

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 outlines:

- 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

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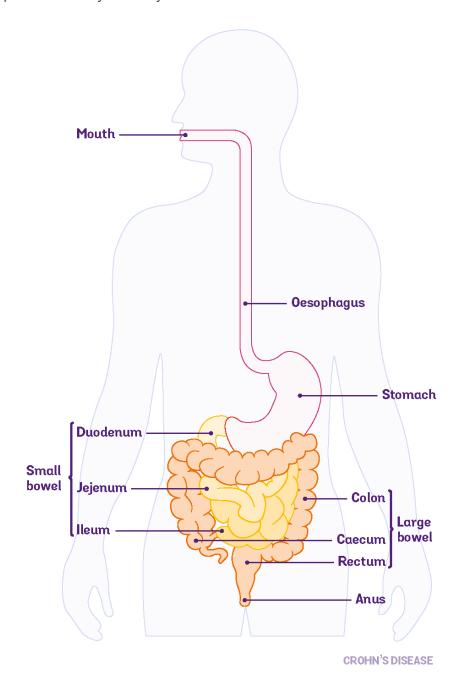
Key facts about surgery for Crohn's Disease

- Fewer people with Crohn's are needing surgery than 20 years ago.
- Around 1 in 5 people with Crohn's will need major surgery in the first five years after diagnosis.
- You may be offered surgery if medicines are not controlling your symptoms, or if you develop severe complications.
- Surgery is an effective treatment option for many people.
- Many of the common surgeries for Crohn's can be done by keyhole (laparoscopic) surgery. 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 (absorbs) food and nutrients and carries poo out. The gut starts at your mouth, where you eat, and ends at your bottom (anus), where poo passes out of your body.





The bowel

The bowel is the largest part of the gut and is made up of two sections – the small bowel and the large bowel (also called the small intestine and large intestine).

The small bowel is made up of three parts:

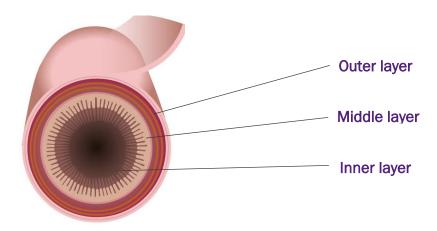
- The duodenum
- The jejunum
- The ileum

The small bowel helps to break down food and take in (absorb) 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 ileum (end of the small bowel). At the end of the large bowel is the bottom (also called the anus). The large bowel takes in (absorbs) water and removes toxins and waste products from our body. As water is absorbed the brokendown 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 (diarrhoea). It can also make you need to poo more often and reach the toilet quickly (urgency). If your body cannot take in nutrients properly you may lose weight and feel extreme tiredness (fatigue). You may also have poor nutrition, also called malnutrition.

While Crohn's can be found at any point in your gut, it won't 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 - stricture

Ongoing inflammation in the gut wall can cause scar tissue to form. This can create a narrow section of the gut known as 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 - 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
- Fever
- Feeling sick (nausea) and being sick (vomiting)



Number of people with Crohn's having surgery

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

Recent studies show that 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 <u>support you</u>.

When surgery is considered

Many people think surgery is the last option, but that is not true. Surgery is offered when doctors think it will help your symptoms. Some people may be offered both medicines and surgery. See our <u>information on treatments</u> 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 <u>Crohn's information</u>. 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 <u>balloon dilatation during</u> <u>endoscopy</u>. But if these are not suitable, surgery can help. The most common reason for surgery in the small bowel is a blockage due to a stricture.

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 if you've had Crohn's in your large bowel for 10 years or more, you have an increased risk of bowel cancer. If you are at higher risk of developing bowel cancer you will be offered more regular <u>colonoscopies</u> (a camera test to look closely at the lining of your bowel). Colonoscopies can help to spot precancerous changes in the bowel. If found, you may need surgery. See our information on <u>bowel cancer risk</u>.

Severe complications

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



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

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

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. As well as those who may already be involved in your care (such as your gastroenterologist, GP or IBD nurse), 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



Surgery and feeling better

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

Reducing your symptoms may mean you can do other things more easily – like 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.

