CROHN'S & COLITIS UK

CROHN'S? COLITIS? WE'LL FACE IT TOGETHER.

# SURGERY FOR CROHN'S DISEASE

Medicines are an important treatment for Crohn's Disease, but surgery can also help. Having surgery can feel like a big step. But you're not alone. We're here to help you understand your options and make an informed choice about your care. This information is for anyone who is thinking about having surgery. It's also for anyone who has been advised to have surgery by their healthcare professional. It covers:

- Why you might be offered surgery
- The risks and benefits of surgery
- The different types of surgery used to treat Crohn's
- What to expect when preparing for and after having surgery

This information is for people in the UK. It should not replace advice from your IBD team.

## CONTENTS

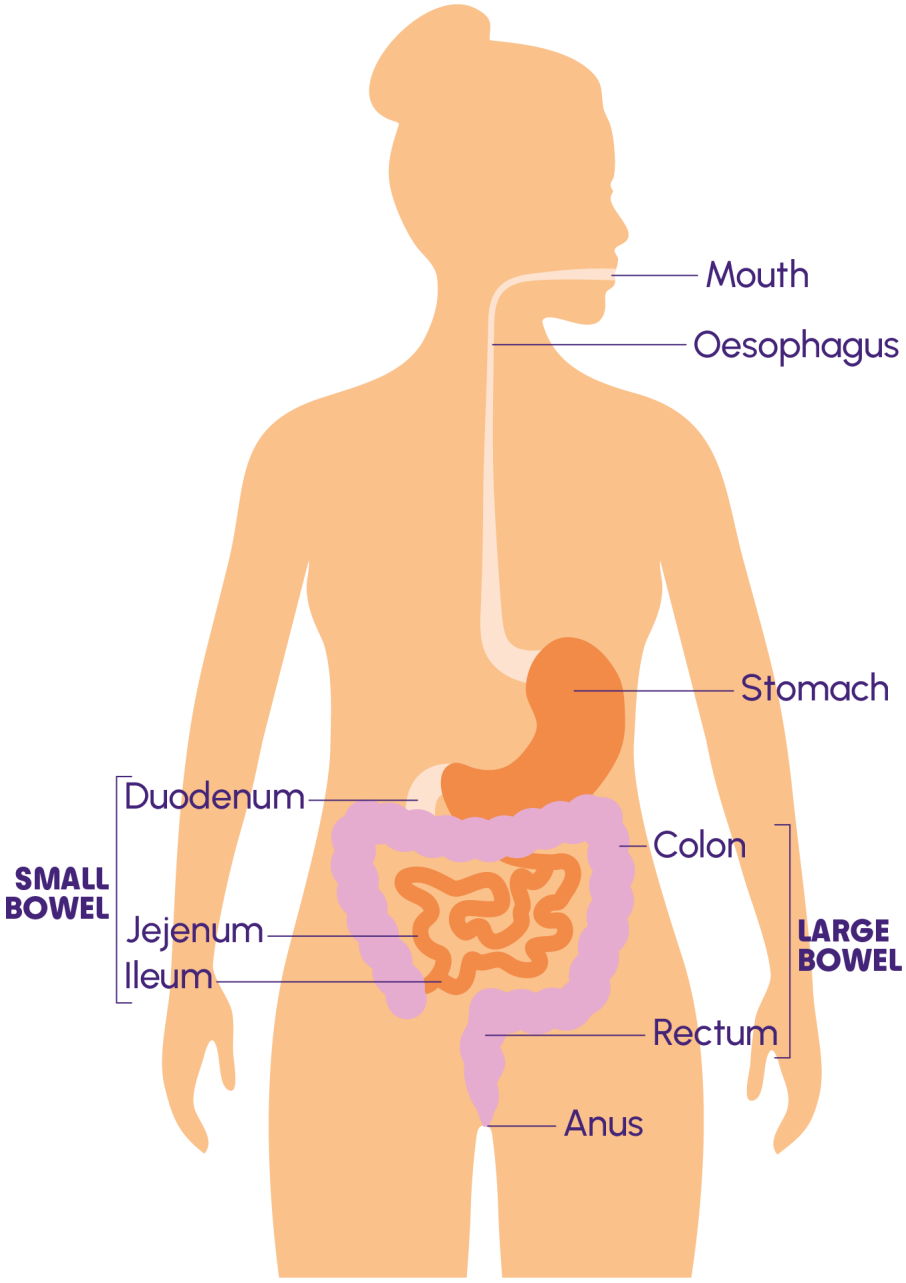
## KEY FACTS ABOUT SURGERY FOR CROHN'S DISEASE

- Fewer people with Crohn's need surgery than 20 years ago.
- Around 1 in 5 people with Crohn's will need surgery in the first 5 years after diagnosis.
- You may be offered surgery if medicines are not controlling your symptoms, or if you have severe complications.
- Surgery is an effective treatment option for many people.
- Many of the common surgeries for Crohn's can be done by keyhole surgery, also called laparoscopy. There are many benefits to keyhole surgery, including a faster recovery.
- Common types of surgery for people with Crohn's are strictureplasty, bowel resection with or without a stoma, and surgery for abscesses and fistulas.

## THE GUT AND CROHN'S

The gut is the part of your body that takes in food and nutrients and carries poo out. The gut starts at your mouth, where you eat, and ends at your bottom, also called your anus. This is where poo passes out of your body.



## The bowel

The bowel is the largest part of the gut and is made up of 2 sections:

- The small bowel, also known as the small intestine
- The large bowel, also known as the large intestine

The small bowel is made up of 3 parts:

- The duodenum
- The jejunum
- The ileum

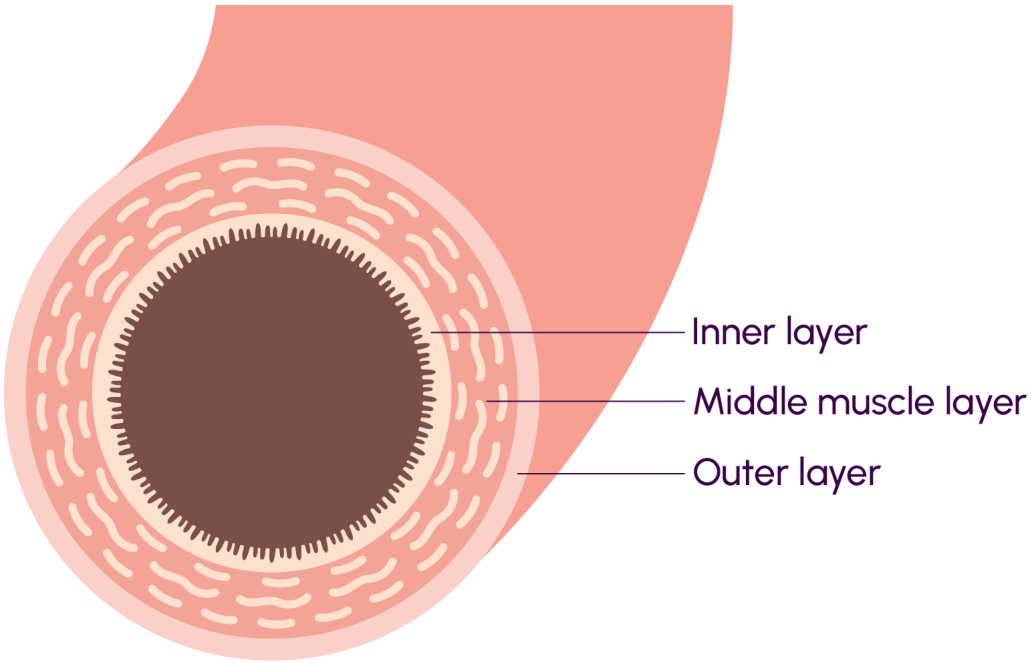
The small bowel helps to break down food and take in nutrients.

The large bowel is made up of the colon and rectum. The first part of the colon is called the caecum. The caecum joins to the end of the small bowel, known as the ileum. At the end of the large bowel is the bottom, also called the anus. The large bowel absorbs water and removes toxins and waste products from our body. As water is absorbed, the broken-down food turns into solid poo. When the bowel is healthy, the poo drops into the rectum, and you feel the urge to go to the toilet. The poo then passes out through the bottom.

## The bowel wall

The walls of your bowel have layers. The inner layers take in nutrients from food, and the outer layers help move food through the gut and poo out of the body.




## How Crohn's affects the gut

Crohn's Disease is an Inflammatory Bowel Disease (IBD), which causes your immune system to start attacking your gut. Crohn's causes painful ulcers and inflammation in the gut. It can be found anywhere in the gut, from your mouth all the way down to your bottom. This inflammation can cause watery poo, also known as **diarrhoea**. It can also make you need to poo more often and reach the toilet quickly, known as urgency. If your body cannot take in nutrients properly, you may lose weight. You may also feel extreme tiredness, known as **fatigue**. You may also have poor nutrition, called malnutrition.

While Crohn's can be found at any point in your gut, it will not be everywhere. It is most common in the small bowel and colon. Areas of inflammation are often patchy,

with sections of healthy gut in between. A patch of inflammation may be small, only a few centimetres across. Or the inflammation can extend quite a distance along part of the gut.

