
Living with a stoma

This information is for people with Crohn's or Colitis who have a stoma or might be getting one. It explains what a stoma is, why you might need one and what different types there are. It covers how to look after your stoma and how to manage common worries about stomas.

We have separate information on [Surgery for Crohn's Disease](#) and [Surgery for Ulcerative Colitis](#).

Contents

Key facts about living with a stoma	2
What is a stoma?	2
Who might need a stoma?	3
Types of stoma	4
What other options are there?	10
Planning a stoma	11
Stoma supplies	12
Learning how to manage your stoma	18
Stoma care	20
Eating and drinking with a stoma	23
Life with a stoma.....	26
Stoma problems and how to deal with them	35
Crohn's & Colitis Healthcare Direct	42
Other organisations	42
Help and support from Crohn's & Colitis UK.....	42
About Crohn's & Colitis UK	44

Key facts about living with a stoma

- A stoma is an opening made by a surgeon on the wall of your tummy. It brings your bowel to the outside. Poo comes out of the opening into a bag you wear on your tummy.
- You might need a stoma if you have surgery to remove part of your bowel.
- Some stomas are temporary. They give your bowel time to heal after surgery. Some stomas are permanent.
- Stomas can be made from your small bowel. These are called ileostomies. Or they can be made from your large bowel. These are called colostomies.
- You can get different types of stoma bag in lots of shapes and sizes. Your stoma nurse will help you find one that suits you.
- It takes time to become confident looking after your stoma. But with practice, people usually find a routine that works for them.
- Most people with a stoma can eat a normal, balanced diet. Like everyone with Crohn's or Colitis, there might be some foods or drinks that are a problem for you.
- Having a stoma should not stop you doing the things you enjoy. But it will take time to adjust to your stoma, the changes in your body, and how you feel about it. Most people with a stoma agree that it is almost always better than they expected.
- You will sometimes have problems with your stoma. Your stoma nurse can help you with these.

What is a stoma?

A stoma is an opening on the wall of your tummy that brings your bowel to the outside. If you have a stoma, the contents of your gut do not travel all the way through your bowel to come out of your bottom. Instead, they come out of the stoma into a bag you wear on your tummy.

An ostomy is another name for a stoma. Some people who have stomas call themselves 'ostomates'.

If you have a stoma, you're not alone. Around 190,000 people in the UK have a stoma.

Who might need a stoma?

You might need a stoma if you have surgery to remove part of your bowel. Your IBD team might suggest this if:

- You have severe Crohn's or Colitis that is not responding to medicines
- You have ongoing symptoms even when you are on appropriate treatment
- You are not able to come off steroids
- You have serious complications in your bowel, like severe bleeding, a blockage or narrowing (stricture), a tear in your bowel wall, or a serious infection
- You have bowel cancer, or a high risk of getting bowel cancer

Some people choose to have a stoma if they feel it will improve the quality of their lives. This might be because they feel it will relieve their symptoms, or because they prefer the idea of a stoma to treatment with medicines. If you are thinking about stoma surgery, talk to your IBD team. You can decide together on whether it is appropriate for you.

Not everybody who has part of their bowel removed needs a stoma. Sometimes, surgeons join the cut ends of the bowel back together straightaway. If you need surgery, your surgeon will talk to you about your options.

Types of stoma

There are different types of stoma. They have names based on:

- Whether they're temporary or permanent
- The part of the bowel they're made from
- Exactly how they're made

Temporary or permanent stoma

Stomas can be temporary or permanent. About half the people who need a stoma have a temporary one and half have a permanent one.

Temporary stoma

If you have surgery to remove part of your bowel, the joined ends of the bowel can be delicate and leaky at first. Or sometimes it might not be appropriate to join the bowel straightaway. A temporary stoma keeps the contents of your gut away from the delicate sections of bowel. This gives your bowel time to heal. Once it's healed, you have more surgery to remove the stoma. This is usually months or sometimes years later.

Depending on the type of surgery you've had, you might need more than one operation to reverse the stoma. After stoma reversal, you usually have a scar 1 to 2cm longer than the stoma. This might be a straight line or a circle.

Some people decide they do not want to have the stoma reversed. Sometimes, it cannot be reversed.

Initially my stoma was going to be temporary but in time I decided I wanted to keep it. I had got so used to it and the freedom it brought me, I didn't want to jeopardise having my life back. So I made the decision to not have a reversal.

Louise

Living with a stoma for Colitis

You might have a temporary stoma if you have part of your small bowel or large bowel removed, but you keep your anus.

Permanent stoma

Some stomas cannot be reversed. These are called permanent stomas. You might need a permanent stoma if:

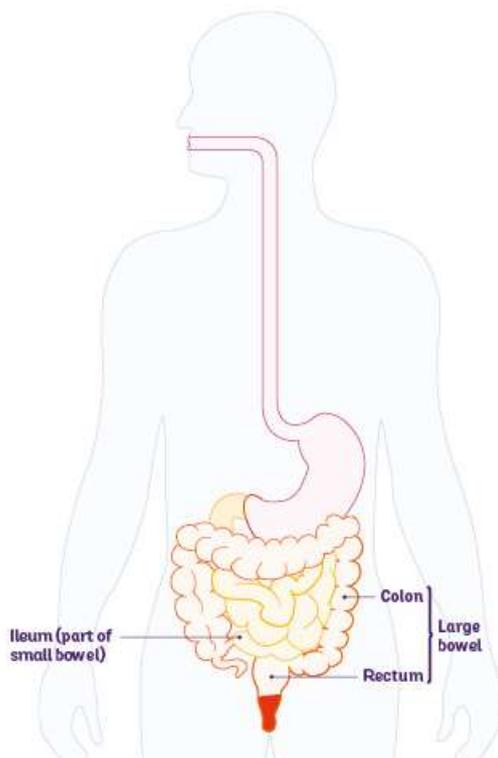
- You have a large section of your bowel removed and the cut ends cannot be joined back together
- You have your back passage (anus) removed

Some people have a temporary stoma at first but later choose to keep it.

Ileostomy or colostomy

An ileostomy is made from a part of your small bowel called the ileum. A colostomy is made from a part of your large bowel called the colon.

