

# **Surgery for Ulcerative Colitis**

Medicines are an important treatment for Ulcerative Colitis, 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 Colitis
- What to expect when preparing for and after having surgery

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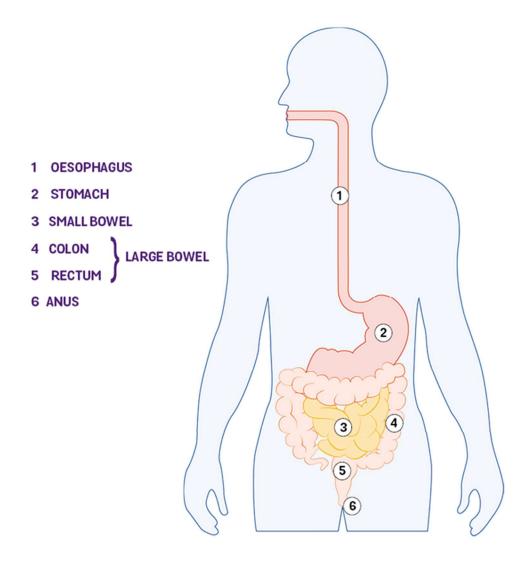
# **Key facts about surgery for Ulcerative Colitis**

- Fewer people with Colitis are needing surgery than 20 years ago.
- Around 7 in 100 people with Colitis will need major surgery in the first 5 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 Colitis 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 Colitis include ileostomy (stoma) surgery and pouch surgery.

# The gut and Colitis

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.

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#### 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 helps to break down food and take in (absorb) nutrients.

The large bowel is made up of the colon and rectum. 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 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.



#### **How Colitis affects the gut**

Ulcerative Colitis is an Inflammatory Bowel Disease (IBD) that causes your immune system to start attacking your gut. The term colitis means inflammation in the colon. As well as Ulcerative Colitis, there are other types of colitis, including:

- Microscopic Colitis.
- Crohn's Colitis this is Crohn's Disease in the colon. See our information on Crohn's Disease.
- Colitis caused by an infection or an allergy this is not IBD.

When we talk about Colitis in this information, we mean Ulcerative Colitis.

Colitis causes painful ulcers and inflammation in the large bowel. This inflammation can cause watery poo (diarrhoea) and tummy (abdominal) pains when you need to poo. You may need to poo more often (frequency) and reach the toilet quickly (urgency). There may be blood and mucus in your poo. You may feel extreme tiredness (also known as fatigue).

### **Types of Colitis**

The types of Colitis are based on how much of your large bowel is affected. This can affect the symptoms you experience and the treatment you're offered. The main types are:

- Proctitis inflammation affects the rectum only
- Left sided Colitis (also called distal Colitis) inflammation affects the rectum and the left side of the colon only
- Total Colitis (also called pancolitis) inflammation affects most of the colon and rectum

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# **Number of people with Colitis having surgery**

Fewer people with Colitis are needing 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.

Recent studies show that:

- Around 7 in 100 people with Colitis will need major surgery to remove their colon in the first 5 years after diagnosis.
- Around 10 in 100 will need major surgery in 10 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>.

Although my first surgery was an emergency and decided for me, the decision to have an internal pouch gave me my life back from Colitis symptoms and I would make the same choice again. Yes, it was painful in recovery but since then I have never looked back. My dad and brother both have Colitis (although neither have had surgery) and I am grateful that I no longer experience the flares and painful symptoms that they still do on occasion.

Nia

Living with Colitis

# When surgery is considered

Many people think surgery is the last option, but that isn't 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 Colitis.



There are a number of reasons you may be offered surgery:

#### **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.

#### 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.

#### 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 Colitis will be treated with medicines. But sometimes surgery may be needed to help with growth or development.

#### **Higher risk of bowel cancer**

Colitis is not cancer. However, the risk of developing bowel cancer increases around 8 to 10 years after the start of Colitis symptoms. Your risk of cancer is highest if all, or most, of your colon is affected by Colitis (known as extensive, total or pancolitis). 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>.

#### **Acute Severe Ulcerative Colitis (ASUC)**

ASUC is a serious medical emergency that requires a stay in hospital for treatment and monitoring. Around 1 in 3 people with ASUC do not respond to medicines and need surgery. You may be offered medicines first, but if your condition is very severe surgery may be the safest option.



#### **Severe complications**

Sometimes Colitis can cause complications that 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

#### 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 Colitis 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.



Getting used to having a stoma or a pouch will take time, and it can be a challenge. However, most people who have had surgery for Colitis say that they would have the same surgery again.

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

My surgery was an emergency at the age of 37...After the surgery I kept thinking any minute I'm going to look down at my ileostomy and totally freak out but I didn't. I don't know why, maybe because I knew that finally I was going to get better and because I had the support of a loving family and children to look after. I had pouch surgery 18 months later and really have never looked back. I eat whatever I like, I exercise regularly and Colitis is now a distant memory.