## Narrowing of the gut, or stricture

Ongoing inflammation in the gut wall can cause scar tissue to form. This can create a narrow section of the gut called a stricture. This is more common in the small bowel. Strictures can also be caused by severe inflammation alone. They can also be caused by a combination of scar tissue and severe inflammation. A stricture can make it difficult for food to pass through and, if it's very narrow, cause a blockage.

## Fistulas and abscesses

If the inflammation goes through the middle and outer layers of the bowel wall, an abscess or fistula may develop.

An abscess is a painful collection of pus. An abscess is usually caused by a bacterial infection. In people with Crohn's, abscesses may form in the tummy or around the bottom. If they are inside the tummy, they can be harder to diagnose because the symptoms may not be as obvious. Abscesses can lead to fistulas.

A fistula is when a small tunnel develops that connects an organ to another part of your body. In Crohn's, these tunnels can connect the bowel to another internal organ, such as the vagina or bladder, or to the outside of the body through the skin. See our information on fistulas for more details.

"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."

**CAROL**
**LIVING WITH CROHN'S**

## Hole in the bowel, or perforation

If there is severe inflammation, or a blockage, this may lead to a tear in the bowel, making a hole in the bowel wall. This is called a perforation. The contents of the bowel can then leak through. In some cases, the leak may form an abscess.

**A perforation is a medical emergency. You need to see your doctor or go to your nearest accident and emergency (A&E) department. Symptoms include:**

- Severe pain in the tummy area
- A high temperature
- Feeling sick, also known as nausea
- Being sick

## NUMBER OF PEOPLE WITH CROHN'S HAVING SURGERY

Fewer people with Crohn's need surgery than they did 20 years ago. There are many possible reasons for this, such as increasing use of **biologic medicines** and new tests which can help earlier diagnosis.

Around 1 in 5 people with Crohn's will need major surgery to remove part of their bowel in the first 5 years after diagnosis.

Your individual risk of needing surgery at some point will depend on many factors. If you do need surgery, you are not alone. We are here to **support you**.

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## WHEN SURGERY IS CONSIDERED

Many people think surgery is the last option, but that is not true. Surgery is offered when your healthcare professionals think it will help your symptoms. Some people may be offered both medicines and surgery. See our **information on treatments** to find out more about medicines for Crohn's.

Your Crohn's may affect one place in your gut or many places. This will affect your symptoms and what type of surgery you are offered. You can find out about the different types of Crohn's in our **Crohn's information**. Some of the most common reasons for surgery are:

### Your choice

You may be given the option to continue taking medicines or to have surgery. Some people choose to have surgery rather than trying to manage unpleasant side effects of medicines. For some types of Crohn's, surgery can have similar results to medicines. If you have a type of Crohn's called ileocaecal Crohn's, you may be offered either medicines or surgery. Your surgeon should give you the information to help you make a decision. This is called shared decision making and is an important part of your care.

## If medicines are not working for you

If medicines are not suitable or are not working well for you, your doctor may suggest surgery to help control your symptoms.

## Strictures

Sometimes strictures can be treated with medicines, or **balloon dilatation during endoscopy**. But if these are not suitable, surgery can help. Blockages due to strictures are a common reason for surgery in the small bowel.

## Abscesses or fistulas

If small, abscesses can sometimes be treated using medicines alone. Other abscesses may need drainage. If they cannot be fully treated with medicines or drainage, then surgery may help. If you have a fistula you may benefit from surgery. See our information on **fistulas**

## Slow growth in children and teenagers

For children and teenagers, being poorly and unable to get enough nutrients from food can affect their growth and development. Taking steroids can slow growth even further. Most children and teenagers with Crohn's will be treated with medicines. But sometimes surgery may be needed to help with growth or development.

## Higher risk of bowel cancer

Crohn's is not cancer. But people with Crohn's that affects much or all of their colon have a higher risk of getting bowel cancer. Even with this greater risk, the overall risk of getting bowel cancer is still low.

You'll be offered a colonoscopy about 8 years after your Crohn's symptoms started. A colonoscopy is a camera test to look closely at the lining of your bowel. It's used to check for early changes in the colon before cancer develops. This is known as a

surveillance colonoscopy. If bowel cancer is found, you may need surgery. See our information on **risk of bowel cancer**.

### Severe complications

Sometimes Crohn's can cause complications that may need emergency surgery. These complications include:

- Severe bleeding from the gut.
- A hole or tear in the gut, known as a perforation.
- Toxic megacolon. This is when the colon becomes severely inflamed and enlarged, and is at risk of tearing.
- A blockage in part of your gut causing severe symptoms and risk of perforation.

### Who you'll see: your IBD team

**Not everyone's IBD team looks the same. But whoever you see, they're all working to help keep you as healthy as they can. You may already have a gastroenterologist, GP or IBD nurse involved in your care. If you're having surgery your IBD team may also include your:**

- Surgeon. They will carry out your bowel surgery.
- Anaesthetist. They will manage the anaesthetic and pain relief during your surgery.
- Stoma nurse. They will provide information and ongoing support if you have a stoma.
- Physiotherapist. They will help you with movement and exercise after the surgery.

> "It can be frightening to hear you may need surgery but it is important to understand that not everyone with IBD will require the same type of surgery. Just like everyone's IBD is different, the surgery you need will be unique to you, your IBD and your circumstances."
>
> **ZIYAD**
> **LIVING WITH CROHN'S**

## SURGERY AND FEELING BETTER

Surgery can help to ease Crohn's symptoms that are difficult to manage.

Easing your symptoms may mean you can do other things more easily. This could include seeing friends and family, going to work, or playing sports. It may mean you need to take fewer medicines and can avoid the side effects of many medicines. Surgery could give you more freedom to do what you want to do in life.

Let your surgical team know what is important to you, and how surgery may impact that.

## Life after surgery

The thought of having surgery, especially stoma surgery, can be scary. You may worry about how much your life may change, and it is likely to change. But studies show that most people find their life changes for the better after surgery.

In one study, looking at ileocaecal resection, almost 9 in 10 people said they would have the surgery again. In another study looking at stoma surgery, more than 7 in 10 people interviewed said their physical wellbeing had improved. And 6 in 10 said their mental wellbeing had improved. In this same study, 3 in 10 people wished their surgery had been offered sooner.

### Crohn's coming back after surgery

Symptoms of Crohn's can happen anywhere in the gut, including in previously healthy sections of the gut. Surgery cannot cure Crohn's. It's possible that Crohn's may come back after surgery, known as recurrence. This may be close to where the surgery was or in another part of the gut. This means it's possible you could have another flare-up at some point, even after having surgery.

The risk of Crohn's coming back after surgery is generally higher for:

- People who smoke
- People with fistulas or abscesses
- People with Crohn's around their bottom, known as perianal Crohn's
- People with Crohn's in the jejunum part of the small bowel
- People who have their first surgery at a young age

Medicines may be able to help symptoms and lower your risk of having another flare-up. If you have a high risk of Crohn's coming back, you may be advised to take medicines such as a **thiopurine** or an **anti-TNF** soon after surgery to lower this risk.

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## OTHER TREATMENT OPTIONS

Your treatment options will depend on you and the type and severity of your Crohn's. Medicines do not work for everyone, and some complications of Crohn's can be life-threatening without surgery. Speak to your IBD team and decide together which treatment options are best for you.

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## RISKS AND COMPLICATIONS OF SURGERY

Crohn's is different for everyone, and the risks and benefits of each treatment will vary from person to person. Having any type of surgery will carry some risks. These include a risk of:

- Infection.
- Having an allergic reaction to the anaesthetic.
- Having blood clots after surgery. This risk is higher in people with Crohn's. Your surgical team should assess your risk of blood clots before you have surgery and should put measures in place to lower this risk.

Some surgeries for Crohn's carry other risks. Your surgical team can tell you more about these complications, how common they are, and how they are usually treated. They include:

- Anastomotic leak. When 2 bits of bowel are joined together, they may not join properly, and this can lead to a leak.
- Bowel blockages, or obstructions. Having surgery can increase the risk of scar tissue, called adhesions, forming inside your tummy area. These can cause blockages in your bowel.

- Post operative ileus. Having surgery can temporarily disrupt movement of the bowel. This stops the usual movement of food, liquid and gas through the gut. Post operative ileus can happen after any surgery. But it is more common after surgery on your tummy. This is known as abdominal surgery.

**If you live with other conditions like diabetes or high blood pressure, your chance of complications may be higher. Ask your surgical team how this would affect your risk of complications.**

Your surgical team should go through your individual risk with you. They should tell you how to lower your risk of complications. For example, if you smoke, stopping smoking can help to lower your risk.

It's important to know what your risks are so you can make an informed decision about your treatment. Do not be afraid to ask your surgical team about your risks. See our **Appointment Guide** for tips on getting the most from your appointments.

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## RISKS OF NOT HAVING SURGERY

Your risk will depend on your own situation. The risks of delaying or not having surgery could include:

- Symptoms getting worse
- Having changes in the bowel that could lead to cancer
- Increased risk of side effects or complications from medicines
- Future operations may be more risky
- Increased chance of needing emergency surgery

Your surgical team can advise you on your personal risk factors. Speak to them about your risk and when the best time to have surgery is.

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## KEYHOLE SURGERY, LAPAROSCOPY OR MINIMALLY INVASIVE SURGERY

Keyhole surgery, also called laparoscopy, uses very small cuts and cameras to operate. This is instead of open surgery, where one larger cut in the tummy is made. Many of the common operations for Crohn's can use keyhole surgery. Keyhole surgery is done under general anaesthetic, which means you are fully asleep and cannot feel any pain.