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

Living with Crohn's

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

Crohn's can develop anywhere in the gut, including in previously healthy sections of the gut. Surgery cannot cure Crohn's. It's possible that Crohn's will come back (recur) after surgery, either close to where the surgery was or in another part of the gut. This means it's possible you could have another flare-up (recurrence) 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 (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 your surgery to reduce this risk.

Other treatment options

Your treatment options will depend on you and the type and severity of your Crohn's. Medicines don't 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.

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 and risks linked to having a general anaesthetic – such as having an allergic reaction to the anaesthetic.



There is also a risk of developing blood clots after surgery. And this risk is higher in people with Crohn's. Your surgical team will assess your risk of blood clots before you have surgery and will put measures in place to reduce 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 two bits of bowel are joined together, they may not join properly, and this can lead to a leak.
- Bowel blockages (obstructions). Having surgery can increase the risk of scar tissue, called adhesions, forming inside your tummy (abdomen) area. These can cause blockages (obstructions) in your bowel.
- Post operative ileus. Having surgery can temporarily disrupt movement of the bowel. This stops the normal movement of food, liquid and gas through the gut. Post operative ileus can happen after any surgery. But it is more common after 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 reduce your risk of complications. For example, if you smoke, stopping smoking can help to reduce your risk.

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

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
- Developing 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.

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 (abdomen) 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 four or five small cuts, each only about 1cm (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 (abdominal) wall in the area where your healed surgical scar is.
- A shorter stay in hospital.
- Better fertility outcomes in women.



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 (laparotomy)

Open surgery, also called laparotomy, is the more traditional way of operating on the gut. The surgeon makes one larger cut in the tummy (abdomen) 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.

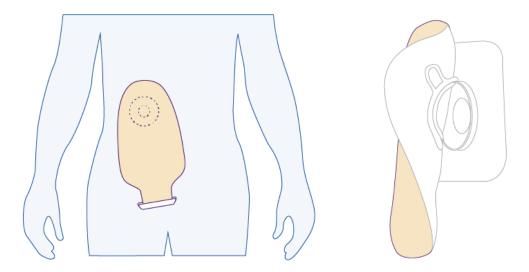
Stomas

This is just a short summary on stomas. Our information <u>Living with a Stoma</u> explains more about what a stoma is, different types of stoma, how to look after your stoma and how to manage common worries about stomas.

A stoma is an opening made by a surgeon on the wall of your tummy (abdomen). 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.

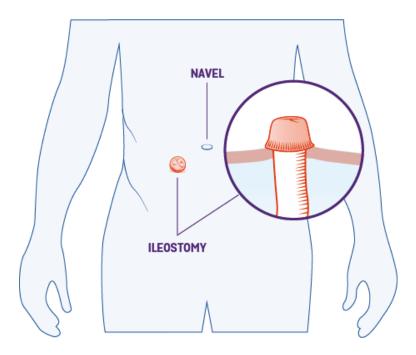
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A two-piece stoma bag. One-piece stoma bags are also available.



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



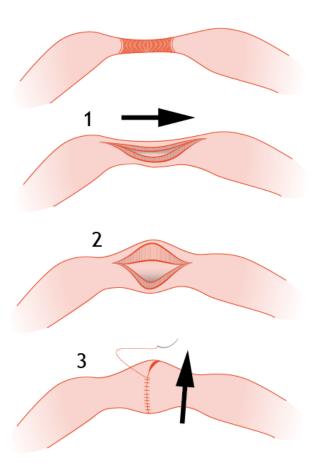
A stoma nurse will support you and give you practical help and information on living with a stoma.



Types of surgery

Strictureplasty (Stricturoplasty)

Stricture plasty 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 stricture plasty, the surgeon:

- 1. Cuts open the narrowed section of the bowel (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.

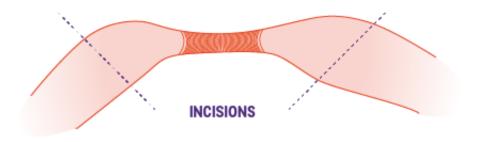
There are some other more complicated ways that the surgeon can sew the bowel back together. Ask your surgeon what type of stricture plasty they plan to use.

