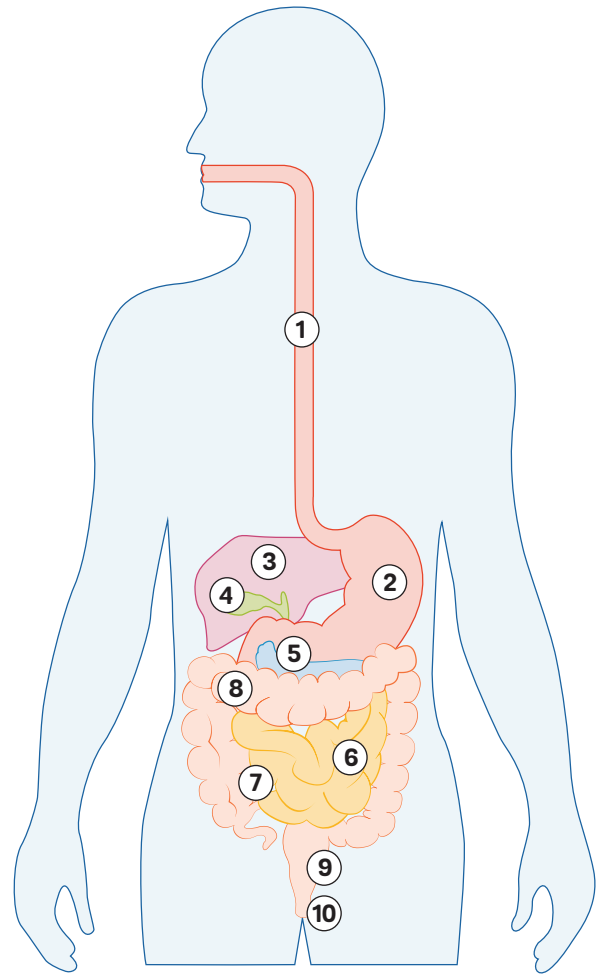
The partly digested food then moves from the stomach into the small intestine (also known as the small bowel). This has three sections: the duodenum, jejunum and ileum. Here the food is broken down even further so that nutrients can be absorbed into the bloodstream through the wall of the intestine.

The waste products from this process, which include liquid and undigested parts of food, are then pushed from the ileum into the colon (also known as the large intestine or large bowel).

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 END OF ILEUM
- 8 LARGE INTESTINE (COLON)
- 9 RECTUM
- 10 ANUS



HOW DOES CROHN'S DISEASE AFFECT THE GUT?

Crohn's Disease causes ulceration and inflammation that can affect the body's ability to digest and process food as described above. Crohn's can develop in 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 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 the severity of the symptoms. Treatment may be medical (with drugs and nutrition) or surgical, or a combination of both. For some children, and in rare cases for adults, nutritional therapy (using an exclusive liquid diet to treat or reduce inflammation) can be a useful treatment option.

WHEN IS SURGERY NECESSARY?

Recent 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 managed. For example, extensive resections (removal of diseased sections of the intestine) are now less common. However, surgery remains an important treatment option, often in combination with medical therapies. It is estimated that up to eight out of 10 people with Crohn's will need surgery at some point in their lives.

Some of the most common reasons for surgery are:

- **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 damaged sections of intestine.
- **Strictures in the intestine**
The inflammation from Crohn's may cause scarring which can lead to a stricture (a narrowing of 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 before treatment can continue.
- **Abscesses or fistulas**
Sometimes the inflammation spreads through the bowel wall and forms an abscess, a collection of pus, which can cause pain, fever and a general sense of feeling unwell. As the abscess develops it may 'hollow out' a chamber or hole. This can become 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 one in four people with Crohn's develop fistulas. While symptoms can be very distressing, surgery can be used to treat both abscesses and fistulas. For more information on fistulas, see our information sheet, **Living With a Fistula**.
- **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 of the large bowel**
Crohn's Disease is not a form of cancer. However, if a person has had severe Crohn's Disease affecting all or most of the colon for at least 8-10 years, there is a slightly increased risk of 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 detect precancerous changes in the bowel, which if found may require surgery. For more details see our information sheet **Bowel Cancer and IBD**.
- **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.

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I try not to worry about every twinge or loose motion, but I do think it's important to talk to your GP or IBD team if you are experiencing a symptom which isn't usual for you. I went to my GP with what I thought was a urine infection – he picked up that it was actually an abscess on my tummy wall, so I was relieved I had made an appointment to check as I knew something wasn't right.

