Life with a stoma

Finding out that you need to have a stoma can be a lot to deal with. You might have questions about what this means for you and your future. But you're not alone, we're here to help. This information is for people with Crohn's or Colitis who have a stoma or might be getting one. This information looks at:

- What a stoma is
- Why you might need a stoma
- Different types of stomas
- How to look after your stoma
- How to manage common worries and problems

Where we use 'Colitis' in this information, we are referring to Ulcerative Colitis only. People with Microscopic Colitis are unlikely to have a stoma.

We have separate information on surgery for Crohn's Disease and surgery for Ulcerative Colitis. Our information on surgery includes what to expect on the day of your operation and what your recovery might look like.

This information might use words you have not heard before. Our page on medical words can help provide an explanation.

Contents

Key facts about life with a stoma

- A stoma is an opening made by a surgeon that connects an internal organ, like the gut, to the outside skin of the body. Around 1 in 335 people in the UK live with a stoma.
- Ileostomies and colostomies are types of stomas seen in Crohn's and Colitis. An ileostomy is made from the small bowel. A colostomy is made from the large bowel.
- Ileostomies and colostomies bring your bowel to an opening in the wall of your tummy. 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. Or you might need a stoma to stop gut contents travelling through part of your bowel.
- Stomas can be temporary or permanent.
- It takes time to become confident in 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. But 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.
- Sometimes, you might have problems with your stoma. Your stoma nurse can help support you with this.

What is a stoma?

- A stoma is an opening made by a surgeon that connects an internal organ, like the gut, to the outside skin of the body.
- Ileostomies and colostomies are types of stomas seen in Crohn's and Colitis.
- Stomas are usually pinkish-red. They can sometimes change size or shape, especially if your weight changes.
- An ostomy is another name for a stoma. Some people who have stomas call themselves 'ostomates'.

Click here if you would like to see a photo of a stoma

Types of stoma

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

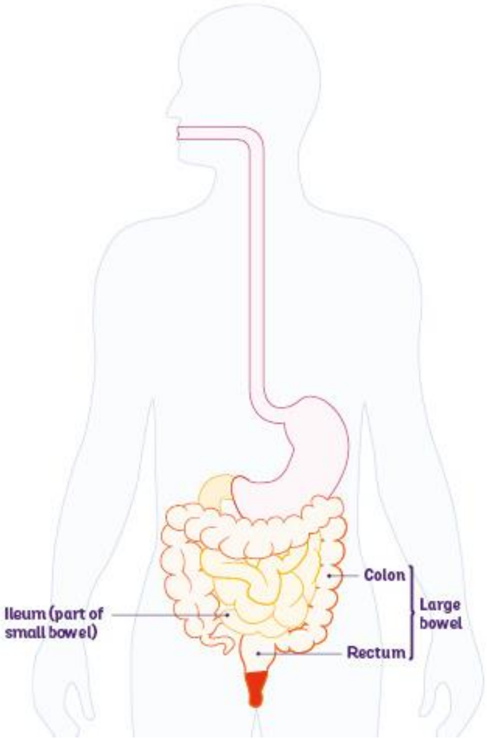
- Whether they're temporary or permanent
- The part of the bowel they're made from
- How they're made

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. This will depend on which part of the bowel is affected.

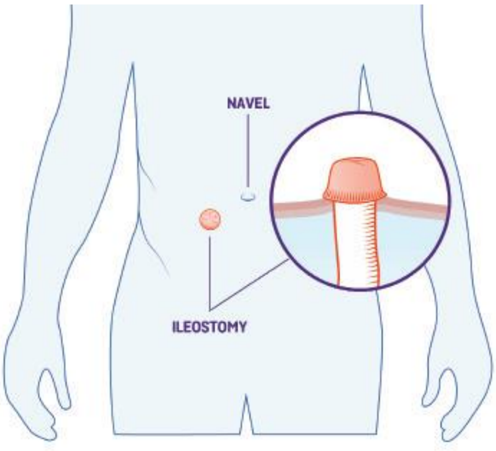
Your surgeon and stoma nurse will talk to you about where to put your stoma before you have surgery. This should include a discussion about your comfort and wellbeing with the stoma.