In keyhole surgery, the surgeon makes 4 or 5 small cuts, each only about 1cm or half an inch long. In single-port laparoscopy only one cut is made, though this is slightly bigger.

A very small camera, a light and surgical tools are passed through the cuts. A harmless gas is used to inflate the tummy so the surgeon has more space to see and work on the bowel. If part of the bowel needs to be removed, this can be done through a larger cut.

Keyhole surgery takes longer than open surgery, but the benefits are:

- Less pain after the operation.
- Smaller scars.
- Faster recovery. For example, being able to eat and drink more quickly after the operation.
- Lower risk of a wound infection or a hernia. This type of hernia happens when bowel tissue pokes through the tummy wall in the area where your healed surgical scar is.
- A shorter stay in hospital.
- Better fertility outcomes.

Keyhole surgery may not be an option in all hospitals. It may also not be possible if you have had open surgery or major surgery on your tummy area before.

## OPEN ABDOMINAL SURGERY, OR LAPAROTOMY

Open surgery is also called laparotomy. It is the more traditional way of operating on the gut. The surgeon makes one larger cut in the tummy and can see inside without using cameras. This may be used in some emergency surgeries, where surgery needs to happen quickly. It may also be preferred if you have had surgery before. Open surgery is done under general anaesthetic, which means you are fully asleep and cannot feel any pain.

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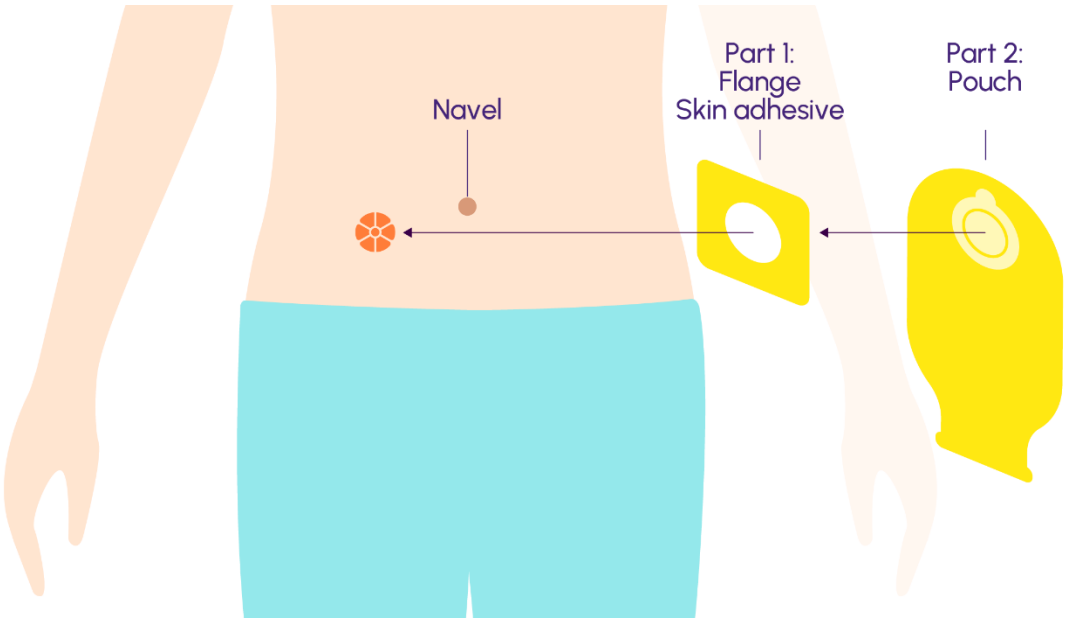
## STOMAS

**This is just a short summary on stomas. Our information on life with a stoma explains more about:**

- What a stoma is
- Different types of stoma
- How to look after your stoma
- How to manage common worries about stomas

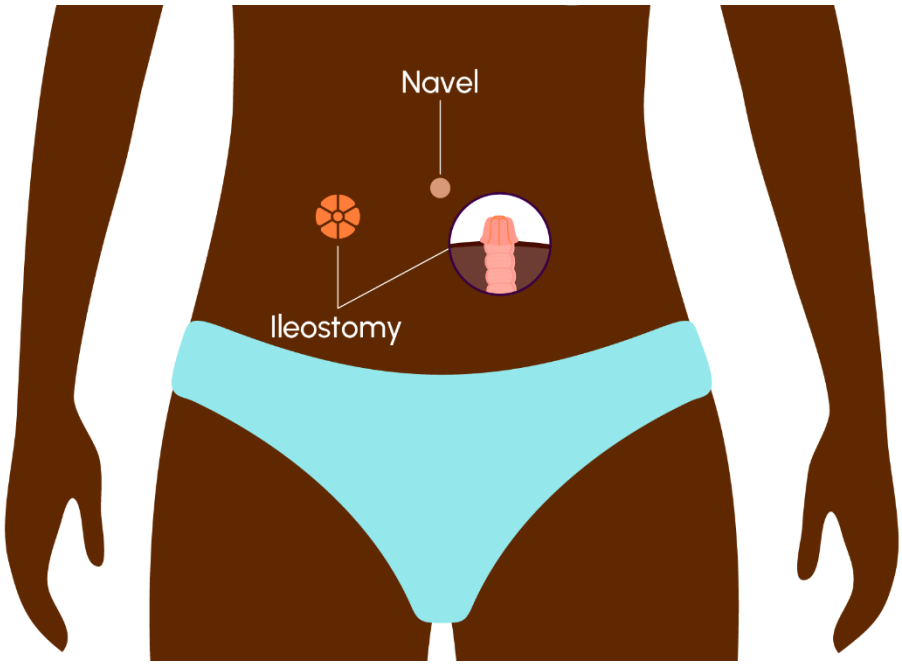
A stoma is an opening made by a surgeon on the wall of your tummy. It brings your bowel to the outside. The contents of your bowel, called your 'stoma output' empty straight into a bag. The bag is called a stoma bag. You can get different types of stoma bag in lots of shapes and sizes.

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




Stomas can be made from part of the small bowel called the ileum. These stomas are called an ileostomy. Or they can be made from part of the large bowel called the colon. These stomas are called a colostomy. Stomas can be permanent or temporary.

An ileostomy showing the stoma opening

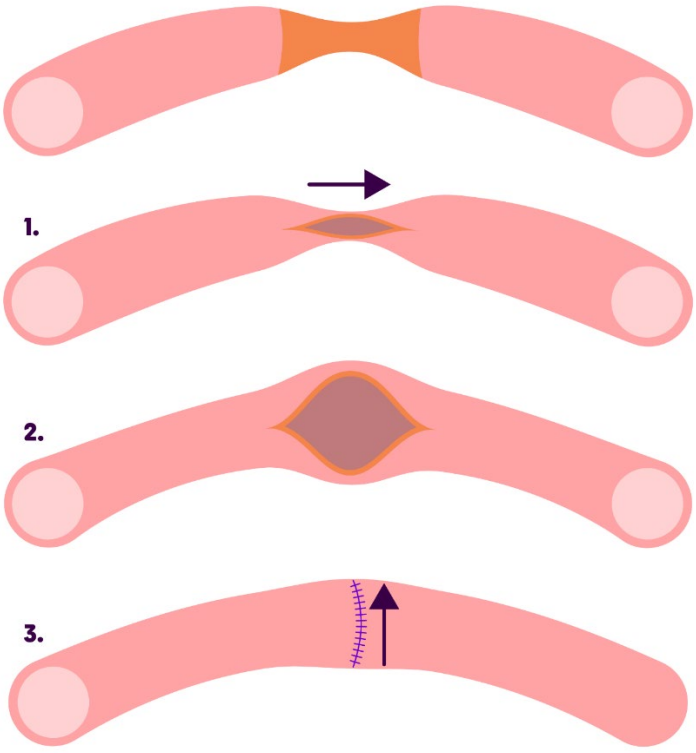


A stoma nurse should support you and give you practical help and information on living with a stoma.

## TYPES OF SURGERY

### Strictureplasty, or stricturoplasty

Strictureplasty is a way to repair strictures caused by scarring in the small bowel without having to remove any bowel. Strictures can cause blockages in the bowel. This is sometimes called bowel preserving surgery.