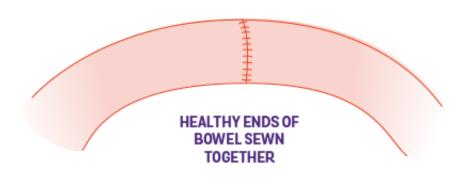


Resection

Resection means taking part of the gut out. This is one of the most common surgeries 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.

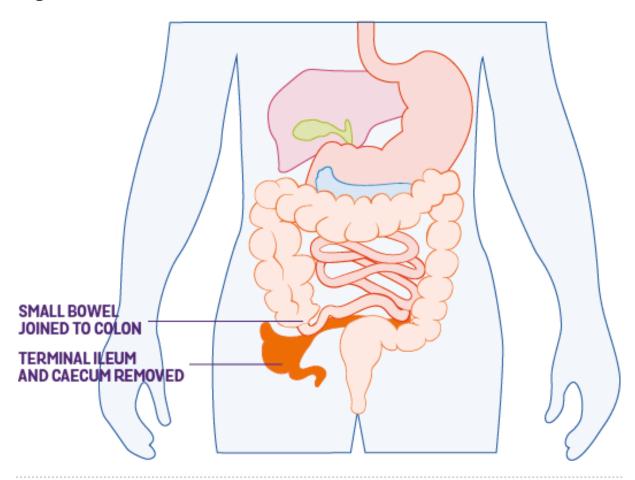






lleocaecal resection (ileocaecectomy)

Ileocaecal resection (also known as an ileocaecectomy) is when the ileocaecal part of the bowel is removed. The ileocaecal part is where the end of the small bowel (the terminal ileum) meets the start of the large bowel (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 two healthy ends of the colon are then joined together.

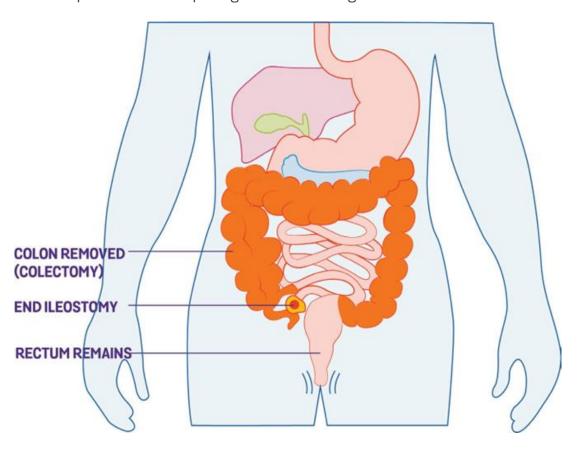


Right hemicolectomy

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.

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 (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.



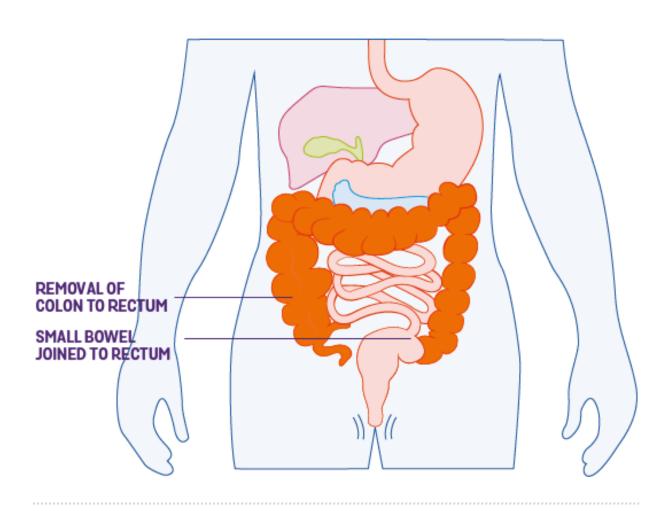


Colectomy with ileo-rectal anastomosis

In this surgery the colon is removed and the end of the small bowel (terminal ileum) is attached to the rectum. This means you can poo out of your bottom and would 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 normal, so your poo may be quite watery. You may have to go to the toilet many times during the day and night.