#### **Tracy**

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#### **Colitis coming back after surgery**

Colitis can't come back if the whole large bowel (your colon and rectum) has been removed. However, some people still have symptoms outside of the gut, such as in their **joints** or eyes.

For most people, removing the large bowel should mean:

- Relief from tummy (abdominal) pain
- Lessening of symptoms such as urgency and diarrhoea
- Being able to stop taking medicines that may be causing side effects
- No risk of bowel cancer

Colectomy with ileo-rectal anastomosis is a type of surgery where your rectum is not removed. If you have surgery that leaves your rectum inside, you could still get



inflammation in your rectum. Medicines such as <u>5-ASAs</u> may be able to help control this inflammation.

# **Other treatment options**

Your treatment options will depend on you and the severity of your Colitis. Medicines do not work for everyone, and some complications of Colitis 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**

Colitis 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 Colitis. 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 Colitis 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.
- Pouchitis. Half of people with pouch surgery develop inflammation of the pouch at some point. The risk of pouchitis is increased if you have both Colitis and Primary Sclerosing Cholangitis (PSC). Pouchitis is usually treated with antibiotics.
- 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.



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 <a href="#">Appointments Guide</a> 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 Colitis 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.

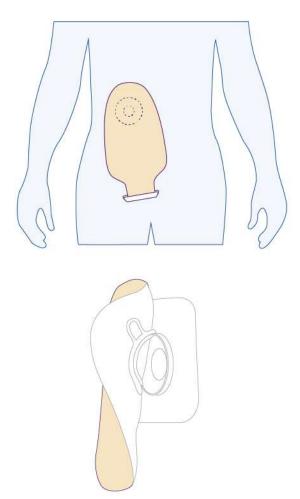


#### **Stomas**

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.

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

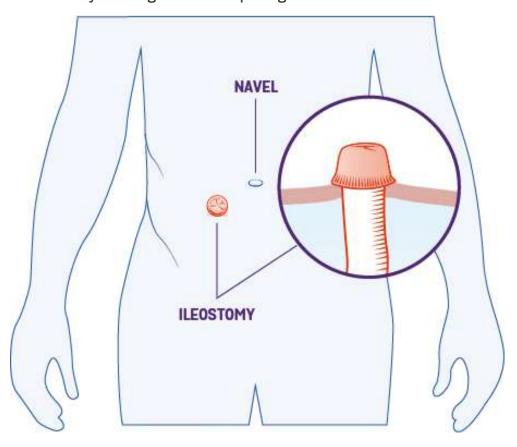


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You might need a stoma if you have surgery to remove a large part of your bowel.

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. People with Colitis have ileostomies. 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.

Having ileostomy surgery gave me my life back, I returned to school, took no medication and was able to live my life again.

Lou

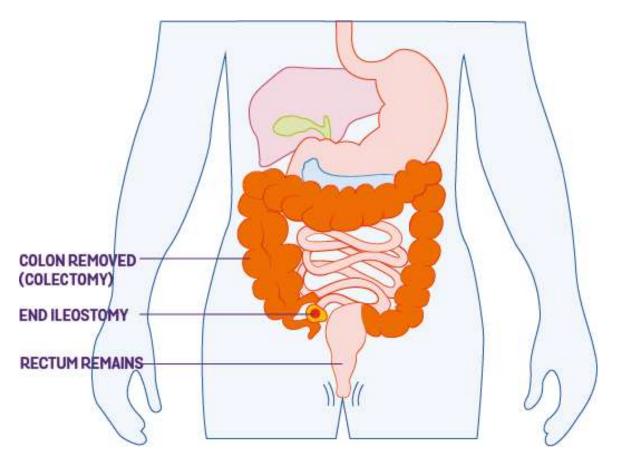
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# **Types of surgery**

#### **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.



The ileostomy may be temporary or permanent. Some people may be able to have pouch surgery in the future, so the ileostomy is only temporary. Other people may decide to live with a permanent ileostomy.

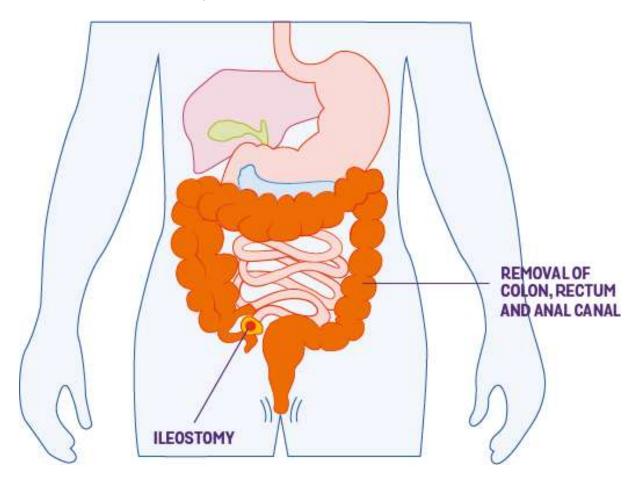
This type of surgery may be done in emergency situations.