In a strictureplasty, the surgeon:

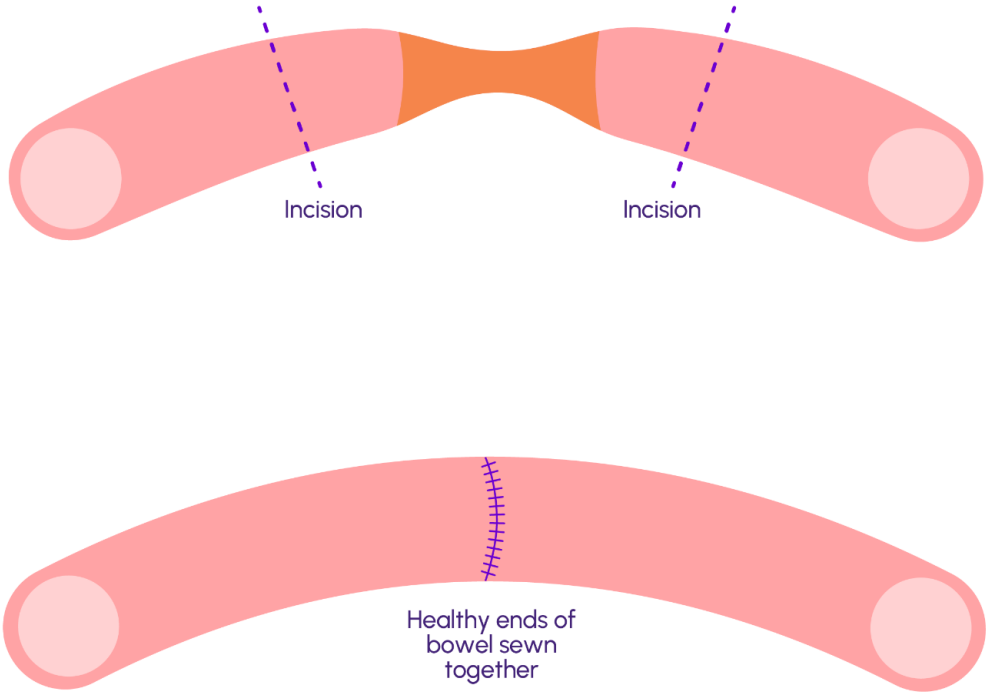
1. Cuts open the narrowed section of the bowel, the stricture, along the longest side of the bowel.
2. Opens the cut and reshapes it.
3. Sews the cut back together along the opposite way it was cut open. This makes the narrowed section wider.

There are other more complicated ways the surgeon can sew the bowel back together. Ask your surgeon what type of strictureplasty they plan to use.

## Resection

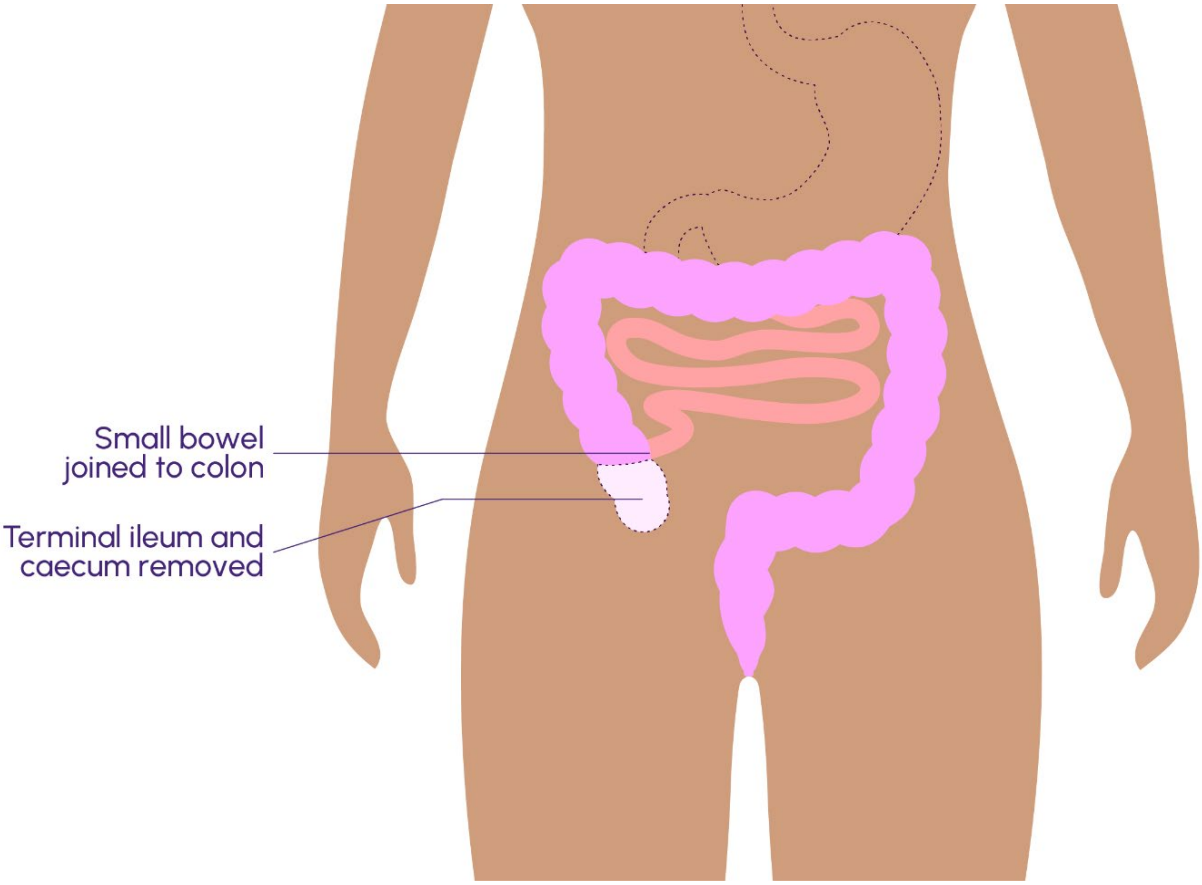
Resection means taking part of the gut out. This is a common type of surgery in people with Crohn's. A resection can be helpful for people who have long strictures, or lots of strictures close together.

In a resection, the surgeon removes the damaged part of the gut. They then join the healthy sections of bowel back together. This join is called an anastomosis. Resections are sometimes used for fistulas and abscesses in the small bowel.



## Ileocaecal resection, or ileocaecectomy

Ileocaecal resection is also known as an ileocaecectomy. It is when the ileocaecal part of the bowel is removed. The ileocaecal part is where the end of the small bowel, called the terminal ileum, meets the start of the large bowel, called the caecum. Crohn's commonly affects this section of the gut. Ileocaecal resection may be offered if you have severe inflammation or a stricture in this area. The healthy end of the small bowel is then joined directly to the large bowel.




## Segmental colectomy

If your Crohn's is only affecting a small part of your colon, you may be offered a segmental colectomy. This means taking out just a small section of the colon. The 2 healthy ends of the colon are then joined together.

## Right hemicolectomy

Right hemicolectomy is when the first half of the colon is removed. The surgeon also removes the appendix and a very small part of the small bowel. The small bowel is then joined up to the remaining half of the colon. You may be offered this if you have inflammation or a blockage in the first part of the colon.

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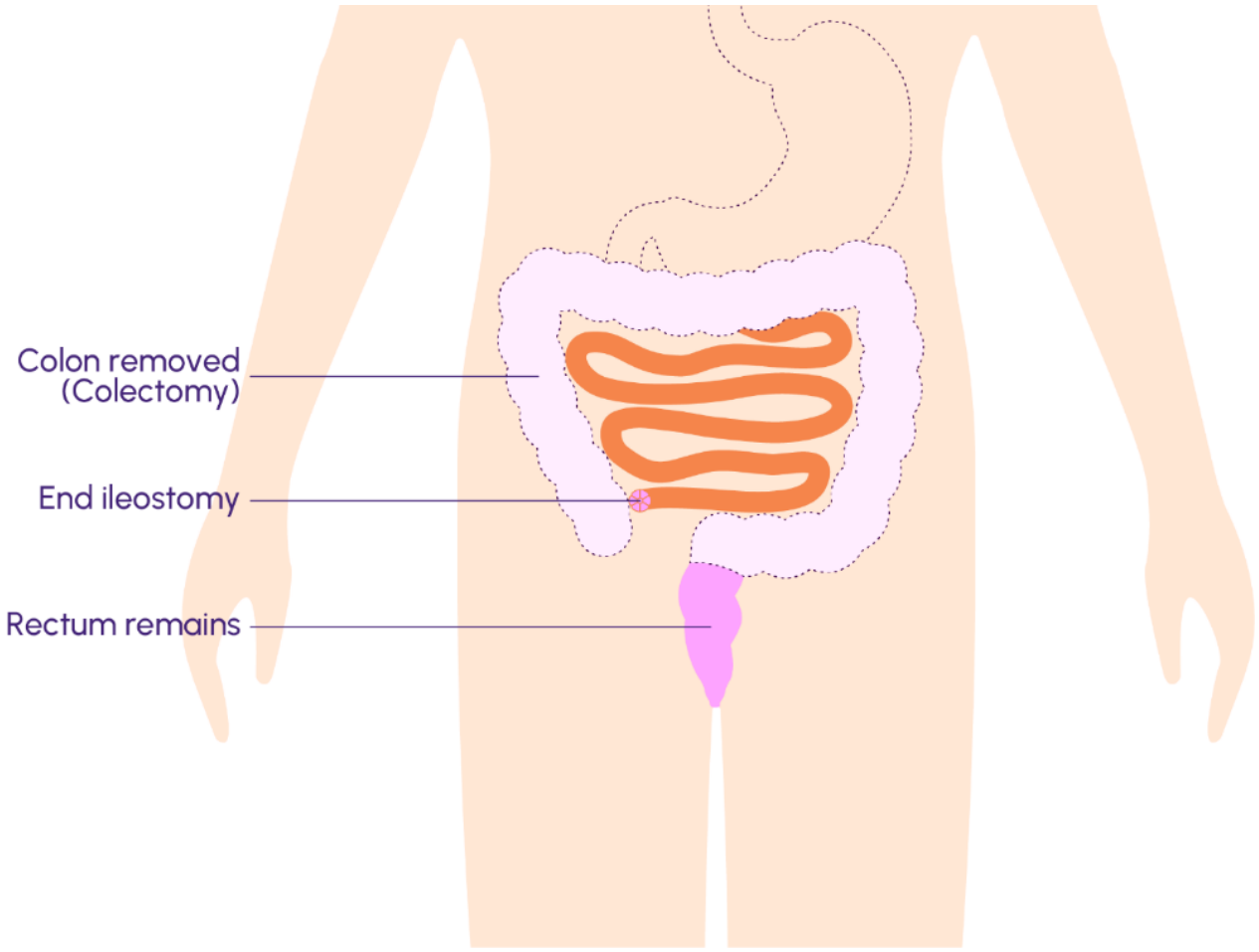
## Subtotal colectomy with ileostomy

During a subtotal colectomy the surgeon removes the colon but leaves the rectum. The colon and rectum together make up the large bowel. The surgeon makes an ileostomy, also called a stoma, by joining a section of the small bowel to the surface of the tummy. Bowel contents pass out of this opening into a stoma bag.