The gut



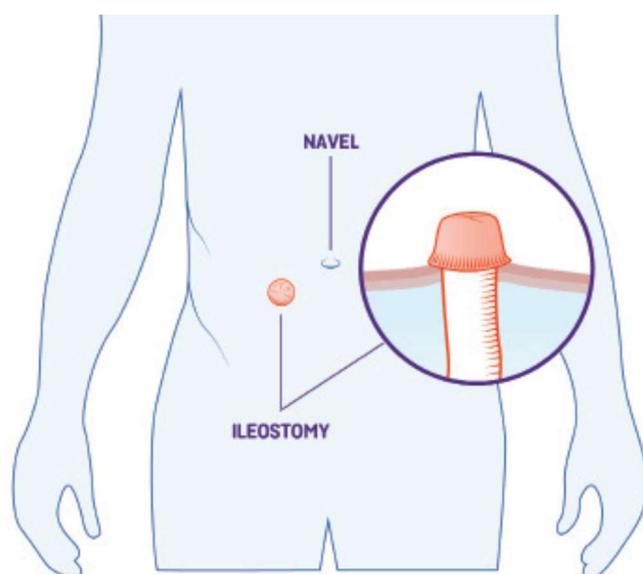
People with Colitis who need a stoma usually have an ileostomy. People with Crohn's who need a stoma might have an ileostomy or a colostomy, depending on which part of the bowel is affected.

Ileostomy

Surgeons make an ileostomy by joining a section of your small bowel to the surface of your tummy. They make a short spout of bowel that sticks out about 2 to 3cm above your skin. This means the contents of your bowel, called your 'stoma output', can empty straight into the stoma bag without touching your skin.

Ileostomies are usually low down on the right side of your tummy. But they can be in other places on your tummy depending on the exact surgery you're having, and your preferences. Your surgeon and stoma nurse will talk to you about where to put the ileostomy before you have surgery. This will include a discussion about your comfort and wellbeing with the stoma.

An ileostomy



An ileostomy is red or pink and feels warm and moist when you touch it. It does not have any nerve endings so it does not hurt to touch it.

The output of an ileostomy is usually quite liquid – like a paste or porridge. But this can vary. It also changes depending on what you have had to eat or drink. It does not flow all

the time. Wind also comes out of the stoma into the bag. You cannot control when the stoma empties into the bag.

Most people with an ileostomy use drainable stoma bags that you empty down the toilet. You empty them when they are less than half full – usually around 4 to 6 times a day. You often need to empty them during the night too. You usually need to change the bag every 1 to 3 days. Some people prefer to change them more often.

Continent ileostomy

Some people with Ulcerative Colitis might be able to have a 'continent' ileostomy. This is also called a 'Kock pouch', after the person who first did the operation. The surgeon uses part of your small bowel to make an internal pouch that can store your bowel contents. They attach this to an ileostomy with a valve that does not let the contents out. So you do not have to wear a bag. Instead, you use a special tube to empty the ileostomy into the toilet a few times a day.

Surgery to make a continent ileostomy is complicated. It is not often done in the UK. People who have one often need to have more surgery if the valve stops working properly or if the stoma gets too narrow. But most people who have one say they are satisfied with it even if they need more surgery.

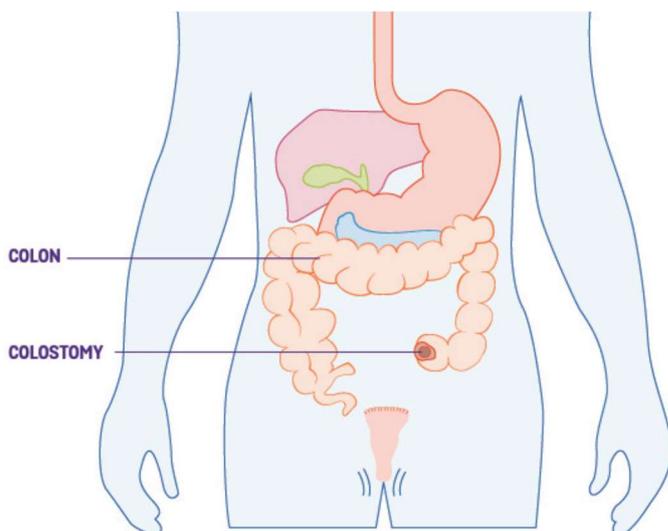
A continent ileostomy is not suitable for people who have Crohn's.

Colostomy

Surgeons make a colostomy by joining a section of your large bowel to the surface of your tummy. A colostomy is often quite flat to your skin, or only sticks out a small amount.

Colostomies are usually low down on the left side of your tummy. But they can be in other places on your tummy depending on the exact surgery you're having, and your preferences. Your surgeon and stoma nurse will talk to you about where to put the colostomy before you have surgery. This will include a discussion about your comfort and wellbeing with the stoma.

A colostomy



The output of a colostomy is usually semi-solid and can be like normal poo. But this varies depending on how much of your large bowel you have left. If you do not have much large bowel left, the output will be more liquid. Your stoma output also depends on what you've had to eat and drink. Many people say their colostomy gets into a pattern of being active at certain times of the day or a certain length of time after they've eaten. But you do not have any control over when the stoma empties into the bag. Wind also comes out of the stoma into the bag.

Most people with a colostomy use sealed stoma bags that you change when they are a third to a half full. Drainable bags are not usually suitable because the stoma output is too solid. You usually need to change a colostomy bag 1 to 3 times a day, but this varies from person-to-person.

Some people with a colostomy might be able to wash out (irrigate) their bowel through their stoma instead of wearing a bag. This involves using a special tube to wash out the poo with warm water. It can take around an hour and you usually have to do it every day. In between, you wear a cap to cover your stoma. If you think this might suit you, talk to your stoma nurse.

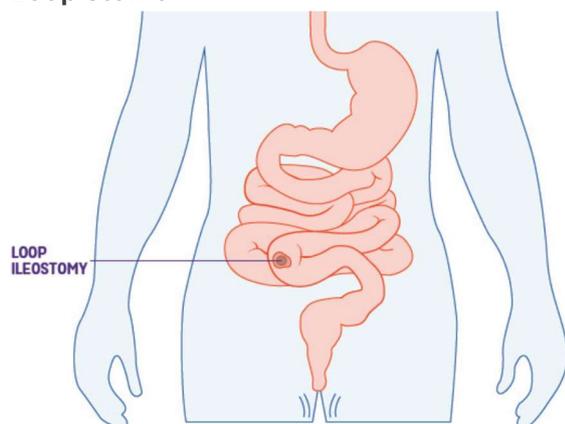
Do not irrigate your stoma unless your stoma nurse has taught you how to do it properly.

Loop and end stomas

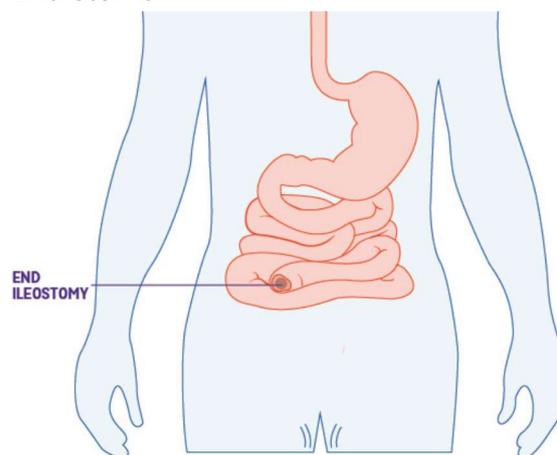
Stomas can be made from:

- A loop of bowel. These are called loop stomas.
- The cut end of the bowel. These are called end stomas.