#### **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.

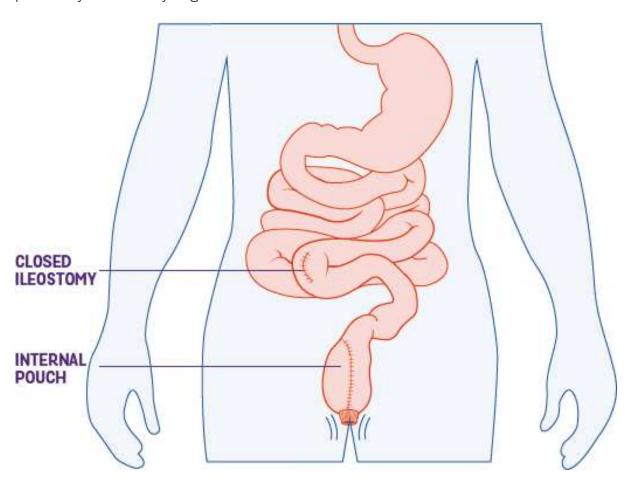
Proctocolectomy with ileostomy surgery is irreversible. This means the ileostomy is permanent. But this also means that there is no colon and rectum (large bowel) to become inflamed or develop bowel cancer.





# Pouch surgery: restorative proctocolectomy with ileo-anal pouch (IPAA)

This surgery is commonly known as J-pouch surgery, or IPAA (ileal pouch-anal anastomosis) surgery. The colon and rectum (large bowel) are removed and the small bowel is joined to the anus. A pouch is made from the small bowel. This pouch can store poo until you are ready to go to the toilet.



This type of surgery is usually done in stages, so you'll need to have more than one surgery. It's most commonly done in three stages, but can be done in two stages, or in rare circumstances, one stage. Your surgeon will discuss which option is best for you.

In the first surgery, the surgeon removes the whole colon, but leaves the rectum and anus. The surgeon makes a temporary 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.

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In the second surgery, the surgeon makes a pouch from the lower end of the small bowel (ileum) and joins it to the anus.

For people having a two-stage procedure, the pouch is made in the first surgery. A looped section of the small bowel is joined to the surface of the tummy to create a temporary ileostomy. The ileostomy gives the newly formed pouch a chance to heal. This usually takes about three months. The temporary ileostomy is closed in the second or third surgery so the pouch can be used.

Having pouch surgery means you can still poo out of your bottom. A pouch can give you some control of when you pass poo and wind.

A pouch can't hold poo for quite as long as a healthy rectum. This means you will need to poo more times a day than if you had a healthy rectum. Typically, people with a pouch go to the toilet for a poo about six times a day, and at least once at night. Some people will experience some unintended leaking of poo (bowel incontinence), but this usually reduces in the months following surgery. See our information on **bowel incontinence**.

Pouch surgery involves cutting into the lower tummy area (pelvic area), which may affect fertility in some people. See the later section **Surgery and everyday life.** 

Pouch surgery can be a more complicated type of surgery, so it may not be carried out in your local hospital. If your doctor thinks pouch surgery could be suitable for you, you may be referred to a specialist hospital.

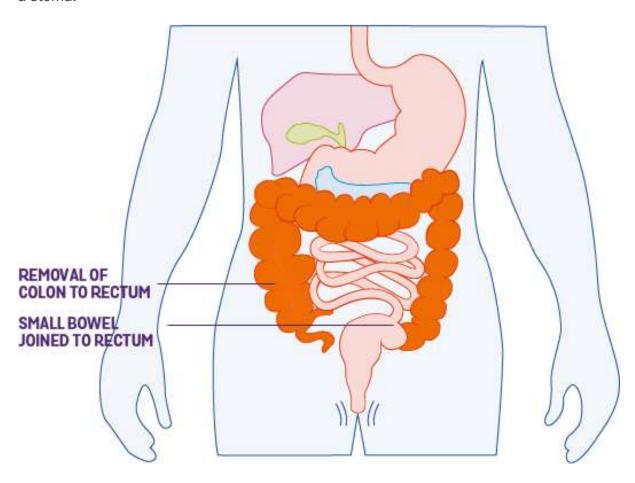
Surgery was 100% the best option for me and I have been living symptom- and medication-free for 13 years with an internal pouch.

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#### **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. For these reasons, this type of surgery is not commonly used in Colitis. If you still have a rectum there's a risk of it becoming inflamed from Colitis. There's also a risk of developing cancer in the rectum.

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.