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Carol, age 52

diagnosed with Crohn's Disease in 2012

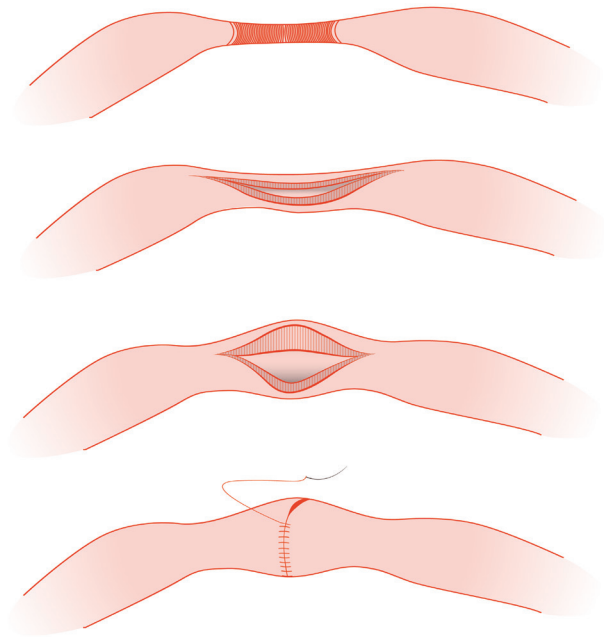
WHICH ARE THE MOST COMMON OPERATIONS?

The operations most likely to be carried out for Crohn's Disease are:

- **Strictureplasty**

(Also known as Stricturoplasty)

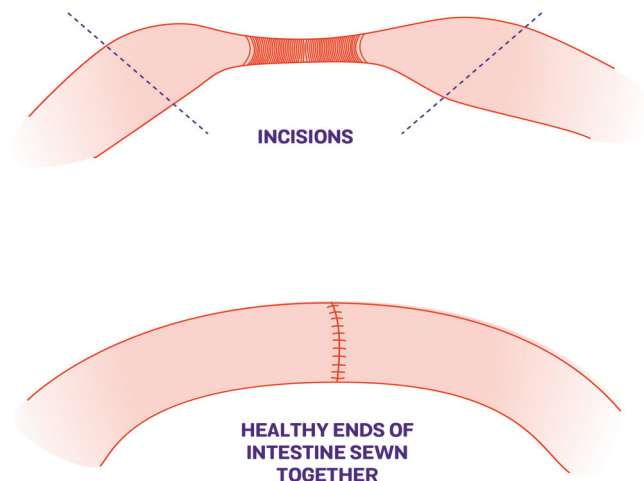
This is a way to treat strictures and blockages in the small intestine without having to remove any gut. The surgeon opens up the narrowed section of the intestine with a lengthwise cut, and then reshapes it by closing it up the opposite way. Food can then pass freely through the reshaped section of the intestine.



For very short strictures that are accessible by colonoscopy, it may be possible to have an endoscopic balloon dilation. In this procedure, an endoscope with a balloon attached is used to widen the narrowed part of the intestine.