Loop stoma



End stoma



Loop stoma

A loop stoma is made when a surgeon brings a loop of bowel to the surface of the tummy. They make an opening in the wall of the bowel and use this to make a spout that they stitch to the skin of your tummy. The contents of your bowel pass through the spout into your stoma bag. Bowel contents do not go through the other end of the loop, although you can sometimes get some overspill into the part of your bowel that is not being used. The lining of your bowel can also make mucus. So you might pass some mucus through your back passage. This can be poo-stained.

Loop stomas are usually temporary. They can be made from:

- The small bowel: a loop ileostomy
- The large bowel: a loop colostomy

End stoma

An end stoma is formed from the cut end of the bowel. The surgeon brings the end of the bowel to the surface, folds it over and makes a spout that they stitch to the skin of your tummy. The rest of your bowel is not connected to the stoma, so your bowel contents can only pass through the stoma. They cannot move on through the rest of your bowel.

The lining of any bowel you have left can make mucus. So if you still have a back passage, you might pass some mucus.

End stomas are usually permanent. They can be made from:

- The small bowel: an end ileostomy
- The large bowel: an end colostomy

What other options are there?

Before you have a stoma, your IBD team will talk to you about your treatment options. You usually have time to ask questions and talk to other people before deciding.

Pouch surgery

If you need to have all of your large bowel taken out, including your rectum, you might be given the choice between having a stoma or having pouch surgery. Your rectum is the very end of your gut that joins your large bowel to your back passage.

- In pouch surgery, a surgeon removes your large bowel and your rectum. The surgeon then uses part of your small bowel to make a pouch that can store poo. They join this pouch to your back passage. This means you can still poo out of your bottom. Pouch surgery is done in stages during two or three operations. You may have a temporary ileostomy while your bowel heals.
- People who have pouch surgery have a similar quality of life to people who have a permanent ileostomy. But pouch surgery is not right for everybody. It is not suitable for most people with Crohn's because the pouch can get inflamed (pouchitis).

Ileo-rectal anastomosis

If you need to have your large bowel taken out but you are keeping your rectum, your surgeon might be able to join your small bowel directly to your rectum.

- This operation is called an 'ileo-rectal anastomosis'. It means you can still poo out of your bottom and do not need a stoma.
- An ileo-rectal anastomosis is not right for everybody. For the operation to work, your rectum has to be healthy. Your rectum can still get inflamed after the operation. Most people need to keep taking anti-inflammatory medicines. Some people need more surgery.

You can find out more about pouch surgery and ileo-rectal anastomosis in our information on [Surgery for Ulcerative Colitis](#).

Planning a stoma

Most stoma surgery is planned in advance. You will meet your surgeon or specialist stoma nurse to talk about the surgery and what it's like to have a stoma. This might be at your usual hospital, or you might be referred to a different hospital.

Your stoma nurse or surgeon will ask about your lifestyle so you can discuss how having a stoma might affect you. They will cover things like:

- What happens during and after your operation
- Your work or education, and how much time you might need to take off
- Exercise
- Sex
- Eating with a stoma

They should give you written information to take away with you. They might also give you some stoma bags to practise with. Trying out a stoma bag before your surgery might help you feel less anxious. It can also help make sure you're happy with where your stoma will be.

You will have a chance to ask any questions you have. The surgeon or stoma nurse might be able to arrange for you to meet someone who already has a stoma.

Deciding where your stoma will be

Your stoma nurse or surgeon will talk to you before your surgery about where on your tummy your stoma will be. About 1 in 5 stomas are done as an emergency. In this case, there might not be time to plan where you will have your stoma beforehand.

An ileostomy is usually low down on the right side of your tummy. A colostomy is usually low down on the left side of your tummy. But they can be in other places.

Your surgeon or stoma nurse will look at your tummy to help choose the best place. They try to avoid areas of skin that have creases, scars or folds. They will try to place your stoma out of the way of the waistbands of your clothes. They will also talk to you about things that are important to you. This includes cultural or religious beliefs that might affect where you'd like to have your stoma. And practical issues, like being able to see your stoma well and reach it easily. It might not always be possible to have the stoma exactly where you'd like it.

Once you've agreed on the best place for your stoma, your stoma nurse or surgeon will mark it on your skin with a pen. They will check that you're happy with it.

Stoma supplies

We offer a stoma supply home delivery service, in partnership with Bullen Healthcare, an independent dispensing appliance contractor. Visit [Crohn's & Colitis Healthcare Direct](#) for more information.

Your stoma nurse will talk to you about the stoma supplies you'll need and explain the different options. You can also get information from stoma supply companies. Many of these have telephone helplines and information on their websites.

You get your stoma supplies on prescription. When you're in hospital, your stoma nurse will give you the supplies you need. You need a prescription to get more. Your stoma nurse might be able to prescribe these for you. They will also let your GP know exactly what supplies you need. Your GP will prescribe your supplies once you're at home, based on what your stoma nurse has recommended. If you need to change your prescription or order a different amount, check with your stoma nurse to make sure they're happy with the change.

In Scotland, Wales and Northern Ireland, prescriptions are free. So you do not have to pay for your stoma supplies.

In England:

- Prescriptions are free if you're under 16, under 18 and in full-time education, or over 60. If you have a temporary stoma and you are not in these age groups, you have to pay for prescriptions for your stoma supplies. You can get a [prescription prepayment certificate](#). This is cheaper than paying each time if you have more than one or two things on prescription each month. If you are on a low income, you can apply to the [NHS Low Income Scheme](#) for help with prescription costs.
- If you have a permanent stoma, stoma supplies are free on prescription whatever your age. If you do not usually qualify for free prescriptions, you will need to fill in a form to apply for them. You can get this from your GP surgery or your hospital doctor.

You can get your stoma supplies from a pharmacy or from a stoma supply company that delivers to your home. You can choose whichever suits you better. It's important not to order too many supplies in one go. Otherwise you might end up with a lot of wastage if your needs change.

Order your supplies in plenty of time so you do not run out.

Stoma bags

You can get different types of stoma bag. They come in lots of shapes and sizes. Some are clear so you can see the stoma output. Others are not.

The stoma bag that is right for you depends on:

- The type of stoma you have
- Where it is
- How far it sticks out from your tummy
- How solid your stoma output is
- Your body shape
- Your preference

Your stoma nurse will help you find a bag that works for you. Sometimes, you might need to change to a different bag. For example, your tummy might be swollen after surgery and you might need a different bag once the swelling goes down. Or your stoma might change shape over time and a different bag could work better for you.