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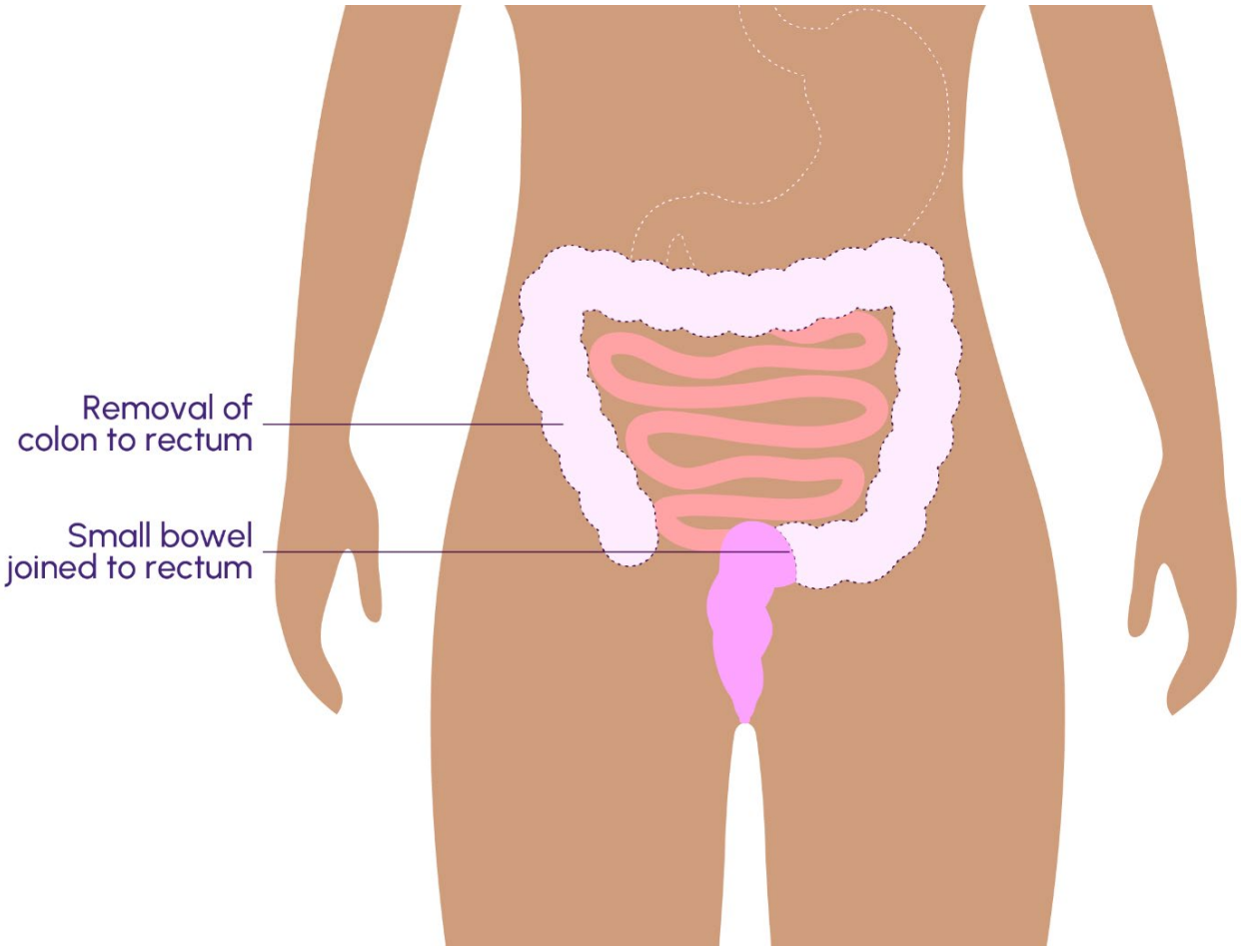
## Colectomy with ileo-rectal anastomosis

In this surgery, the colon is removed and the end of the small bowel, known as the terminal ileum, is attached to the rectum. This means you can poo out of your bottom and do not have a stoma.

For this surgery to work, the rectum has to be healthy and not inflamed or scarred. If your anal muscles are damaged, there's also a high risk this surgery will not work.

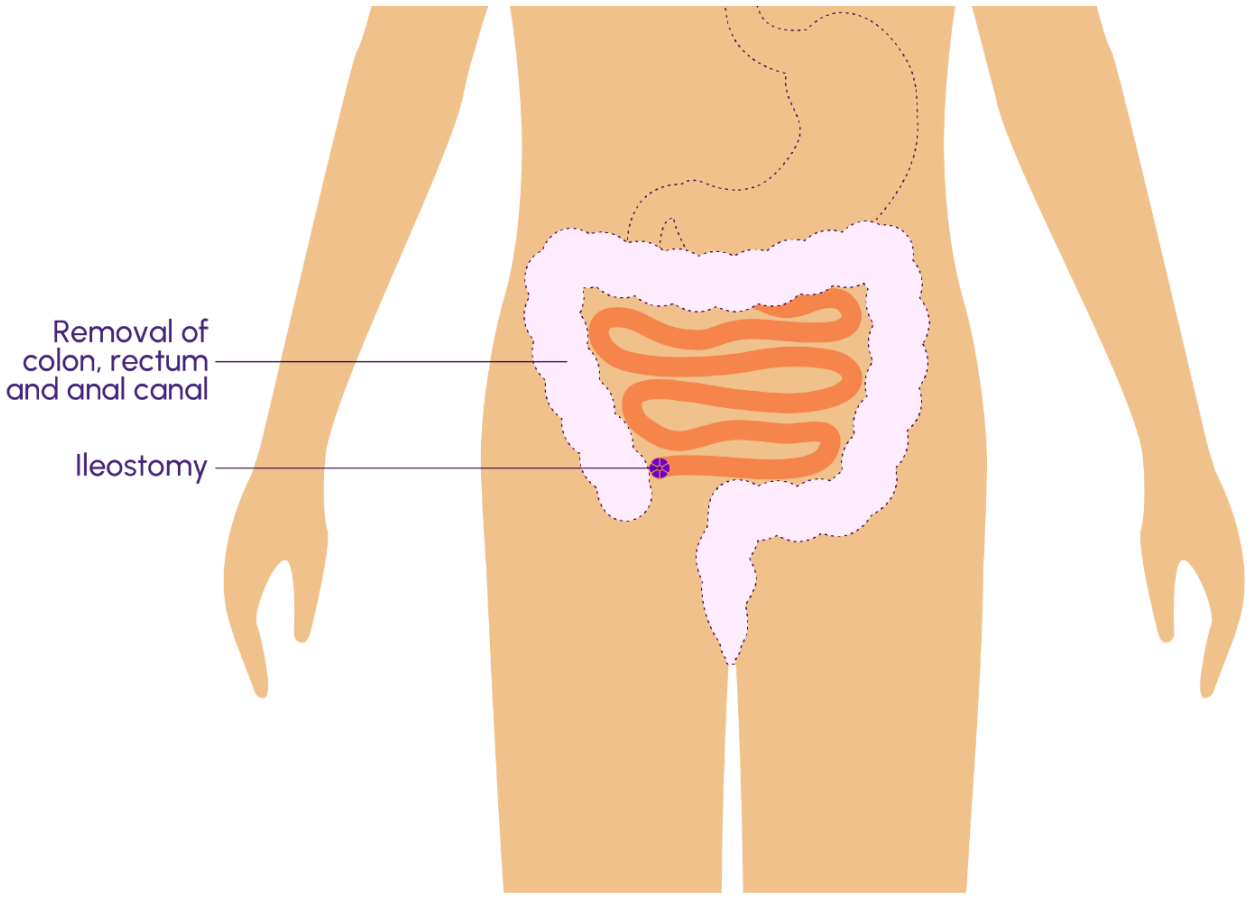
Removing the colon means water cannot be absorbed like usual, so your poo may be quite watery. You may have to go to the toilet many times during the day and night.



### Panproctocolectomy with ileostomy

In this surgery, the whole colon, rectum and anal canal are removed. The surgeon makes an ileostomy, also called a stoma, by joining a section of the small bowel to the surface of the tummy. Bowel contents pass out of this opening into a stoma bag.

Panproctocolectomy with ileostomy surgery is irreversible. This means the ileostomy is permanent. But this also means that there is no colon and rectum to become inflamed or get bowel cancer.