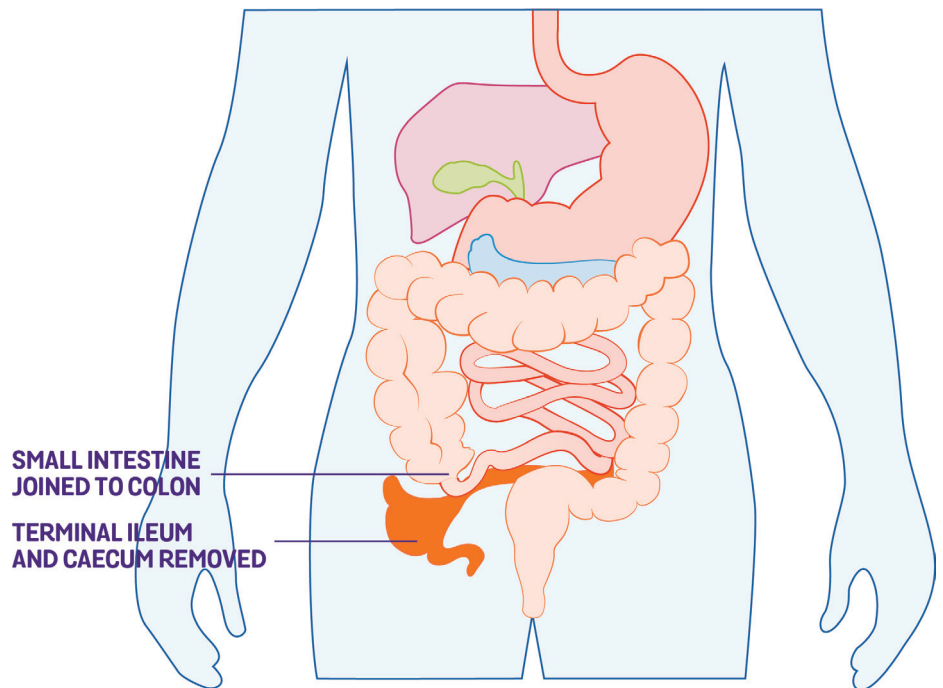
- **Resection**

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 part of the gut, and then joins together the ends of the remaining healthy sections. This join is called an anastomosis.



- **Ileocaecal 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 (the first part of the large intestine). If the inflammation is severe and persistent, then it may be necessary to remove this section. The healthy end of the small intestine is then joined directly to the colon (large intestine). This operation is known as an ileocaecal resection, or an ileocaecectomy.

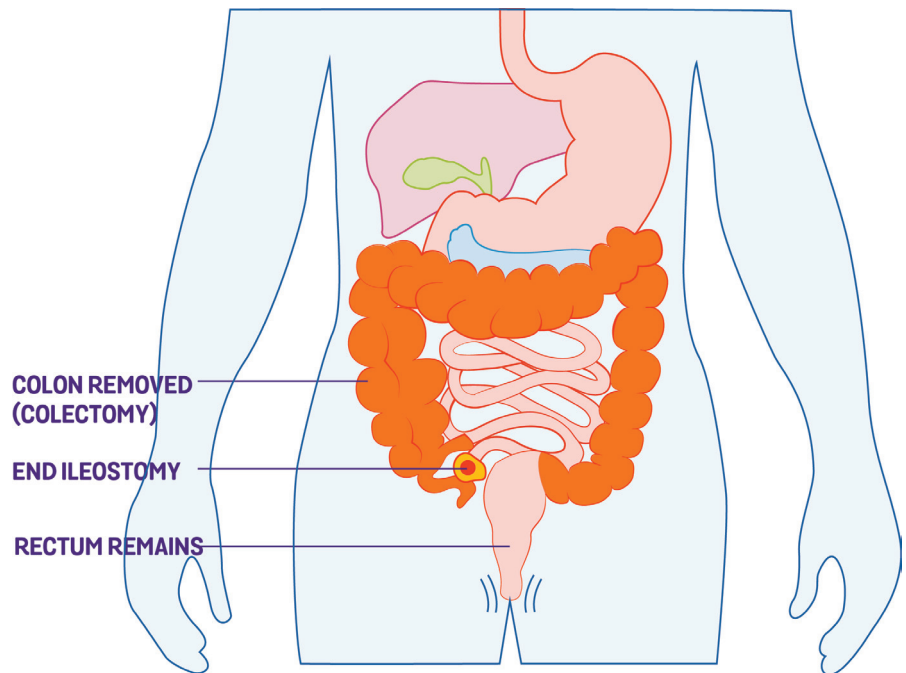


- **Limited right hemicolectomy**

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

- **Colectomy with ileostomy**

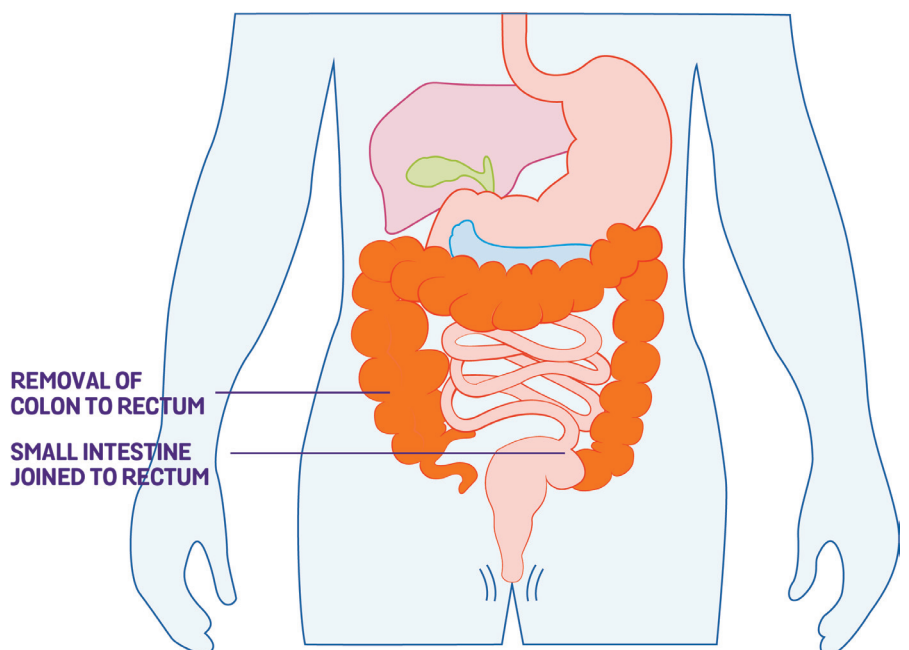
For those with severe Crohn's Disease in the large intestine or colon, it may sometimes be necessary to remove most or all of the colon (a colectomy).