One-piece or two-piece systems

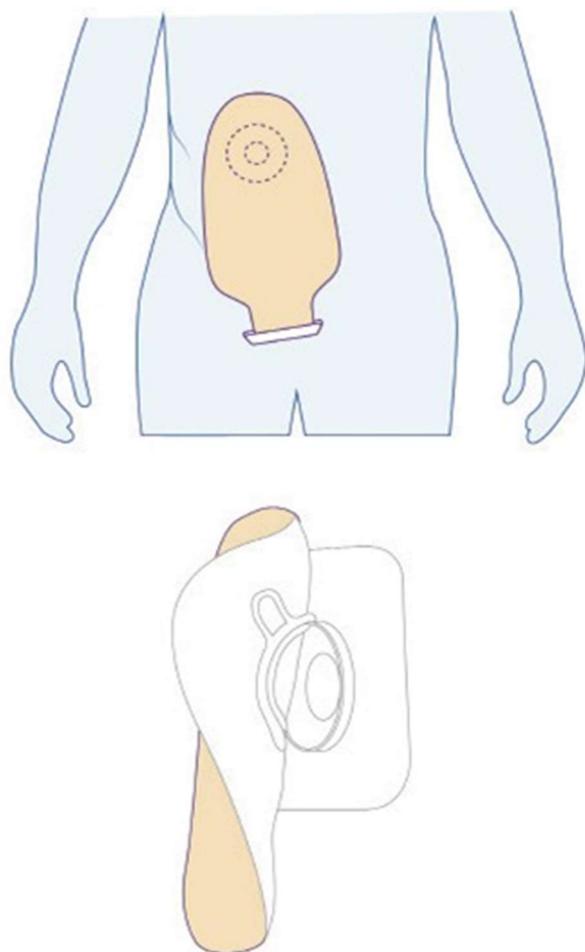
Stoma bags are made up of:

- The part that sticks to your skin. This is called the baseplate. Other names for it are the flange or faceplate.
- A bag that collects the stoma output. Most bags have a filter that lets wind out but keeps the smell inside.

In one-piece systems, the baseplate and bag are joined together. You use a new baseplate and bag every time you change your bag. This might be suitable if you change your bag once a day or less.

In two-piece systems, the baseplate and bag are separate. The bag attaches to the baseplate with a ring or adhesive. You can leave the baseplate on your skin for up to 4 days and change the bag as often as you need. If you need to change your bag several times a day, a two-piece system is probably a better option for you than a one-piece.

A two-piece stoma system



Closed or drainable bags

Bags can be closed or drainable.

- Closed bags are sealed. You cannot empty them. When they are a third to a half full, you have to change the whole bag. Closed bags are suitable for people who have fairly solid output – usually from a colostomy.
- Drainable bags have a Velcro fastening or clip that lets you empty the contents without having to change the bag. You only need to change the bag every 1 to 3 days. They are suitable for people who have liquid output – usually from an ileostomy.

A one-piece drainable bag



Shaped bags

Bags come in different shapes and sizes. You might use different ones at different times. For example, some people like to use smaller bags that sit flatter against their skin if they are going swimming.

Bags can also come in different shapes.

- If your stoma has a spout that sticks out from your tummy, a flat bag is probably OK.
- If your stoma is flat against your skin or pushes inwards, your stoma nurse might suggest a convex bag. This is shaped to help prevent leaks. Convex bags can put pressure on the skin around the stoma so you should only use them if your stoma nurse recommends it.

How many bags will I need?

This varies from person-to-person. But in general:

- People who have a colostomy use 30 to 90 closed stoma bags a month. If you use a two-piece system, you also need around 15 baseplates a month.
- People who have an ileostomy use 15 to 30 drainable bags a month. If you use a two-piece system, you also need around 15 baseplates a month.

Other products

Every stoma is different and every body shape is different, so there are lots of products available to help you manage your stoma. You can get many of these on prescription if your stoma nurse has recommended them for you.

Products your stoma nurse might recommend include:

- Skin wipes to clean and protect the skin around your stoma
- Sprays to remove the adhesive
- Stoma seals, rings or collars to help the bag fit better around your stoma and prevent leaks
- Skin filler pastes to fill creases and dips in the skin around your stoma and help the bag stick better
- Deodorising sprays or powders you can put in your bags if you're having problems with smells
- Belts or girdles to support your stoma and tummy muscles

A support belt



Learning how to manage your stoma

It can take time to become confident looking after your stoma. But with practice, most people get into a routine that works for them. Your stoma nurse is there to help you. They are usually your main point of contact before surgery, while you are in hospital and once you are back home.

Most people who have a stoma say they can tell when their bag needs emptying or changing from the weight of it.

In hospital

Your stoma nurse should come to see you the day after your surgery. They will check on your stoma and the skin around it. They will help you choose a stoma bag that is right for you and show you how to change it.

To start with, I was very self-conscious about my stoma and constantly worried if people could see it through my clothes. Now, I hardly think about it and sometimes forget it's even there. Taking care of it is like second nature and I don't let it stop me from doing any of the things I want to do. I live a very active life, not in spite of but because of my stoma and the stability it's given me.

Samantha

Living with a stoma for Crohn's

While you are in hospital, your stoma nurse will also talk to you about:

- Eating and drinking with your stoma.
- Any changes you might need to make in your day-to-day life.
- Any concerns you have about body image, relationships or sex.

- Exercises to reduce your risk of getting a hernia. A hernia is a bulge under the skin around your stoma. It happens if some of your bowel pushes through the gap in your tummy muscles around your stoma.

They will give you written information, and give you details of organisations or support groups that you might find helpful.

They will check how well you are adjusting to having a stoma. If you need it, they can refer you for counselling.

Before you go home

Before you go home, your stoma nurse should:

- Check you know how to look after your stoma, and that you're able to do it yourself
- Tell you how to spot problems with your stoma, and what to do about them
- Make sure you know who to contact if you need to
- Talk to you about getting back to your day-to-day life after surgery
- Give you information about eating with a stoma
- Explain what to do with your used stoma supplies
- Give you enough stoma supplies for at least 2 weeks
- Explain how to get more stoma supplies when you need them

If you have any questions or concerns, tell your stoma nurse. Make sure you have their contact details.

At home

In the first few months after you go home, your stoma nurse might:

- Visit you at home
- See you in clinic
- Talk to you by phone or online

They will check your stoma is healthy and your stoma supplies are suitable. They will make sure you feel confident looking after your stoma. They will also talk to you about how you are adjusting to your stoma in your day-to-day life, including your relationships.

Once you're confident looking after your stoma, you'll have a review once a year with your stoma nurse. But you can contact them in between if you have any issues.