Ileostomy or colostomy

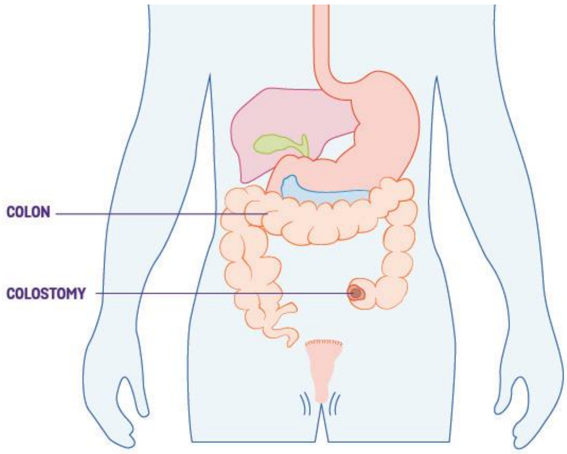
An ileostomy is made from a part of your small bowel called the ileum. A colostomy is made from a part of your large bowel called the colon.



Ileostomy



Colostomy



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 2cm to 3cm above your skin. This means the contents of your bowel, called your ‘stoma output’, can empty straight into stoma bag.

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.

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. Gas 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. This is 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.

Colostomy

Surgeons make a colostomy by joining a section of your large bowel to the surface of your tummy. A colostomy is often flat against 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.

The output of a colostomy is usually semi-solid and can be like normal poo. But this depends on how much of your large bowel you have left after surgery. 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 for a certain length of time after they've eaten. But you do not have any control over when the stoma empties into the bag. Gas also comes out of the stoma into the bag.

Most people with a colostomy use sealed stoma bags that they change when they are 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, or 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.

Temporary or permanent stoma

Temporary stoma

If you have surgery to remove part of your bowel, the joined ends of the cut bowel can be delicate and leaky at first. Or sometimes it might not be appropriate to join up 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 and join up the bowel. This is usually months or sometimes years later. Some people decide they do not want to have a temporary stoma reversed.

You might have a temporary stoma if you have part of your small bowel or large bowel removed, but you keep your anus. The anus is the opening where poo comes out of your body. 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 1cm to 2cm longer than the stoma width. This might be a straight line or a circle.

> **"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

Stoma reversal

Some people living with a temporary stoma choose to not have their stoma reversed. There are lots of different reasons you might choose to do this, these include:

- Not wanting to have another operation
- Not wanting to go through another recovery
- Being happy with the quality of life your stoma gives you

- Feeling that your quality of life with a stoma is better than the quality of life you might have after reversal

Deciding whether to have a stoma reversal is a personal decision, and it can take time to decide what is right for you. It's important to remember there is no right or wrong answer, and everyone is different. Talk to your IBD team or stoma nurse about your options. They can help support you in making this decision.

Permanent stoma

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

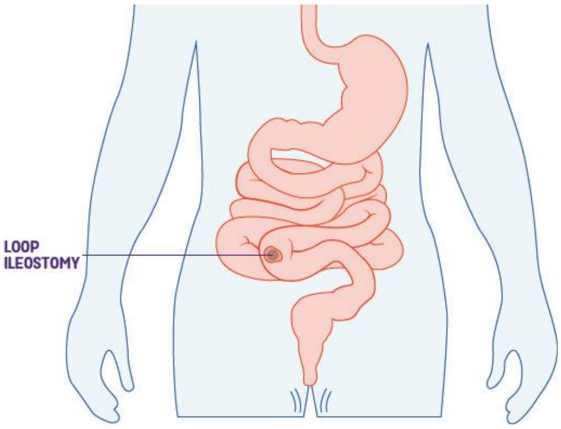
- You have a large section of your bowel removed, and the cut ends cannot be joined back together
- You have your anus removed

Loop and end stomas

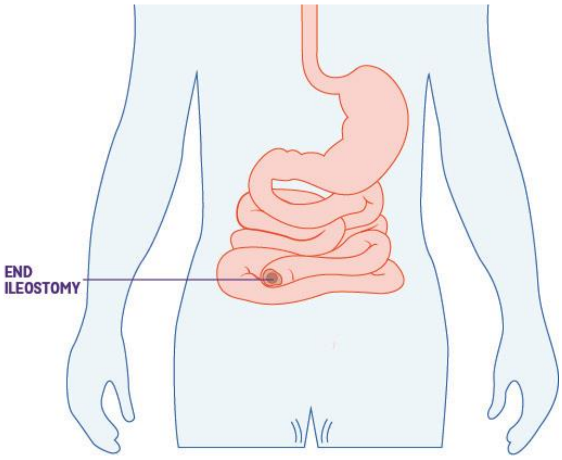
Stomas can be made from:

- 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 an opening in 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 bottom. This can be poo-stained.