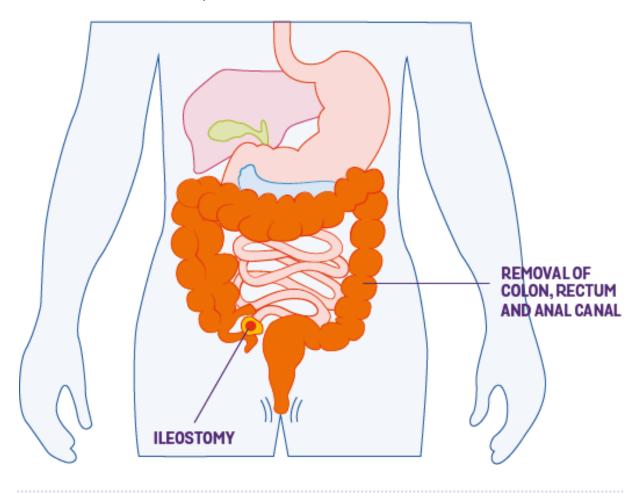




Proctocolectomy with ileostomy

In this surgery the whole colon, rectum and anal canal are removed. The surgeon makes an ileostomy (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.

Proctocolectomy with ileostomy surgery is irreversible. This means the ileostomy is permanent. But this also means that there is no colon and rectum (large bowel) to become inflamed or develop 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.

Surgery for fistulas

This is just a summary on fistulas. See our information on <u>Fistulas</u> for more about treatment options (including surgery) and 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 (perianal fistulas) can be more difficult to treat. Surgically removing them can risk damaging the strong muscles in your anus (anal sphincters) that help you control when you poo.

Perianal fistulas are normally 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 <u>biologic medicines</u> 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.



New and emerging types of surgery for Crohn's

A small number of specialist hospitals across the UK are offering new surgeries and techniques. These include:

- New ways of joining bowel together (anastomosis).
- Small bowel transplant. This is an option for people who have had lots of small bowel removed, who cannot have nutrition into their veins (total parenteral nutrition, TPN).

These surgeries for Crohn's are only offered in very specific cases. Your surgeon can give you more detailed information on these if you are eligible.

Before surgery

Talking to your surgical team

Before a planned surgery is booked in, you will meet a surgeon to discuss your operation. The surgeon will explain your surgical options in more detail. They will 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 Appointments 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 <u>information on consent</u>.

At this stage, you may also meet a stoma care nurse – if you're going to have a stoma. They will 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 will 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 will 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 will 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 (ECG) and chest X-ray. The tests you have will depend on your age, medical history, and 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 will 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
- Anti-TNF medicines like adalimumab, golimumab, and infliximab
- 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've 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 develop any these symptoms seek urgent medical attention.

Anti-TNF medicine may also need to be stopped before surgery. Anti-TNF medicines include adalimumab, golimumab and infliximab. Anti-TNF medicines might cause a small increase in the risk of infection. This risk is less than the risk of infection with steroids. If possible, these medicines should be stopped before surgery. If this isn't possible your surgery should be arranged to ensure enough time has passed since receiving anti-TNF. Find out more in our information on <u>Adalimumab</u>, <u>Golimumab</u> and <u>Infliximab</u>.

It's important to tell your surgical team about all the medicines you are taking, including over the counter or herbal medicines. They will 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 whilst you are in hospital and whilst 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 will 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 toothbrush and toothpaste, soap, shampoo, deodorant.
- Charger for your phone.
- Things to keep you busy 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/comfortable shoes.
- Small comforts 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 will include a:

 Surgeon – they will speak to you about the surgery and examine you before the operation.



- Nurse they will check your temperature, blood pressure, pulse, and weight.
 These will also be checked regularly during your surgery and while you recover in hospital.
- Anaesthetist they will 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 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.

You'll usually be given a pair of compression stockings to wear during your time in hospital. Compression stockings reduce 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 section Lower 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've had surgery on your tummy (abdomen) before. If you've 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.

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. 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 wee (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 reduce 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 normal 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 (IV)
- An injection into a space in your spine (epidural)
- An injection into your tummy (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 shouldn't 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 normally 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 aren't 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've had surgery, are in a flare 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 reduce 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 reduce 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.