If you need to change your stoma supplies, your stoma nurse should let your GP and hospital team know.

You become so in tune with your stoma. I know instantly when there's the slightest leak or blockage, I know what she likes or dislikes to eat, sometimes she likes to be hidden, sometimes she likes to be on show – it all depends upon my mood!

Louise

Living with a stoma for Colitis

Stoma care

It's important to look after your stoma and make sure the skin around it stays healthy. Check it when you change your bag. Stomas are usually pinkish-red and about the size of a 50p piece. They can sometimes change size or shape, especially if your weight changes.

A stoma



Your stoma might bleed slightly when you change your bag. This is common. The bleeding should stop quickly. But if the blood is coming from inside your bowel, contact your stoma nurse.

Contact your stoma nurse if you are worried about any changes to your stoma or the skin around it.

I often get funny looks or rude remarks made if I use a disabled toilet - but I need to use a disabled toilet for when I change my stoma bag. Rather than be angry at the person, I try to explain to them why I'm using this particular toilet, and that not all disabilities are visible.

Ailish

Living with a stoma for Colitis

If you have a stoma, you are entitled to use accessible toilets. Some accessible public toilets are kept locked. You need a Radar key to open these. Crohn's & Colitis UK

members can request a Radar key as part of their [membership package](#). You can also buy keys from The [Radar Key Company](#) or [Disability Rights UK](#).

The instructions below are for people with a one-piece system, or for people with a two-piece system who are changing both their bag and baseplate.

How to change your stoma bag and baseplate

1. Take off your used stoma bag and baseplate.
2. Get rid of your used supplies. In some areas, you will need to use a clinical waste bag. Your stoma nurse can tell you what's needed where you live.
3. Clean the skin around your stoma with water or wipes. Make sure it is completely dry.
4. Measure the size of your stoma. Your stoma supplies should have a measuring guide you can use. Once your stoma has settled, it might not change size or shape much and you can skip this step.
5. Cut a hole in the baseplate the same size and shape as your stoma. Once your stoma has settled, you can get baseplates precut by your stoma suppliers if you prefer.
6. If you use a two-piece system, you can attach a bag to the baseplate before you stick it on. Or you can apply the baseplate on its own and attach the bag later.
7. Take off the backing paper and stick the baseplate to your skin. Hold it in place for about 30 seconds.
8. If you use a two-piece system, attach the bag to the baseplate if you have not already.

You could wear disposable gloves when you change your bag. This might be helpful if you are Muslim and you wish to keep your right hand clean. Or you could try changing your bag one-handed, although this can be difficult.



I felt, since having an ileostomy, that I was not worthy enough of praying because I felt that no matter how much I cleaned out my bag there would always be some form of wastage left in. I decided to speak to a notable Imam (teacher) in my local town, who reassured me and explained that emptying the bag was enough. My feelings of impurity were perhaps misplaced. The Imam told me there is flexibility to accommodate a variety of circumstances and I should pray as normal.

Muneeb

Living with a stoma for Crohn's

Eating and drinking with a stoma

Having a stoma does not mean you cannot enjoy eating and drinking. Once you've recovered from surgery, you should be able to eat a normal, balanced diet. If you follow a particular diet for cultural, religious or ethical reasons, you should still be able to do this. But there might be some foods or drinks that make your stoma more active or give you

bad wind. This is different for everyone. Foods that are OK for you might not be for someone else, even if they've had the same surgery as you.

It can take a while for your gut to recover from stoma surgery. At first, you might not feel like eating much. While you're in hospital, your healthcare team will help you gradually increase the amount you eat and drink.

You might find it easier to start with plain, light foods that are easy to digest. It can help to eat five or six small meals a day instead of a few larger ones. You can add new foods gradually, to find out what works for you. If a food causes problems with your stoma, you could stop eating it for a while and then try it again. If it still causes problems after a few tries, you might want to avoid it in future.

Some foods or medicines, like beetroot, strawberries, food colouring or iron tablets, can change the colour of your stoma output. This is not harmful but it might be worrying if you're not expecting it. You do not need to avoid these foods if they are not causing problems with your stoma.

We have more information on [Food](#) for people living with Crohn's and Colitis.

Eating and drinking with an ileostomy

If you have an ileostomy, food passes through your small bowel but not your large bowel. Most of the goodness from food is absorbed in your small bowel. The large bowel is where water and salts are usually absorbed. As you recover from surgery, your small bowel slowly adapts and gets better at absorbing water and salts. But your stoma output will still be quite runny, and you lose more salt from your body than you used to.

Some people with an ileostomy can develop short bowel syndrome. This is when the amount of bowel you have left is too short to absorb food and water properly. If you have short bowel syndrome, your symptoms might get worse symptoms if you drink too much. Your IBD team can tell you if you have short bowel syndrome, and how to manage it.

Most people with an ileostomy can eat a healthy diet without problems. But you will need to drink more than you used to so you do not get dehydrated. You might also need to add

extra salt to your food – about a teaspoon a day is recommended. This is especially important in hot weather, when you also lose salt and water in your sweat.

If you want to, you can drink caffeine and alcohol (within healthy limits). But they can increase your stoma output. Fizzy drinks might cause more wind in your stoma bag.

I always drink plenty of fluids to help keep the output a porridge consistency. I find if I do not drink enough then output slows and blockages are more likely. If I get a blockage I have a drink and gently massage the area around the stoma, which helps move the output into the bag. Moving around also helps.

Michelle

Living with a stoma for Colitis

Fibre is not absorbed in your small bowel. So high-fibre foods, like wholegrain foods, raw fruit and vegetables, beans or lentils, can increase your stoma output. You might notice some foods, like sweetcorn, pass into your stoma bag undigested. You might have to empty your bag more often if you eat a lot of fibre. Some people notice that certain foods cause a lot of wind in their stoma bag.

An ileostomy is quite narrow, so some foods might cause blockages. Chewing your food well helps prevent this. You might want to avoid small, hard foods like sweetcorn, nuts and seeds. Peeling and cooking fruit and vegetables, and only eating small amounts of raw fruit and vegetables, can also help.

Eating and drinking with a colostomy

Once you have recovered from surgery, you should be able to eat a balanced, healthy diet. If you want to, you can drink caffeine and alcohol (within healthy limits). But they might make your stoma output more liquid. Fizzy drinks might cause more wind in your stoma bag.

Life with a stoma

Having a stoma should not stop you doing the things you did before your surgery. But you will take time to adjust to your stoma, the changes in your body, and how you feel about it. Everyone deals with their stoma differently and how it affects you will be personal to you. With time, you will find out what works for you. Your stoma nurse and your IBD team are there to help you.