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

- The small bowel, which is known as a loop ileostomy
- The large bowel, which is known as 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 an opening in 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. It 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 an anus, you might pass some mucus.

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

- The small bowel, which is known as an end ileostomy
- The large bowel, which is known as an end colostomy

Who might need a stoma

You might need a stoma if:

- **You have surgery to remove part of your bowel.**
- **You have Crohn's that affects your bottom and medicines are not helping to control it.**

Not everybody who has part of their bowel removed needs a stoma. Sometimes, surgeons join the cut ends of the bowel back together straightaway.

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 over 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.

> **"Stoma surgery is a really daunting thing to go through. Before, I couldn't go to the toilet without being in excruciating pain. Crohn's disease took away my quality of life. When I got my loop ileostomy I was 12 years old and it gave me my life back, I can now do more than I ever thought I would be able to!"**
>
> **Romana**
>
> Living with Crohn's

Emergency surgery

Around 1 in 5 stomas are made as an emergency. Getting a stoma is a big change for anyone. But having emergency surgery means you do not have a chance to prepare mentally or physically. You might find our information section on your emotions helpful.

What other options are there?

- **If you are thinking of a stoma surgery, your IBD team will also talk to you about other options. You should have time to ask questions and talk to other people before deciding.**
- **Other options might include pouch surgery, ileo-rectal anastomosis, or trying another medicine.**
- **You can find out more about pouch surgery in our information on surgery for Ulcerative Colitis.**
- **You can find out more about ileo-rectal anastomosis in our information on surgery for Ulcerative Colitis or surgery for Crohn's Disease.**

Pouch surgery

If you need to have all 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 bottom.

- 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 bottom. 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. This is called 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.
- People with an ileo-rectal anastomosis might need to poo between two and six times a day.

Planning a stoma

- Most stoma surgery is planned. But around 1 in 5 stomas are made as an emergency.
- Your surgeon or stoma nurse will look at your tummy to choose the best place for your stoma. An ileostomy is usually low down on the right side of your tummy. And a colostomy is usually low down on the left side of your tummy.
- You might find it helpful to talk to someone who has a stoma before you have surgery. The Ileostomy & Internal Pouch Association provides support volunteers who can talk to.
- Our information on surgery for Crohn's and Colitis can help you understand what to expect on the day of surgery.

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. You should have time to ask questions and talk to other people before deciding.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. If your stoma is made as an emergency, there might not be time to plan where you will have your stoma beforehand.

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. Also 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.

> **“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 live, not in spite of but because of my stoma and the stability it's given me.”**
>
> **Samantha**
>
> Living with a stoma for Crohn’s

Stoma bags and other products

Crohn’s & Colitis UK offer a stoma home delivery service in partnership with Bullen Healthcare. You can visit Crohn’s & Colitis UK Healthcare Direct for more information.

- There are 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.
- Stoma bags come as one-piece or two-piece systems.
- Bags can be closed or drainable.
- Your stoma nurse will help you find a bag that works for you. They might also recommend other products to help you manage your stoma.

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

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

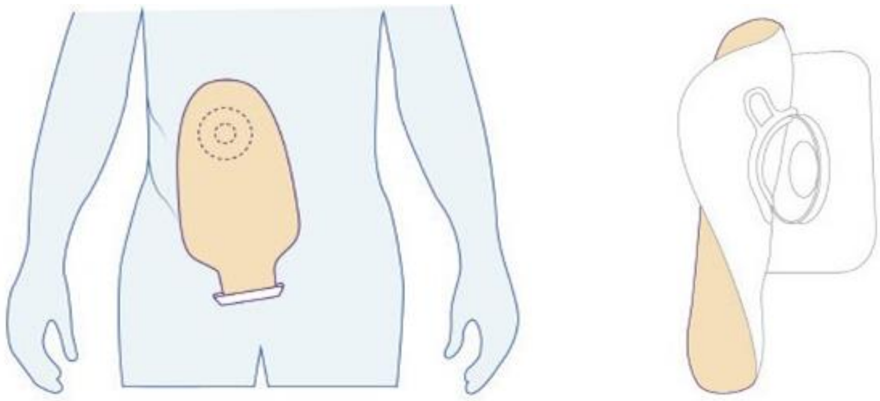
Stoma bags are made up of:

- 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 gas 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

Closed bags are sealed. You cannot empty them. 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.

- If your stoma has a spout that sticks out from your tummy, a flat bag should work.
- If your stoma is flat against your skin or pushes inwards, your stoma nurse might suggest a convex bag. The seal of the bag curves into your stoma 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.