## SURGERY FOR ABSCESSES

Small abscesses can sometimes be treated with antibiotics through a drip into your vein. Bigger abscesses in the tummy may need percutaneous drainage. This is when a tube is placed through a small hole in the skin to drain out the abscess. Usually a

scanning machine, like an X-ray or ultrasound machine, is used to guide the placement of the tube. Some abscesses may need to be opened surgically and drained, or taken out via resection.

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## SURGERY FOR FISTULAS

**This is just a summary on fistulas. See our information on fistulas for more about:**

- Surgery
- Other treatment options
- Tips for living well with a fistula

Fistulas connecting the small bowel to other parts of the bowel do not always need surgery if they're not causing problems. However, if a fistula is causing symptoms, or you're losing weight, you may be offered surgery to remove that section of the bowel. This is a type of resection.

Fistulas around the bottom, called perianal fistulas, can be more difficult to treat. Surgically removing them can risk damaging the strong muscles in your anus, called anal sphincters. These muscles help you control when you poo.

Perianal fistulas are usually treated using setons. A seton is a loop of thread or rubber band passed through an anal fistula. The seton helps drain away pus and allows the inflamed tissue to heal. You may be advised to have **biologic medicines** at the same time to help the fistula heal. Fistulas sometimes need more than one surgery.

Examination under anaesthesia, also called EUA, is common for people who have perianal Crohn's. This is when you're put to sleep with general anaesthetic medicines

so the surgeon can check your bottom for fistulas. It's done under anaesthetic so you do not feel any pain.

## BEFORE SURGERY

### Talking to your surgical team

Before a planned surgery is booked in, you may meet a surgeon to discuss your operation. The surgeon should explain your surgical options in more detail. They should also talk through the benefits and risks of the surgery. They should mention any possible complications that can happen as a result of surgery. Let them know if there's anything you do not understand. This is your chance to ask questions and find out more information. Our **Appointment Guide** includes questions you may want to ask in your appointments.

If you decide to have surgery, you'll be asked to sign a consent form. This is an agreement to say you understand the risks and benefits of the surgery. It is written proof that you give permission for the surgeon to carry out the operation. Even if you sign a consent form, you can change your mind and withdraw consent at any point. If you cannot give consent, for example if you are under 16 years old, there are rules in place to help protect you. The NHS has more **information on consent**.

At this stage, if you're going to have a stoma, you may also meet a stoma care nurse. They should be able to help with any questions you have about the surgery or your care after the surgery.

### Pre-operative assessment

Before planned surgery, you should have a pre-operative assessment. This helps your surgical team to make your surgery the safest it can be. It will also help the anaesthetist plan the best anaesthetic for you. Even if your surgery is done as an emergency, a surgeon and an anaesthetist should both assess you first.

The pre-operative team is usually made up of doctors and nurses. They may call you to assess you, or invite you to the hospital for an assessment. They should ask about your medical history and home life. They may ask you to do some tests before your surgery. This could include:

- Blood tests
- A heart tracing, known as an ECG
- A chest X-ray

The tests you have will depend on your:

- Age
- Medical history
- The type of surgery you're going to have

If possible, it's good to be as fit as you can before surgery. This can help your recovery and lower your risk of complications. Your surgical team can give you advice on how to improve your fitness before surgery. This could include eating well, not smoking and being as active as you can be. If you are underweight, you may be advised to take extra nutrients. This may be in the form of a special liquid feed to have as well as your usual diet. If you are a smoker, your IBD team should support you to stop smoking. It's important to stop smoking before you have surgery, as smoking increases your risk of complications.

Anaemia is common in people with Crohn's. Anaemia is when you have fewer red blood cells to carry oxygen around the body. If you have anaemia you should be treated for this before surgery, if possible. There are lots of different causes of anaemia. If you have iron deficiency anaemia, then you may be given a top up with tablets or through a drip. Vitamin B12 and folate are also used to treat some types of anaemia. In more severe cases, a blood transfusion may be needed to treat your anaemia.

## Medicines and surgery

Your surgical team may advise you to stop taking certain medicines before surgery. They should give you a plan for when and how you should stop taking them. Medicines that may be stopped or changed include:

- Steroids
- The combined oral contraceptive pill
- Blood thinning medicines

Steroids can increase the risk of infection. Stopping or reducing your steroids can help prevent infection after your operation. If your steroids need to be stopped before your operation, you may need to slowly reduce how many you take. Stopping steroids suddenly can be dangerous if you have taken them for a long period of time. If you stop taking steroids look out for symptoms of steroid withdrawal. These include weakness, fatigue, loss of appetite and vomiting. These symptoms can be difficult to identify, as they are like Crohn's symptoms. If you have any these symptoms get urgent medical attention.

It's important to tell your surgical team about all the medicines you are taking, including over-the-counter or herbal medicines. They should tell you which ones you need to stop or change before surgery. They may also advise you to start medicines before surgery. If you have other conditions such as diabetes or high blood pressure, they will want to make sure these are under control before surgery.

In some cases, you may need to take a strong laxative called a bowel preparation the day before surgery. This is used to completely empty your bowel. In other cases, you may be asked to have an enema to clear the last part of your bowel.

## Things to think about before having surgery

- Transport. How will you get to and from hospital?
- Next of kin. Who should the hospital contact with updates about your hospital stay? Are they ok with being contacted?
- Work and volunteering. Will you need to take time off and who should you talk to about this?
- Caring responsibilities. Do you care for anyone, such as children, a relative, or a partner? Any pets? Who will be looking after them while you are in hospital and while you recover at home?
- Pre-hospital instructions. Did your surgical team give you any instructions on what to do before coming in, like stopping medicines?
- Going home. Will somebody be able to help you when you go home? Can you get food delivered?
- Hospital visiting policy. When can people come to visit you?

## Packing for hospital

**This is not a full list but may help you plan your packing. Think about the size of the bag you take in. The hospital may not let you take in a big suitcase if there is limited space on the ward.**

- Loose fitting, comfortable clothing. Try to bring both day and night clothing.
- Your usual medicines, including inhalers, creams, and ointments.
- Toiletries, such as toothbrush and toothpaste, soap, shampoo, deodorant.
- Charger for your phone.
- Things to keep you busy, like books, puzzle books, journals to write in.
- Some people bring their laptop or tablet. Be aware there may not be somewhere secure to store this. You will be responsible for looking after your valuables.
- Lip balm.
- Slippers or comfortable shoes.
- Small comforts, such as a dressing gown, your own pillow.
- Some people also like to bring squash for their water or their own snacks.

Though most hospitals have Wi-Fi, it is not always reliable. You may want to download music, podcasts, or things to watch before coming into hospital, just in case there is no internet to use.

## ON THE DAY OF THE SURGERY

Before the day of your surgery, your surgical team should tell you:

- Which hospital to go to. This may not be the usual hospital that you have your clinic appointments at.
- What time to arrive.
- When to have your last meal and drink before surgery.

On the day of your surgery, you will see a number of people. This includes a:

- Surgeon. They may speak to you about the surgery and examine you before the operation.
- Nurse. They may check your temperature, blood pressure, pulse, and weight. These should also be checked regularly during your surgery and while you recover in hospital.
- Anaesthetist. They may talk about how you will be given the anaesthetic and how your pain will be controlled after the surgery.
- Stoma care nurse. If you may need a stoma, and have not met your stoma nurse already in earlier appointments.

Ideally, you should not be asked to sign a consent form on the day of your operation. Consent forms should be signed at the point you decided to have surgery. For planned surgery, this is before the day of your operation. An anaesthetist should 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.

You'll usually be given a pair of compression stockings to wear during your time in hospital. Compression stockings lowers the risk of blood clots. You may also be given daily injections to help thin the blood to prevent blood clots. Your doctor should let you know if you need this or not, and should advise you on how long you will need

this for. See the later section on **Lowering your risk of complications while you recover** for more information.

### How long your surgery will take

This will depend on the type of surgery you're having, whether it is keyhole or open surgery and if you have had surgery on your tummy before. If you have had surgery on your tummy before you may have scar tissue called adhesions. Adhesions can sometimes make surgery more complicated, so it can take longer. Your surgical team can tell you how long they expect your surgery to take.

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## AFTER SURGERY

After surgery you'll be moved to a recovery ward. This is a small ward where nurses will monitor you as you wake up properly. The medicines that put you to sleep take a couple of hours to fully wear off. You may not remember waking up, or the first couple of hours after you wake up.

The medicines used during surgery can make you feel sick. This is known as nausea. You may also have a sore throat. This is usually because of the tube that's put into your throat to help you breathe during surgery. This tube is taken out when you wake up. If you feel unwell, let the nurses know and they'll be able to help you.

### What are the tubes coming out of my body?

When you wake up, you may find some tubes attached to you. These could include:

- Catheter. This takes pee, also called urine, out of your bladder. This is because you cannot naturally empty your bladder when you are put to sleep during surgery. A catheter is usually removed after a few days when you are able to move around again and go to the toilet by yourself.
- Wound drain. This drains blood and fluid from your wound after surgery. This is taken out when there is no more, or very little, blood or fluid left to drain.