Once they've adjusted to it, most people find that living with a stoma is much better than they expected. Many people find it a positive experience. No longer being in pain or having diarrhoea means they can do more of the things they did before they had Crohn's or Colitis. They also say they feel more confident leaving the house, knowing they will not have to rush to the toilet.

Long gone are the days when stomas and bags were reserved for the elderly - check out all the positive stoma role models on social media. Young, fit, vibrant, living their best lives! Be proud of your bravery and own your story!

Louise

Living with a stoma for Colitis

Talking to family and friends can help you feel more positive about your stoma. Most people also find it helps to talk to others who have a stoma, especially if they are at a similar stage in their life. Some people tell us they find it helpful to look on social media for positive role models who have stomas. You might like to read some of our blog posts about life with a stoma, like [Anna's story](#), [Lauren's story](#) or [experiences of men with stomas](#).

You could join a stoma support group, where people share their experiences. Ask your stoma nurse if there are any in your area, or any virtual support groups you could join.

Some people who have spiritual beliefs find these can help them adjust.

Your emotions

Having a stoma is a big change and it can affect how you feel. Many people have difficult feelings at first. You might feel low, angry or hopeless, or that you have lost control over your body. You might find it especially difficult if you had your stoma surgery as an emergency, without the chance to get used to the idea beforehand. Some people might become depressed.

I had an emergency ileostomy in 2011. At that time I had never even heard of Crohn's or Colitis. It was a long and challenging journey, but with the support of family, friends and IBD nurses I have grown in confidence to show my body and scars. I have named my stoma Joey and talk about him to work colleagues, family, friends and on social media.

Laura

Living with a stoma for Crohn's

It can take a long time to come to terms with what you have been through and to manage your stoma alongside the social, sexual and work aspects of your life.

Your stoma nurse is there to help you with all aspects of having a stoma, including your feelings.

When I looked in the mirror after surgery I saw a completely different person. I would say affirmations to myself to help me mentally deal with this lifestyle change. I got back into exercising to help my body confidence and feeling like myself again.

Joel

Living with a stoma for Crohn's

Talking therapies can be very effective at helping you adjust to your stoma. Your GP or stoma nurse can help you access these. But the waiting lists can be long.

- In England, adults can refer themselves directly for [talking therapy on the NHS](#). You do not need a referral from your GP, but you do need to be registered with a GP.
- You cannot refer yourself for talking therapy in other nations of the UK. But in Wales, people over 16 can [register for online Cognitive Behavioural Therapy \(CBT\)](#). Scotland offers a [free telephone helpline](#) offering support for people with mental health problems.

We have more detail on talking therapies in our information on [Mental health and wellbeing](#).

Body image

Having a stoma can affect how you see yourself and how you feel about your body. At first, you might feel shocked or upset by the change to your body. Or you might feel positive about your stoma if you no longer have symptoms of Crohn's or Colitis.

I couldn't even look at my bag when I first got it; I felt ugly and disgusting. I now appreciate it more than ever as I know I wouldn't be here without it, but this doesn't mean I don't have difficult days.

Anna

Living with a stoma for Crohn's

Other people cannot usually see the stoma bag under your clothes. Emptying your bag regularly helps it lie flat against your body so it cannot be seen. Some people like to wear support belts or clothes with high waists, to help keep the bag flat against the body. You can also get underwear and swimwear specially designed for people who have stomas.

You should be able to wear the same clothes you wore before surgery. But some people choose to wear looser or tighter clothes to help hide the bag. Others are comfortable having their stoma on show. This is a personal decision. Do what feels right for you.

I went through a 9 hour operation to have my colon removed, so I was conscious of how I'd look and what my body would look like post-op. I now love it.

Ailish

Living with a stoma for Colitis

Getting out and about might help you feel more confident about your body. Talking about how you feel may also help. If you find it tricky to start the conversation, you could try using our [It Takes Guts](#) resources.

If you are struggling to adjust, talk to your stoma nurse or IBD team. They are there to support you.

Sex and relationships

Many people worry about how a stoma might affect their sex life. You might be worried about starting a new relationship. Or you might be anxious about how your partner will react to your stoma. Having a stoma should not stop you having an active sex life if you want one. But it can take time to adjust. Some people find that having a stoma improves their sex life because they no longer have symptoms.

Any person who didn't want to love me because of my stoma is not good enough for me anyway. We rock the world together, me and my little lifesaver!

Louise

Living with a stoma for Colitis

People with a stoma usually find their partners are not put off by it. As long as your bag is attached well, it should not get in the way of sex. If you're worried it might leak, try to empty it beforehand. You could choose a smaller, more discreet bag when there's a possibility you'll have sex. You can also buy attractive stoma covers and lingerie designed for stomas, which may help you feel more confident.

Do not use your stoma for sex. Bowel tissue is very fragile and can easily be damaged.

We have separate information about [Sex and relationships](#). This has more about how a stoma might affect your sex life, and when you might choose to tell someone you're dating about your stoma.

Fertility, pregnancy and contraception

Some people worry whether having a stoma will affect their fertility. Most people with Crohn's or Colitis have similar fertility levels to the general population. But surgery to the tummy or pelvis can sometimes cause scarring, which could affect your fertility. If you're planning to become pregnant, it's a good idea to talk to your surgical team about this. Find out more in our information on [Reproductive health](#).

Your fertility might be lower if you are in a flare. If you plan to start a family, try to wait until your Crohn's or Colitis is under control.

If you get pregnant, tell your stoma nurse early. They can talk to you about how being pregnant might affect your stoma and how having a stoma might affect your pregnancy.

When you are pregnant, your stoma might change size or shape. Some women develop a hernia or prolapse when they are pregnant.

- A hernia is a bulge under the skin around your stoma. It happens if some of your bowel pushes through the gap in your tummy muscles around your stoma.
- A prolapse is when part of your bowel sticks out of your stoma.

Rarely, your stoma might get blocked during your pregnancy. Your stoma nurse will tell you what to look out for and when to get advice.

Some people who have a stoma give birth naturally. But around 3 in 4 have a caesarean section. This is usually planned in advance. Emergency caesareans are no more common in people with a stoma than in other women. Your obstetric team will talk to you about the best option for you.

Babies born to women who have a stoma are usually healthy. But they are more likely to be born early and to be smaller than babies born to other women. This might be due to Crohn's or Colitis flares.

You are not likely to get a stoma when you are pregnant unless you need surgery urgently. If this is the case, you will only have surgery if your Crohn's or Colitis is a greater risk to your baby than the surgery.

Find out more in our information on [Pregnancy and breastfeeding](#).

Contraception

If you want to have sex but not get pregnant, think about what contraception to use. If you have only have a small section of bowel left, or you have a high stoma output, you might not absorb tablets properly. This means that contraceptive tablets might not work. But there are many other types of contraception that may suit you. For more details, have a look at our information on [Reproductive health](#). This covers contraception choices.