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. A bag is fitted onto the opening to collect waste. See below for more details on stomas.

- **Colectomy with ileo-rectal anastomosis**

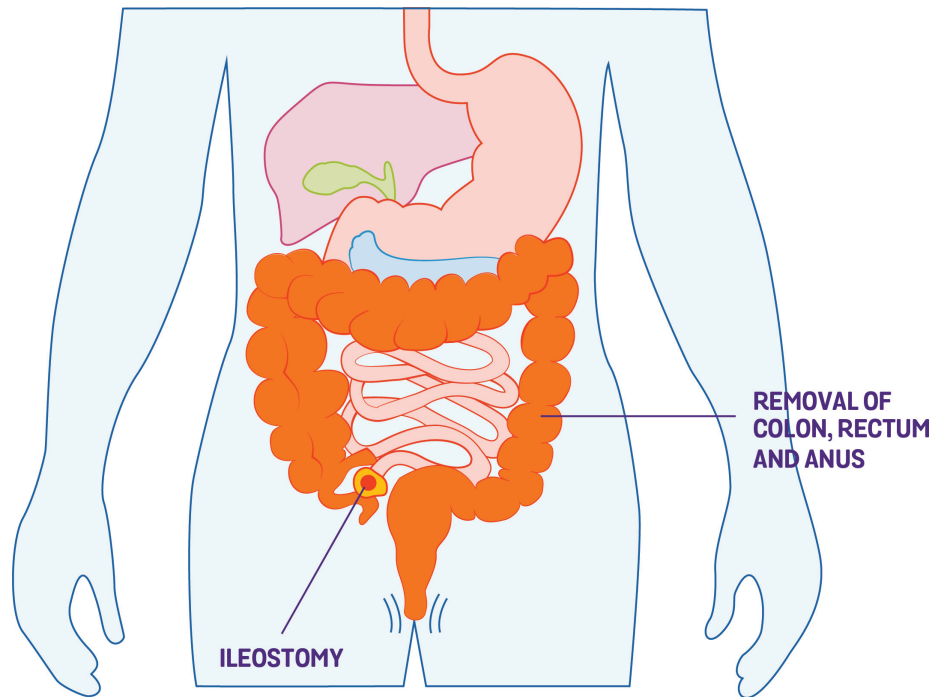
Sometimes when the rectum has remained healthy it may be possible to have a colectomy with ileo-rectal anastomosis. In this operation the colon is removed, but instead of creating an ileostomy, the surgeon joins the end of the ileum (small intestine) to the rectum. This operation is not advisable if 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 more frequently.



- **Proctocolectomy and ileostomy**

If the rectum is also affected by 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. This form of surgery is irreversible, but means that you no longer have a colon to become inflamed or develop bowel cancer.



- **Surgery for abscesses and fistulas**

Abscesses may need to be opened surgically and drained. Fistulas linking a diseased part of the small intestine with the colon usually require the affected bit of bowel to be removed with a resection. However, it is not normally possible to resect fistulas that develop near the anus (perianal fistulas). These are usually managed by draining any infection under general anaesthetic, and inserting a thread into the fistula called a seton. The seton helps drain away pus and allows infected tissue to heal while medications take effect. Fistulas sometimes require more than one operation. For more details see our information sheet **Living With a Fistula**.

LAPAROSCOPY

Many of the above operations 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 an incision 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 an incision 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 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.