- Rectal tube. This tube is inserted up the bottom and helps removes poo or gas.
- Intravenous (IV) drip. These small tubes are used to give you fluids and medicines, like antibiotics and pain relief. Your IV drip may be changed every few days to lower the risk of infection.
- Nasogastric tube. This tube goes in through your nose, down through your throat and into your stomach. This can be used to give you food directly into your stomach. It can also be used to drain or decompress your stomach to keep it empty. This may happen if you have a blockage in your bowel, or if you feel very sick.

When you are fully awake and recovering well from the anaesthetic medicines you will be moved to a ward. For most people this will be a regular surgical ward. Some people need more monitoring. They will be moved to a specialty ward like a high dependency or intensive care unit. This may include people with other conditions, like heart or lung disease. You may also need more monitoring if your surgery was an emergency, as you may be at higher risk of complications.

## Pain relief after surgery

Your tummy will feel sore at first, and it may take a while to feel better. You may also notice some bruising and swelling on your tummy. This is common and it should also get better. If it gets worse or you are worried that it's not getting better, speak to your healthcare professional.

Your doctors and nurses should talk to you about what pain relief may be best for you. The most common ways of having pain relief are:

- Tablets or liquid to swallow
- Skin patches
- An injection into your vein, known as an IV injection
- An injection into a space in your spine, also called an epidural
- An injection into your tummy, also called an abdominal wall block

Patient controlled analgesia (PCA) is a type of IV drip pain relief. The patient controls when they get their pain relief by pressing a button. This is usually used for a short time after surgery when pain may be more severe.

Pain is expected after surgery, but you should not have to suffer. Being in pain can slow down your recovery and increase your risk of complications. If your pain is not under control let someone know.

> **"My husband had a laparoscopic resection. He was in considerable pain afterwards and this unfortunately wasn't managed well. Once the PCA was in place, it was significantly better. Knowing what should be available and when would be very useful to those helping to support a patient undergoing surgery."**
>
> **ERICA**
> **WHOSE HUSBAND IS LIVING WITH CROHN'S**

## Your recovery in hospital

You will be encouraged to move as much as you can. This may mean getting out of bed and into a chair, or walking around as soon as you are able. A physiotherapist may visit you to show you some simple leg and chest exercises.

Having surgery can be a big shock to your body, mentally and physically. Your appetite may change and you may not feel very hungry. It may take some time for your appetite to return, especially if you were unwell before surgery. Depending on the type of surgery, you may be able to start drinking water within 12 hours of your surgery. You'll then move on to a liquid diet such as soup and jelly.

After surgery, your bowel may temporarily stop moving food and gas as it usually does. This can cause you to feel sick and bloated. Your doctor may suggest that you do not eat during this time, usually around 1 to 2 days.

If you have a stoma, your stoma care nurse will teach 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 find that a few days after the surgery they do not feel as well as they did straight after the surgery. They may also feel low in their mood. If you have feelings of a low mood that are not going away, talk to your healthcare professional.

## Lower your risk of complications while you recover

### Chest infections

After surgery you may be at a higher risk of chest infections. You can help lower this risk by doing breathing exercises. Ask your physiotherapist or surgical team how to do these exercises. If it hurts to take deep breaths, ask your nurse or doctor for pain relief.

### Blood clots

You are at a higher risk of blood clots if you have had surgery, are in a flare-up or you're in bed for a long time. You can help lower your risk by keeping moving as much as you can. At first this may only be moving your feet around. When you can get out of bed into a chair you can move your legs more. Try to walk as soon as you are ready. You should also wear the compression stockings given to you to help lower your risk.

### How long you'll stay in hospital

How long you'll need to stay in hospital will depend on your individual situation. For the common surgeries mentioned in this information, it'll probably be around 7 to 10 days. However, some people may only need to stay in hospital for 3 to 4 days. If you were very unwell before your surgery you may need to stay in longer.

It may be helpful to ask your surgical team when they expect you to go home. Generally, people who have had keyhole surgery are able to leave hospital sooner than people who have had open surgery. Hospital stays for planned surgery tend to be shorter than for emergency surgery. People who need emergency surgery are usually very unwell and may have a more complicated recovery.

### Enhanced recovery programmes

Some hospitals have enhanced recovery programmes in place for some types of surgery. These programmes aim to lower your risk of complications after surgery and get people safely home more quickly. Enhanced recovery programmes focus on being as healthy as possible before surgery, as well as getting moving as soon as possible after surgery.

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## GOING HOME AFTER SURGERY

### Feeling better after surgery

When you feel better will be different for each person. When you first get home, you'll probably feel quite weak and tired. You may not feel like doing much.

You should avoid any strenuous exercise for at least a few weeks after your surgery. This is so your wounds can heal properly. This means avoiding any heavy lifting or housework. You may struggle to go up stairs for a short time after surgery.

As time goes on you'll notice your strength coming back. After a few weeks, you should be able to gradually introduce exercise into your daily routine. A gentle

exercise programme may help speed up your recovery and you will likely be given advice on this by your surgical team.

You should be able to start going back to your usual daily activities. It's important to listen to your body and only do as much as feels comfortable. Everybody is different, so try not to put too much pressure on yourself to get back to usual life straight away.

Your follow-up plan will depend on your individual situation. You should still be under the care of a gastroenterology team and a surgical team. You may have a nurse come to your home to help with any wounds if this is needed. Make sure you understand your follow-up plan when you are discharged from hospital. If you do not know, make sure to ask someone. It is also worth asking:

- What symptoms should I look out for?
- Who should I contact if I'm concerned?

If you have had stoma surgery, your stoma nurse is there to help. Having a stoma can be a big change and it may take a while to get used to it. Talk to the stoma care nurses if you need more information or have any issues. Many hospitals have stoma clinics or offer a stoma care advice line. See our information on **life with a stoma**.

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## IMPACT OF SURGERY ON EVERYDAY LIFE

### Driving

In the long-term, surgery should not affect driving. However, you may have to avoid driving straight after surgery. 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. If you still cannot drive safely 3 months after your surgery you need to tell the DVLA. Your car insurance may not cover you if you drive before you are fully recovered, so check the terms of your policy. It may be helpful to ask your

surgeon to confirm that you can drive again in writing, at your follow up appointment.

### Diet

After your surgery, you may have to change what you eat for a short time. Your surgical team will give you specific advice on what you should eat. For example, they may advise you to eat a diet low in fibre. This will make it easier for your gut to break down and absorb food while it recovers from surgery.

As you recover, you may find that you can eat larger meals and a wider range of foods.

Having a varied diet is particularly important if you have had sections of your small bowel removed. This is because it will be harder for you to absorb nutrients. Some people with Crohn's have difficulty in absorbing fat from their food, especially after having part of their bowel removed. If you have had the end of your small bowel, called the terminal ileum, removed you may need to have vitamin B12 injections.

Most people with a stoma do not need to stay on a special diet. But there might be some foods or drinks that make your stoma more active or create more gas. This is different for everyone. Your stoma care nurse or the hospital dietitian should be able to advise you.

**See our information on life with a stoma for specific information on eating with an ileostomy or a colostomy.**

See our information on **food** for more on diet and Crohn's.

### Hydration

Your colon is important for absorbing water. If you have your colon taken out you have a higher risk of dehydration. You may find it helps to drink fluids and

rehydration drinks, including electrolyte mix. Our information on **dehydration** has more on staying hydrated after surgery.

## Work and finances

If you work, you may be wondering how surgery will affect your job and your income. It can take from 2 to 10 weeks before people feel able to return to work. This depends on the type of surgery you're having and the type of job you have. If you work in a very physical job, you may need more time off.

If you can, it's best to let your employer know early on about your medical needs and time off so they can make adjustments. It may help to read our information on **employment.**

If you are absent for more than a week, you will need to get a '**fit note**' from the healthcare professional who is caring for you. They can make suggestions for additional support or adjustments when returning to work. This could include building up slowly to your usual hours and duties. This is called a 'phased' return to work.

See the ACAS website for more information on **returning to work after an absence.**

If you're worried about money, have a look at our information on **money and benefits**. You may be eligible for support.

Your local Citizens Advice service could be a good place to start. They can help with budgeting or maximising your income, and offer benefits advice:

- **England**
- **Scotland**
- **Northern Ireland**
- **Wales**

If you care for a child who lives with Crohn's, you may want to read our information on **Disability Living Allowance (DLA) for children**.

## School and university

You may need to take some time out of studying to recover from surgery. Try to speak to your school, college or university as early as you can so they are aware of the situation. They may be able to give you extended deadlines or adjustments for exams. See **CICRA** for more information on Crohn's and schools.

## Emotional reactions

Everyone reacts to surgery in their own way. And your emotions may even change during the process. You may feel worried or scared, maybe nervous. You may feel a sense of relief. Or you may feel doubt about whether having surgery was the right decision. Going through lots of different emotions can be exhausting. Emergency surgery can be especially difficult as there is less time to adjust. The people close to you may also find it difficult to cope with the thought of you having surgery.

You may find it helpful to talk to someone about these feelings. IBD nurses, stoma nurses and psychologists can support you. You can also speak to your GP about local psychology services. Our information on **mental health and wellbeing** has further details about this.

It may be helpful to talk to other people who have had surgery for their Crohn's or who have a stoma. Check our **support for you** page for ways you can connect to others living with Crohn's or Colitis.