# **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 <a href="Appointments Guide">Appointments Guide</a> includes questions you may want to ask in your appointments.

I spoke to friends and family about it a lot. I tried to keep my focus on why I was having the surgery. I had spent so many months being ill so I was trying to remain positive and concentrate on how much better I would feel once it was done and recovered.

#### Rebecca

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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>.

Surgery is scary but being well informed helps to manage that fear.

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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 Colitis. 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.

### **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

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.

If you've not done so already, you will be asked to sign a consent form. This will confirm that you agree to have the surgery. The doctor should explain the form and what it means. If anything is unclear, ask for it to be explained. If you do not want the surgery to happen, you have a right not to sign the form.

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.
- 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.

#### 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 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'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.



I couldn't even lift a full kettle when I was first home. When I had to be on my own, my dad would make a flask of tea for me to have throughout the day, as this was easier for me to lift and pour. I also found it very useful to wear loose long T-shirts or nightgowns (no bottoms with waistbands) so that clothing didn't pull on my stomach which was very sore for the first few days.

#### Nia

Living with Colitis

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 <u>Living with a stoma</u>.



# 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.

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 food for more on diet and Colitis.

See our information on <u>Living with a stoma</u> for specific information on eating with an ileostomy.



I have had multiple surgeries since being a child.

Once I became an adult I always ate more protein after surgery as I found it helped my wounds heal quicker.

Lou

Living with Colitis

#### **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 extra 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 3 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' ('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 returning to work after an absence.

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</u>



<u>Advice</u> for more information on welfare benefits. If you care for a child who lives with Colitis, you may want to read our information on <u>disability benefits for children</u> to see you if 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 Colitis and schools.

The majority of my surgeries have been during school and university so I arranged studying from home and extensions.

Lou

Living with Colitis

#### **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 <a href="mailto:mental-health-and-wellbeing">mental-health-and-wellbeing</a> has further details about this.

It may be helpful to talk to other people who have had surgery for their Colitis 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 support for you page for ways you can connect to others living with Crohn's or Colitis. Our information on mental wellbeing may also be helpful.

My main worry about having surgery was the body image of having a stoma and then scars (I was 19) but the freedom from symptoms was a much better feeling than any negativity of body image. I was also very worried about incontinence but this has not been an issue for me.

#### Nia

Living with Colitis

### **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.

For some men, having surgery may lead to difficulties with erections. This may resolve itself, but if not, speak to your IBD team, GP or visit a sexual health clinic for ways to 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**

Some types of surgery for Colitis can affect fertility, so if you're thinking of having children it's important to let your surgical team know. 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.

#### **People with male reproductive organs**

After having pouch surgery, you may have problems getting or keeping an erection. Many people can treat this with a medicine called sildenafil (Viagra). After pouch surgery, some people develop a rare complication called retrograde ejaculation. This is when the semen goes back towards the bladder instead of out the penis. The risk of this is lower after having keyhole surgery.

#### **People with female reproductive organs**

Having surgery for Colitis can make it more difficult to get pregnant. It's thought that surgery in your tummy can cause scarring around the fallopian tubes and ovaries. This leads to fertility issues.

Having pouch surgery can increase your risk of fertility problems, but this risk may be lower in people who have had keyhole surgery. Up to 5 in 10 women have difficulty getting pregnant naturally after pouch surgery. Of those women that become pregnant after pouch surgery, around 3 in 10 become pregnant after using in vitro fertilisation (IVF) treatment. Your chances of getting pregnant after using fertility treatments are similar to people using fertility treatments who do not have Colitis.

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 disease in the rectum.
- If you've had pouch surgery, you will be advised to have a caesarean section.
   Vaginal delivery is possible, but it may increase your risk of incontinence.

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

#### **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 Colitis in our information on <u>travelling</u>.

#### Insurance

When declaring your medical conditions, insurance companies will normally ask you if you've had surgery because of your Colitis. 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 <u>stoma</u>, 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 Colitis 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.

**CICRA** has more information on surgery in children with Colitis.

I was only 10 so I spent some time wearing a bag pre surgery to get used to it on my tummy, sometimes we filled it with water to get used to the sensation of it being full, we also put a bag on my teddy bear.

Lou

Living with Colitis



# Other organisations

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

 $\underline{\textbf{Royal College of Anaesthetists}} - \text{information for } \underline{\textbf{adults}} \text{ and } \underline{\textbf{children}}$ 

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: <a href="mailto:crohnsandcolitis.org.uk/livechat.">crohnsandcolitis.org.uk/livechat.</a>

#### 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 <a href="mailto:crohnsandcolitis.org.uk/membership">crohnsandcolitis.org.uk/membership</a> 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 <a href="mailto:evidence@crohnsandcolitis.org.uk">evidence@crohnsandcolitis.org.uk</a> 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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Patient Information Forum