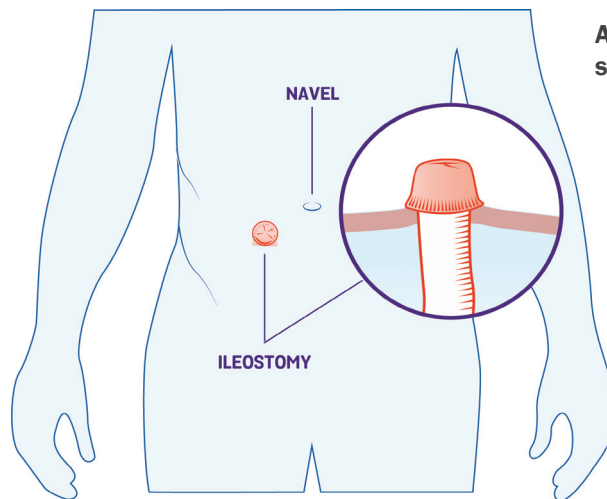
Laparoscopic surgery may not be available in all centres, and may not be appropriate if you have already had abdominal surgery.

STOMAS

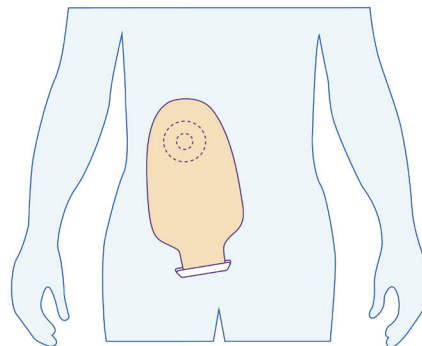
As described above, sometimes in surgery for Crohn's the intestine is brought to the surface of the abdomen, and an opening is made so that digestive waste (liquid or faeces) drain into a bag rather than through the anus. If the part of the intestine brought to the surface is the ileum, this is known 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 two to five times 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.

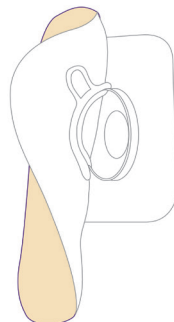
Our information sheet **Living With a Stoma** has more details about different types of ostomies, and how to manage them in your everyday life.



An ileostomy showing the stoma opening



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



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

ARE THERE RISKS ASSOCIATED WITH 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. 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?

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

- relief from pain
- lessening of symptoms such as diarrhoea, vomiting and fatigue
- 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

Getting used to having a stoma or a pouch will take time, and for some, can be a challenge. However, many people have found that once they have recovered from their operation their quality of life is much improved. For example, people find they are able to leave the house in a more relaxed frame of mind and their IBD symptoms are not as troublesome. In one study looking at resection surgery from the patient's point of view, the majority said they wished they had had their operation earlier.

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After surgery I began a different combination of drug treatments, including a biologic treatment, and have now been in remission for two and a half years! I feel like myself again and am able to live my life to the full.

”

Glenda, age 35
diagnosed with Crohn's Disease in 2012

COULD THE CROHN'S COME BACK AFTER SURGERY?

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, it is possible that Crohn's 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, and there is growing evidence that biological therapies may be particularly effective in helping to treat postoperative Crohn's, and reduce the likelihood of future surgeries.

However, despite advances in medical therapy, further operations may be necessary. Research suggests that about half of those who have an ileocolonic resection will need another operation within 10 years. Smoking has been shown to be one factor that increases the risk of needing repeat surgery.

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 Crohn's 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, though 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 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 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 care after the operation.
- In some cases 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. 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 are allowed to start drinking water within 12 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 at least 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 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, the surgery should have helped to reduce your Crohn's symptoms, and you should begin to feel a lot better than before the operation.

Most people are advised not to do any heavy lifting or housework like 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 programme 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 your 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 on not 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 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 difficulty 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. 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 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 can take four to twelve weeks before 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 a low-fibre diet to make it easier for you to digest food. Once you have recovered from the surgery you may find that you can 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. If you have had your terminal ileum removed you may need to have vitamin B12 injections.

Initially you may be at an increased risk of dehydration if you have an ileostomy, as the large intestine plays an important role in helping absorb water from food waste. You may find it helps to take extra fluids, including 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 problem for people with an ileostomy, while if you have a colostomy you may need to eat more fibre to prevent constipation. 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 Crohn's Disease.

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While I try to limit strenuous physical activity, I try not to let the fact I had surgery interfere in what I enjoy doing, for instance travelling.

”

Jake, age 22
diagnosed with Crohn's Disease in 2007

- **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, 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 no reason for women not to consider pregnancy after having surgery for Crohn's, although in some cases, a caesarean section may be recommended. Couples who may want to have children after surgery for Crohn's Disease should discuss this with their consultant. 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 before and after their operation. You may feel anxiety, fear, doubt, acceptance, relief, confidence, a sense of wellbeing and perhaps 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. IBD and stoma care 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 and 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.

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