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 normal 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 normal 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've 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 **Living with a Stoma**.



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've had the end of your small bowel (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 give you bad wind. This is different for everyone. Your stoma care nurse or the hospital dietitian should be able to advise you.

See our information on <u>Living with a stoma</u> 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 (part of your large bowel) 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 <u>Dehydration</u> 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 '<u>fit note</u>' ('statement of fitness for work') 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 normal hours and duties. This is called a 'phased' return to work.

See the ACAS website for more information on <u>returning to work after an absence.</u>

If you're worried about money, have a look at our information on <u>finance and benefits</u>. You may be eligible for support. You can also visit the <u>UK Government website</u> or <u>Citizens Advice</u> for more information on welfare benefits. If you care for a child who lives with Crohn's, you may want to read our information on <u>disability benefits for children</u> to see if you are eligible for financial help.



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 <u>CICRA</u> 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 <u>mental health and wellbeing</u> 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 <u>support for you</u> 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 – friends, family, or other people who have been through a similar experience. Check our



<u>support for you</u> page for ways you can connect to others living with Crohn's or Colitis. Our information on <u>mental wellbeing</u> may also be helpful.

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 <u>Sex and relationships</u> information has more on how surgery may affect sex and suggests other ways you could be intimate with a partner.

Fertility and pregnancy

If you're thinking of having children it's important to let your surgical team know. Anyone with female reproductive organs having surgery in the lower tummy area (pelvic area) may be at risk of reduced fertility. It's thought that surgery in this area of your tummy can cause scar tissue (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 disease 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, or do not want to make someone 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 (perianal Crohn's).

Any surgery in the tummy, including a caesarean section, or surgery for your Crohn's, can lead to scar tissue forming (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 <u>Reproductive health</u> and on <u>Pregnancy</u> and <u>breastfeeding.</u>

After receiving emergency surgery for an anal abscess brought about by my Crohn's Disease, I went on to have two healthy pregnancies via caesarean section (the first pregnancy was 6 months following my surgery).

Stephanie

Living with Crohn's

Travelling

Having surgery shouldn't stop you travelling. You may be advised not to fly in the first few weeks after surgery. Blood clots are more likely to develop when you sit still for a long time – like on long-haul flights. And this risk is higher if you've 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 normally ask you if you've 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 <u>insurance</u> gives more details about this.

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 reduce 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 <u>Living with Crohn's or Colitis</u> information. <u>Colostomy UK</u> and the <u>Ileostomy and Internal Pouch Association</u> 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.

<u>CICRA</u> has more information on surgery in children with Crohn's.	



Other organisations

<u>ACAS</u> – free, confidential advice on employment issues and laws www.acas.org.uk

Helpline: 0300 123 1100

<u>CICRA</u> – <u>surgery information</u> for children and young people with Crohn's and Colitis www.cicra.org
020 8949 6209

<u>Colostomy UK</u> – information and support for people living with a stoma. www.colostomyuk.org 0800 328 4257

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

0800 0184 724

Royal College of Anaesthetists – information for adults and children

www.rcoa.ac.uk 020 7092 1500

Royal College of Surgeons - information on having surgery

www.rcseng.ac.uk 020 7405 3474



Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships and employment. We'll help you find answers, access support and take control.

All information is available on our website: crohnsandcolitis.org.uk/information

Our Helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis and treatment options
- Provide information to help you live well with your condition
- Help you understand and access disability benefits
- Be there to listen if you need someone to talk to
- Help you to find support from others living with the condition

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

See our website for LiveChat: crohnsandcolitis.org.uk/livechat.

Crohn's & Colitis UK Forum

This closed-group community on Facebook is for everyone affected by Crohn's or Colitis. You can share your experiences and receive support from others at:

facebook.com/groups/CCUKforum.

Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See



<u>crohnsandcolitis.org.uk/membership</u> for more information, or call the Membership Team on 01727 734465.

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit <u>crohnsandcolitis.org.uk</u>.

About our information

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

We hope that you've found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the research on which the information is based
- 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 contact us through the Helpline: 0300 222 5700.

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