## Body image

Your body may look different after surgery and you may find this difficult to come to terms with. On the other hand, you may feel that having surgery improves your body confidence. You may feel better and able to do the things you enjoy. Maybe you can start going to the gym. Or maybe you have the energy to be intimate with a partner again. If you're having worries, talk to your IBD team. Your nurses will likely have spoken to lots of people about their body image worries. It may also be helpful to speak to others like friends, family, or other people who have been through a similar

experience. Check our **support for you** page for ways you can connect to others living with Crohn's or Colitis. Our information on **relationships and dating** has more on body image.

## Sex and relationships

You may be worried about how surgery will affect your sex life. Your surgical team can give you specific advice about when they think it's safe for you to have sex after surgery. Going back to sexual activity may mean exploring other ways of being intimate or new positions. It can be difficult to talk about sex, but being open about your needs and concerns can help.

Our information on **sex and sexual health** has more on how surgery may affect sex and suggests other ways you could be intimate with a partner.

## Fertility in men

After having pouch surgery, you may have problems getting or keeping an erection. For most men, this improves with time, or with sildenafil medicine. Sildenafil is also known by the brand name Viagra.

The risk of fertility problems is lower with keyhole surgery.

You should still use contraception if you do not want to make someone pregnant after surgery.

## Fertility and pregnancy in women

If you're thinking of having children, it's important to let your surgical team know. Women having surgery in the lower tummy area, known as the pelvic area, may be at risk of fertility problems. It's thought that surgery in this area of your tummy can cause scar tissue, called adhesions, around the fallopian tubes and ovaries. This can make it more difficult to get pregnant. Ask your surgeon whether your type of surgery may increase your risk. But if you do not have surgery, active Crohn's may also make it more difficult to get pregnant.

For some people, it may be possible to delay surgery until they have completed their family. For other people, they may be able to have keyhole surgery. The risk of fertility problems is lower with this type of surgery.

You should still use contraception if you do not want to get pregnant after surgery.

If you do become pregnant, either before or after surgery, your doctors will advise you on what options are safest for you and your baby. For example:

- If you have a stoma, it's still possible to deliver vaginally, but you may need a caesarean section if any complications arise.
- Vaginal deliveries are not advised if you have active Crohn's in the area around your bum, known as perianal Crohn's.

Any surgery in the tummy, including a caesarean section, or surgery for your Crohn's, can lead to scar tissue forming. These are called adhesions. Adhesions can make any future surgery a bit more complicated. Your surgeon should be able to give you further advice on this.

You may find it helpful to read our information on **reproductive health** and on **pregnancy and birth.**

## Travelling

Having surgery should not stop you travelling. You may be advised not to fly in the first few weeks after surgery. Blood clots are more likely to happen when you sit still for a long time, like on long-haul flights. And this risk is higher if you have had surgery recently. Ask your surgical team if they have any specific advice for you about travelling. If you have a stoma, you'll have to consider packing your supplies. Read more about travelling with Crohn's in our information on **travelling**.

## Insurance

When declaring your medical conditions, insurance companies will usually ask you if you have had surgery because of your Crohn's. The cost quoted to you may be

affected if you are waiting for surgery, or recently had surgery. Our information on **money and finding financial support** has more on insurance.

## Exercise and physical activity

In the long-term, having surgery should not affect how you exercise. If surgery helps your symptoms, it may mean you can be more active. If you have a stoma, you may have to make sure you have spare bags and other supplies with you.

Having surgery in the tummy area, especially stoma surgery, can put you at higher risk of getting a hernia. A hernia happens when there's some weakness in the muscle wall, so internal organs, such as the bowel, can push through. You can lower your risk of getting a hernia by working on your core strength and practising tummy exercises. Some people also find wearing support underwear can help. Speak to your surgical team about what could help you.

There is more on how you can exercise with Crohn's in our video on **being active**. **Colostomy UK** and the **Ileostomy and Internal Pouch Association** also have information on exercising after surgery.

## Children and young people

Much of the information here will apply to children as well. However, there are some things to be aware of:

- Surgery on children and young people often takes place in specialist hospitals. This may mean you have to travel further for the surgery.
- Children cannot consent to treatment until they are 16 years old.
- The growth and development of a child or young person will be important in deciding if surgery is suitable for them.
- Children and young people may be given some specific instructions before surgery. For example, avoiding vaccinations in the few weeks before surgery.

**CICRA** has more information on surgery in children with Crohn's.

## OTHER ORGANISATIONS

ACAS – free, confidential advice on employment issues and laws

**acas.org.uk**

Helpline: 0300 123 1100

CICRA – **surgery information** for children and young people with Crohn's and Colitis

**cicra.org**

020 8949 6209

Colostomy UK – information and support for people living with a stoma.

**colostomyuk.org**

0800 328 4257

Ileostomy and Internal Pouch Association – information and support for people living with an ileostomy or internal pouch.

**iasupport.org**

0800 0184 724

Royal College of Anaesthetists – information for **adults** and **children**

**rcoa.ac.uk**

020 7092 1500

Royal College of Surgeons of England – information on **having surgery**

**rcseng.ac.uk**

020 7405 3474

## HELP AND SUPPORT FROM CROHN'S & COLITIS UK

We're here for you. Our information covers a wide range of topics. From treatment options to symptoms, relationship concerns to employment issues, our information can help you manage your condition. We'll help you find answers, access support and take control.

All information is available on our **website.**

### Helpline service

Our helpline team provides up-to-date, evidence-based information. You can find out more on our **helpline web page.** Our team can support you to live well with Crohn's or Colitis.

Our Helpline team can provide support by:

- Providing information about Crohn's and Colitis
- Listening and talking through your situation
- Helping you to find support from others in the Crohn's and Colitis community
- Providing details of other specialist organisations

You can call the Helpline on **0300 222 5700**. Or visit our **LiveChat service**. You can read our information on **when the Helpline** is open for more details.

You can email **helpline@crohnsandcolitis.org.uk** at any time. The Helpline will aim to respond to your email within three working days.

Our helpline also offers a language interpretation service, which allows us to speak to callers in their preferred language.

### Virtual Social Events

We offer people affected by Crohn's or Colitis the chance to join a virtual social event with others across the UK. The events will be a chance to chat, share

experiences and potentially learn from others. Each event may have a specific topic but the overall discussion will be driven by what those attending wish to talk about.

Family, friends and colleagues are more than welcome to attend.

Visit our **Virtual Social Events** page to find out what is available.

### Crohn's & Colitis UK Forum

This closed-group Facebook community is for anyone affected by Crohn's or Colitis. You can share your experiences and receive support from others. Find out more about the **Crohn's & Colitis UK Forum.**

### Help with toilet access when out

There are many benefits to becoming a member of Crohn's & Colitis UK. One of these is a free RADAR key to unlock accessible toilets. Another is a Can't Wait Card. This card shows that you have a medical condition. It will help when you are out and need urgent access to the toilet. See **our membership webpage** for more information. Or you can call the Membership Team on **01727 734465**.

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## HOW TO HELP OTHERS LIVING WITH CROHN'S OR COLITIS

We want to make a difference to people affected by Crohn's or Colitis. But we can't do that without help.

If you want to support others in our community, here are some ways you can get involved:

- Volunteering: If you'd like to volunteer, we have a range of ways you can get involved. Find out more about our **volunteering roles**.
- Campaigning: None of our award-winning campaigns would be possible without our amazing community of dedicated campaigners. Your voice really does matter. Find out more about **joining our Campaigner Network**.

- Fundraising: Every pound you give helps power our life-changing work. Together we'll create bold campaigns, fund pioneering research, and give vital support when people need it most. Find out about ways to **fundraise**.
- Research: Research aims to improve the lives of people living with Crohn's or Colitis. One day, it may even find a cure. But good quality research can only happen when people with Crohn's or Colitis are involved. Find out about ways **you can be involved in future research**.
- Share your story. We hear from people every day who rely on the Crohn's and Colitis community for help and support. Why not **share your story** to help others feel seen or inspired?

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## ABOUT CROHN'S & COLITIS UK

We're Crohn's & Colitis UK and we're changing what it means to live with these lifelong gut conditions. 1 in 123 people in the UK have Crohn's Disease or Ulcerative Colitis. These are unpredictable conditions that could flare up at any time.

No one should face that alone. That's where we can help.

We provide trusted information and support cutting-edge research. We also lead bold campaigns to get more people talking about Crohn's and Colitis. We help people understand these conditions, give them the attention they deserve and bring people together to create change.

This year, 25,000 people will be told they have Crohn's or Colitis. Once diagnosed, the obstacles continue. Today, there is no cure. People simply don't understand these conditions. So, we have listened. It's time for change & we're leading the way.

Our information is available thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis by calling **01727 734465.** Or you can visit **our website**.

## About our information

We follow strict processes to make sure our information is based on up-to-date evidence and is easy to understand. We produce it with patients, medical advisers and other professionals. It is not intended to replace advice from your own healthcare professional.

You can find out more on **our website**.

We hope that you've found this information helpful. Please email us at **evidence@crohnsandcolitis.org.uk** if:

- You have any comments or suggestions for improvements
- You would like more information about the evidence we use
- You would like details of any conflicts of interest

You can also write to us at **Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE.** Or you can contact us through the **Helpline** on **0300 222 5700**.

We do not endorse any products mentioned in our information.



**Surgery for Crohn's Disease, Ed 5b**

**Last review: June 2022**

**Last amendment: September 2026**

**Next review: September 2027**

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Patient Information Forum