Ask your GP or stoma nurse for advice on contraception.

Exercise and physical activity

When you go home after surgery, you will probably be able to walk around and do light tasks. You will feel tired to start with but gentle exercise can help build up your energy levels.

I'm nearly 4 weeks post-surgery and amazed that I'm on no medication, not in any pain and able to eat normal food again. I can't wait to get back into exercising. I am trying to increase my walk distance each day and introducing more body weight exercises into my routine. I am trying to focus on upper and lower body exercises which don't target my abdomen too much, and the walks are helping me build my stamina back up.

Lauren

Living with a stoma for Colitis

Once you have recovered from surgery, your stoma nurse or physiotherapist might give you exercises to build up your tummy muscles. This helps prevent a hernia (a bulge under the skin around your stoma that can happen if some of your bowel pushes through the gap in your muscles where you had surgery).

Having a stoma should not stop you doing the sports you enjoy. In fact, many people find they can get back to doing the things they used to before they were ill. Build up the amount of exercise you do gradually. For heavier activities, you could wear a belt or girdle to support your stoma and tummy muscles.

Stoma bags are waterproof so you can go swimming. You can get filter covers to stop the filters getting wet. If you want to cover up your stoma bag, you can buy covers in different colours and patterns. You can also get swimwear that is specially designed for people who have a stoma. If you have a colostomy, you could use a stoma plug while you're swimming. Your stoma nurse can give you information about these.

Work

If you are going back to work after having a stoma, it's a good idea to talk to your employer about how they can support you. Some people worry how their employer or colleagues might react if they tell them they have a stoma. But most people find that telling people helps them understand their needs.

You might have had a long time off work before having your stoma. You might be looking forward to returning. But you might also feel anxious. When you first go back, you could ask for a phased return. Or you could ask for lighter duties to begin with. Some people work out a routine that means they do not have to change their bag too often at work.

We have information about employment for people living with Crohn's and Colitis in our [Guide for employees](#). We also have a [Guide for employers](#), which you could show your manager or HR department.

Education

If you, or your child, are returning to education after having a stoma, you may want to contact staff to discuss what support you or your child need. You might find our [information for schools, colleges and universities](#) helpful. Or Colostomy UK have a [Junior Ostomy Support Helpline](#) (JOSH) that provides support for parents and carers of young people living with a stoma.

Travel

Having a stoma should not stop you travelling, but it takes a bit more planning. Often people find that travelling is easier with a stoma than it was when they had Crohn's or Colitis symptoms.

Ask your surgical team how long you should wait after your stoma surgery before it is safe to drive. You should also check with your car insurance company. If you are travelling as a passenger, it's sensible to make sure you can move around easily and sit comfortably before going on a trip.

The UK Civil Aviation Authority recommends that you do not fly for 10 days after having abdominal surgery. This is to reduce your risk of complications. You are likely to need a 'fit-to-fly' certificate or medical information form from your doctor if you plan to fly sooner. You usually pay for this. It's a good idea to take your stoma supplies in your hand luggage, in case your hold luggage is delayed or lost.

We have more information about [Travelling with Crohn's or Colitis](#), which covers holidays, business trips and longer travel. It includes information for people who have a stoma.

Taking medicines

If you have a stoma, your body might not fully absorb tablets or capsules. Instead, they might pass straight through your gut and come out into your stoma bag. Slow-release tablets and capsules are not suitable for people who have a stoma. Liquids, uncoated tablets or tablets that dissolve in water may work better. Your GP or pharmacist can advise you on what medicines are suitable for you.

Colonoscopy for people with a colostomy

If you have any of your large bowel left after your stoma surgery, you could get Crohn's or Colitis in the remaining bowel. There is also a chance you could get cancer in the bowel you have left. This means you might still need to have colonoscopies. In this case, you have the colonoscopy through your stoma instead of through your back passage. Colostomy UK have a booklet about [having a colonoscopy through a stoma](#) (PDF).

We have separate information on the [risk of bowel cancer in people living with Crohn's or Colitis](#).

If you receive a [bowel cancer screening test by post](#) (a 'FIT' test), call the government's free helpline on 0800 707 60 60. They can check whether it is appropriate for you to do it. If you cannot call the government helpline, you could ask your GP.

Other health issues

People who have a stoma can also have other health conditions. This might affect their ability to manage their stoma. In particular, having dementia can make it hard to look after a stoma.

- Colostomy UK have a booklet on [Caring for a person with a stoma and dementia](#) (PDF).
- The Ileostomy and Internal Pouch Association have an article about [looking after someone with dementia and an ileostomy](#) (PDF).

Stoma problems and how to deal with them

Before having a stoma, people are often worried about leaks, smells, how visible the bag is and how it will affect their everyday life. Most people who have a stoma agree that it is almost always better than they expected. But even when you are confident looking after your stoma, you are likely to have issues from time to time. We cover some of the common problems here. Your stoma nurse will also tell you what to look out for and what to do if you have problems.

Leaks

Bags can leak if there is not a good enough seal between the baseplate and your skin. This might happen if the baseplate does not fit the shape of your body or fit snugly around your stoma. It can also happen if you lose or gain weight or if the shape of your stoma changes. It can be upsetting when your stoma leaks. But it does not usually happen often.

To help prevent leaks:

- Check that the hole in the baseplate is the right size and shape for your stoma
- Make sure there are no creases in the baseplate when you stick it to your skin
- Empty your bag regularly

If you are having problems with leaks, contact your stoma nurse for a review. You might need to switch to different stoma supplies.

Your stoma nurse will check your stoma to find out why your bags are leaking. They can recommend stoma supplies that might help prevent any more leaks. This might include:

- Different bags that fit your stoma and your body shape better
- Stoma seals, rings or collars to help the bag fit more snugly around your stoma
- Skin filler pastes to fill creases and dips in the skin around your stoma and help the baseplate stick better
- Flange extenders or tapes that help stick down the edge of your baseplate

Sore or itchy skin

It's important to make sure the skin around your stoma stays healthy. It should look the same as the skin on the rest of your body. But sometimes, you might get problems, like:

- Sore or burning skin. This can be a sign that you need to change your stoma bag. Or it might happen if your bag leaks and the contents irritate your skin. You can get skin wipes, sprays and powders that help protect your skin.
- Itchy, red skin. This could be because your skin is sensitive to the stoma products you're using. If you think your skin is reacting to your stoma bag, you could test it by attaching a bag to the other side of your abdomen to see if your skin still reacts.
- A skin infection. Your GP can give you treatment for this.

I had constant soreness and itchiness with the skin around my stoma. But the stoma nurses were great in finding alternative options and now everything is much better.