Bags also come in different 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.

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 and every body shape is different. There are lots of products available to help you manage your stoma.

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 to put in your bags if you're having problems with smells.
- Belts or girdles to support your stoma and tummy muscles. These can be particularly helpful when exercising.

A support belt

Prescriptions for stoma supplies

- Your stoma nurse will talk to you about stoma supplies and the different available options.
- You will get your stoma supplies on prescription. Your GP will prescribe your supplies.
- In Scotland, Wales, and Northern Ireland prescriptions are free. You will not have to pay for your stoma supplies.
- In England, you can get free prescriptions if you have a permanent stoma. This means you will not have to pay for your stoma supplies. You will need to fill in a form to apply for this. You can get this from your GP surgery or your hospital doctor.
- If you have a temporary stoma, free prescriptions are only available to certain groups of people. This means you might have to pay for your stoma supplies. You can check if you can get free prescriptions or help with paying costs by speaking to your GP or using the **NHS website**.

When you're in hospital, your stoma nurse will give you the supplies you need. Once these run out, you'll need a prescription to get more. Your GP will prescribe your supplies when 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.

You can get your stoma supplies from a pharmacy, or from a stoma supply company that delivers to your home. You can choose what suits you better. Order your supplies in plenty of time so you do not run out. If you find you run out of supplies, contact your supplier or pharmacy. Out of hours pharmacies may also be able to help. You can find a pharmacy using the NHS website.

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. Unused and unwanted stoma supplies can be donated to charity. Colostomy UK has more information on this.

Prescription charges

If you must pay for your prescriptions it might be cheaper to get a prescription prepayment certificate.This is usually cheaper 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.

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.**
- **Your stoma nurse should come and see you the day after your surgery, and before you go home. They will also follow up with you when you go home.**

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.

Your stoma nurse can 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 lower 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.

Before you go home, your stoma nurse should:

- Check you know how to look after your stoma by yourself.
- Make sure you know who to contact if you need to.
- Give you information about eating with a stoma.
- Give you enough stoma supplies to go home with. This is usually a 2-week supply.
- Explain how to get more stoma supplies when you need them.

You may also want to ask your stoma nurse about:

- How to spot problems with your stoma, and what to do about them.
- What to expect while getting back to your day-to-day life after surgery.
- What to do with your used stoma supplies.

> **"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

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 that your stoma is healthy and that your stoma supplies are right for you. If you need to change your stoma supplies, your stoma nurse should let your GP and hospital team know. 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.

Guidelines recommend that you should have access to a stoma nurse, even if you've had a stoma for a long time.

Changing a stoma bag

- **Your stoma might bleed slightly when you change your bag. This is common, and the bleeding should stop quickly. But if there is blood in your stoma output or bag, contact your stoma nurse.**

- **It’s important to look after your stoma and make sure the skin around it stays healthy. Check your skin when you change your bag.**
- **Contact your stoma nurse if you are worried about any changes to your stoma, or the skin around it.**

How to change your stoma bag

These instructions are for people with a one-piece system, or for people with a two-piece system who are changing both their 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 come with 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

Accessible toilets

If you have a stoma, you can 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. You can also buy keys from Disability Rights UK.

Eating and drinking with a stoma

- You can still enjoy eating and drinking with a stoma. 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.
- Some foods or drinks might make your stoma more active or give you bad wind. But this is different for everyone.
- If you have an ileostomy, you will need to have more salt in your diet.

- **It is important not to cut foods out of your diet without talking to your dietitian or IBD team.**
- **We have more information on food for people living with Crohn's and Colitis.**

Eating and drinking after surgery

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. Do not cut foods out of your diet without talking to your dietitian or IBD team.

Eating 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. Most people with an ileostomy can eat a healthy diet without problems.

High-fibre foods, like wholegrain foods, raw fruit and vegetables, beans or lentils, might 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 gas in their stoma bag.

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.

An ileostomy is quite narrow, so some foods might cause blockages. Chewing your food well helps to prevent this. You might want to avoid small, hard foods like sweetcorn or nuts. Peeling and cooking fruit and vegetablescan also help.

Drinking with an ileostomy

If you have an ileostomy, food passes through your small bowel but not your large 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 may lose more salt from your body than you used to.

You will need to drink more than you used to, so you do not get dehydrated. Around 2 litres a day is recommended. You might also need to add extra salt to your food, about a teaspoon a day overall 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 gas in your stoma bag.