Kevin

Living with a stoma for Colitis

If your skin is sore, contact your stoma nurse for a review. They will check that your stoma bag fits snugly around your stoma. They can also recommend products to help protect your skin.

Wind or gas

As well as your stoma output, wind or gas pass from your bowel into your bag. You do not have any control over when this happens. Although it is sometimes noisy, most people find it's less of a problem than they thought it would be. Stoma bags have filters that absorb smells and let the wind escape.

Some people notice that certain foods cause a lot of wind or gas. Avoiding these can help reduce the amount of wind going through your bowel. You might need to experiment to find out what foods are a problem for you. Things like broccoli, beans and cheese cause wind for some people. Fizzy drinks and high-fibre foods can also cause wind. Taking in lots of air through smoking, chewing gum, drinking through a straw or sucking sweets might also increase the amount of wind in your gut.

If wind builds up in your bag, it is called 'ballooning'. If this happens regularly, contact your stoma nurse. They might suggest changing to a bag with a better filter. If you use closed bags, you could try switching to drainable bags so you can let the wind out.

High or watery output

If you have an ileostomy, you might sometimes get more output from your stoma than usual. This means you have to empty your bag more often, especially at night. And the output might be more watery. This can happen if:

- You have a tummy bug
- You are taking certain medicines, like antibiotics
- You've missed a meal
- You've eaten or drunk something that makes your stoma more active

If this happens, carry on drinking. Sports drinks or rehydration drinks such as Dioralyte are better than plain water. You can buy rehydration drinks from a pharmacy or supermarket. Or you can make your own by adding 6 teaspoons of sugar, 1 teaspoon of salt and half a teaspoon of sodium bicarbonate or sodium citrate to 1 litre of water. This is called St Mark's solution. You can add flavouring if you want. Eating salty foods will also help replace the salt you lose through your stoma.

Eating foods that thicken your stoma output might help. Starchy, low-fibre foods like white rice, bread, pasta, noodles and peeled cooked potatoes are good. Foods containing gelatine, like marshmallows or jelly, can also help. But these are made with pork or beef and are not suitable for people who do not eat pork or beef products.

If your stoma output stays high, you might get dehydrated.

Contact your hospital urgently if your output is more than 2 litres a day for 3 days or more.

Signs of dehydration include:

- Thirst
- Tummy cramps
- Feeling dizzy or faint
- Dark-coloured wee

Contact your stoma nurse if you get any of these symptoms.

They can advise you on the best things to eat and drink. They might also recommend anti-diarrhoeal medicines, like loperamide, or thickening sachets to put in your bag.

We have separate information about [Dehydration](#).

Diarrhoea and constipation

If you have a colostomy, you might get diarrhoea or constipation.

Diarrhoea could happen if:

- You have a tummy bug
- You are taking certain medicines, like antibiotics
- You've eaten or drunk something that makes your stoma more active

Eating foods that thicken your stoma output might help. Starchy foods like white rice, bread, pasta, noodles and peeled cooked potatoes are good. If your diarrhoea does not get better, your stoma nurse might recommend anti-diarrhoeal medicines, like loperamide.

Sometimes, you might get constipated. You can help prevent this by:

- Drinking plenty of fluid. Try to drink around 8 to 10 cups a day. But avoid caffeinated drinks like tea, coffee or cola – or swap to decaf versions.
- Eating enough fibre. Aim for five portions of fruit or vegetables a day. High-fibre foods that are easy to digest include bananas, sweet potatoes and porridge oats.
- Eating regular meals to keep your stoma working well.
- Exercising regularly if you can.

If your constipation does not get better, contact your stoma nurse. They might prescribe medicines to help, or suggest washing out (irrigating) your colostomy.

We have separate information on [Diarrhoea and constipation](#).

Pancaking

Some people with a colostomy find that their output collects around the neck of the stoma bag and does not fully drop down inside the bag. This is called pancaking. It can happen if your output is very thick or if the insides of your bag stick together and stop the output getting in.

To help prevent pancaking, you could try:

- Eating more fibre, like fruit and vegetables, beans, lentils, or brown bread, pasta or rice
- Drinking plenty of fluid
- Putting a drop of oil or lubricant inside the bag to stop it sticking together
- Putting a damp piece of scrunched up toilet roll inside the bag to help keep it open
- Blowing some air into your bag before you attach it
- Using a filter cover or sticker to help keep air inside your bag

If you have a problem with pancaking, tell your stoma nurse. They might suggest switching to a different bag.

Blockage

An ileostomy is quite narrow and can sometimes get blocked. Signs you might have a blockage include:

- Reduced stoma output
- Watery output (if the stoma is only partly blocked)
- Feeling sick or bloated
- Tummy pain

If your stoma is blocked, drinking lots of fluid and not eating for a while might be enough to clear the blockage. Moving around, massaging your tummy or having a warm bath can also help. After the blockage clears, your stoma might be more active than usual.

If your tummy pain gets worse or you are sick, go to your nearest A&E department.

Hernia

A hernia is a bulge around your stoma. It happens if some of your bowel pushes through the gap in your tummy muscles around your stoma. Up to 1 in 3 people with a stoma get one.

You can help prevent a hernia by:

- Doing exercises to build up your tummy muscles
- Keeping a healthy weight
- Not smoking

If you think you might be getting a hernia, contact your stoma nurse for advice.

If you have a hernia, it might help to wear a support belt or girdle to support your tummy muscles. You might also need to switch to a different bag to fit the shape of the bulge better. If your hernia is causing lots of problems, you might need surgery to fix it.

Smells

Stoma bags have filters that absorb smells. Your bag should not smell except when you change or empty it. If you are worried about leaving a smell, you could use a regular air freshener. People who have a stoma say that other people do not seem to notice any smell.

If you are having problems with smells, check the seal between the baseplate and your skin. Changing your bag more often might also help. Some people notice that certain foods make their bag smell, so you could try avoiding those.

If the problem does not get better, talk to your stoma nurse. You can get deodorising sprays or powders that go in your bag. You might need to change to a bag with a better filter.

Crohn's & Colitis Healthcare Direct

Your dedicated home delivery service

- A service for people living with a stoma, offering discreet and efficient delivery of your stoma products, as well as your prescription medications.
- Call 0800 142 2395, email info@crohnscolitishealthcaredirect.org or visit crohnsandcolitis.org.uk/healthcare-direct to register your interest and claim your free stoma support pack.

Other organisations

CICRA: A charity supporting children with Crohn's and Colitis, and their families:

www.cicra.org

Colostomy UK: A charity supporting and empowering people living with a stoma:

www.colostomyuk.org

IA (the Ileostomy and Internal Pouch Association): A national support group for people living with an ileostomy or internal pouch, their families, friends and carers:

iasupport.org/

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 crohnsandcolitis.org.uk/membership 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 crohnsandcolitis.org.uk.

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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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