Short bowel syndrome

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, you might be told to limit drinks like tea, coffee or water. This is because your symptoms might get worse if you drink too much of these liquids.

Your IBD team can tell you if you have short bowel syndrome, and how to manage it.

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 gas in your stoma bag.

Life with a stoma

- Having a stoma should not stop you doing the things you did before your surgery. But it 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.
- It is natural to feel lots of different emotions after stoma surgery. 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.
- Talking therapies can be very effective at helping you adjust to your stoma. Your GP or stoma nurse can help you access these.
- Remember, your stoma nurse and 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.

Your emotions

Having a stoma is a big change, and it can affect how you feel. It is natural to feel lots of different emotions after stoma surgery. Many people have difficult feelings at first. You might feel low, angry or hopeless, or that you have lost control over your body. Some people grieve the future they thought they’d have.

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.

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. You might also find it helpful to talk to someone who has a stoma. The Ileostomy & Internal Pouch Association can provide further support.

Some people might become depressed after stoma surgery. It can be helpful to recognise your feelings and understand what you can do if this happens. You might find our information on mental health and wellbeing useful to support you with this. This information also looks at anxiety and how you can look after your mental health.

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, you may be able to refer yourself directly to an NHS talking therapies service without referral from a GP.
- In Scotland, you can refer yourself for an NHS assessment through Living Life.
- In Wales, you can register for an online cognitive behavioural therapy (CBT) programme through the NHS.

- In Northern Ireland, your GP can refer you. There is no NHS self-referral option.

We have more details on talking therapies in our information on mental health and wellbeing.

> **"Having a stoma completely changed my life – but over time, I found a way to turn that experience into something positive through my art. I started creating stoma-inspired characters to help express feelings I couldn't always put into words. I hope younger people especially can see that even with a stoma, you can still be creative, unique and proud of who you are."**
>
> **Natalie**
>
> Living with Crohn's

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 clothing that hides the bag. Others are comfortable having their stoma on show. This is a personal decision. Do what feels right for you.

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 Talking Toolkit.

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 your bag 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.

Some people with a stoma may not be able to have anal sex, depending on which part of their bowel was removed. We have separate information about this in our sex and relationships resource. It also covers 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

Many people living with Crohn's or Colitis are as fertile as people who are not living with Crohn's or Colitis. But some people worry whether having a stoma will affect their ability to have children.

Surgery to the pelvis can sometimes cause scarring. For women, this can affect their fertility. For men, this can lead to difficulties with getting an erection or ejaculating. If you're planning to have a child, it's a good idea to talk to your surgical team about this. You can find out more in our information on reproductive health and fertility.

Pregnancy

- **Not all pregnancies are planned. But if you are planning on having a child, try and talk to your IBD team. If you find out you are pregnant, contact your IBD team straight away.**
- **Your IBD team can help support you during pregnancy. They can talk to you about how being pregnant might affect your stoma and how having a stoma might affect your pregnancy. If you are unable to reach your IBD team, speak to your GP. Your GP may be able to help contact your IBD team.**

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 vaginally. But around 3 in 4 have a caesarean section. This is usually planned. Emergency caesareans are no more common in women with a stoma than in women without. Your 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 flare-ups.

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.

You can find out more in our information on pregnancy and birth.

If you want to have sex but not get pregnant, you can think about what contraception to use. If you have only 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, our information on sex and relationships covers contraception choices.

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.

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 hernia is when some of your bowel pushes through the gap in your muscles where you had surgery and causes a bulge under the skin.

Having a stoma should not stop you doing the exercise you enjoy· In fact, many people find they can go back to doing the things they used to before their operation. Build up the amount of exercise you do gradually. Do not rush or expect too much of yourself too quickly. For heavier activities, you could wear a belt or girdle to support your stoma and tummy muscles. Your stoma nurse can tell you when you can start playing contact sports again.

Stoma bags are waterproof, so you can go swimming if you want to. You can get filter covers to stop the filters getting wet. Some people like to use a smaller stoma bag when swimming. 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.

Colostomy UK have more information in their booklet: Active Ostomates- Sport and fitness after stoma surgery.

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.

If you have a stoma, you might be classed as disabled under UK law. See the section on stomas and being classed as disabled for more information. If you are classed as disabled, your employer has a duty to make reasonable adjustments. You can find out more about reasonable adjustments 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 need, or your child needs. You might find our information for schools, colleges and universities helpful. Colostomy UK have a young ostomates section on their website. This contains resources for young people and parents affected by stoma surgery.

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.

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.

Cancer screening

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 would have the colonoscopy through your stoma instead of through your bottom. 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, also called a 'FIT' test, call the government's free helpline on 0800 707 6060. They can check whether it is appropriate for you to do it. If you cannot call the government helpline, you could ask your GP.

Dementia and having a stoma

People who have a stoma can also have other health conditions. This might affect their ability to manage their stoma. For example, 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.**
- **Even when you are confident looking after your stoma, you are likely to have issues from time to time.**
- **Problems with any stoma may include leaks , sore or itchy skin , gas build-up , and hernias.**
- **Problems with an ileostomy may include increased output and blockages.**
- **Common problems with a colostomy may include diarrhoea , constipation and pancaking.**
- **If you are having difficulties, talk to your stoma nurse. They are there to help and support you.**

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 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

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 tummy to see if your skin still reacts.
- A skin infection. Your GP can give you treatment for this.

Wind or gas

As well as your stoma output, wind, or gas, passes 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 gas escape.

Some people notice that certain foods cause a lot of gas. Avoiding these can lower the amount of gas going through your bowel. You might need to experiment to find out what foods are a problem for you. Fizzy drinks and high-fibre foods often cause gas. Taking in lots of air through chewing gum or sucking sweets might also increase the amount of gas in your gut.

If gas 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 gas out.

Colostomy UK has more information on wind, ballooning and odour.

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. Up to 1 in 3 people with a stoma get a hernia.

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. Or you might need to change to a bag with a better filter.

Increased ileostomy output

There might be times when you have a higher output from your ileostomy. For example, if you have a tummy bug or are taking certain medicines. It is important to pay attention to your ileostomy output so you can recognise if things change.

Eating foods that thicken your ileostomy 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, so are not suitable for people who do not eat pork or beef products.

If your ileostomy output has increased, it's important to have fluids which are easily absorbed and stop you from losing salt. Sports drinks or rehydration drinks such as Dioralyte are better than water, tea and coffee. You can buy rehydration drinks from a pharmacy or supermarket. Or you can make your own by adding six teaspoons of sugar, one teaspoon of salt and half a teaspoon of sodium bicarbonate or sodium citrate to one litre of water. This is called St Mark's solution. You can add flavouring if you want, such as a small amount of sugar-free squash. Try and sip fluids slowly throughout the day. Eating salty foods will also help replace the salt you lose through your ileostomy.

If your ileostomy output stays high, you might get dehydrated. Signs of dehydration include:

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

Contact your stoma nurse if you get any symptoms of dehydration. Contact your hospital urgently if your output is more than 2 litres a day for 3 days or more.

Blockage

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

- Less 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.

Diarrhoea and constipation

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

Diarrhoea

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.

Constipation

You might get constipated sometimes. You can help prevent this by:

- Drinking plenty of fluids. Try to drink around eight to ten 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 or 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.

Stomas and being classed as disabled

If you have a stoma, you are not automatically classed as disabled under UK law. But you may be classed as disabled if:

- You were previously considered disabled. You are still covered by the law, even if your stoma keeps your Crohn's or Colitis under control.
- Your Crohn's or Colitis still has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

You can find out more about Crohn's and Colitis being considered disability in our guide for employees.

Some people living with a long-term health condition or disability are eligible for benefits. Our information on benefits and finances can help you find out about support you could get.

Crohn's & Colitis UK 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 information covers a wide range of topics. From treatment options to symptoms, relationship concerns to employment issues, our information can help you manage your condition. We’ll help you find answers, access support and take control.

All information is available on our website.

Helpline service

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

Our Helpline team can help by:

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

You can call the Helpline on 0300 222 5700. You can also visit our livechat service. Lines are open 9am to 5pm, Monday to Friday, except English bank holidays.

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

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

Social events and Local Networks

You can find support from others in the Crohn's and Colitis community through our virtual social events. There may also be a Local Network in your area offering in-person social events. Visit our Crohn's and Colitis UK in your area webpage to find out what is available.

Crohn's & Colitis UK Forum

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

Help with toilet access when out

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

About Crohn's & Colitis UK

Crohn's & Colitis UK is a national charity, leading the fight against Crohn's and Colitis. We're here for everyone affected by these conditions.

Our vision is to see improved lives today and a world free from Crohn's and Colitis tomorrow. We seek to improve diagnosis and treatment, fund research into a cure, raise awareness and give people hope and confidence to live freer, fuller lives.

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

About our information

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

You can find out more on our website.

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

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

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

We do not endorse any products mentioned in our information.

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