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The definitive guide to

living with a stoma

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Introduction

If you are reading this guide then chances are you've been told you need to have a stoma or you have had stoma surgery or perhaps you know someone with a stoma and you're looking for information to help your loved one through their stoma journey.

We know that having a stoma can be a confusing, bewildering and often scary time. In the space of a few hours you can go from having a completely 'normal' looking belly to suddenly having this little, crinkly, pink dome protruding from your abdomen demanding regular outfit changes and chatting to you loudly!

This guide has been developed to help you navigate the practical aspects of stoma ownership and point you in the direction of who you can talk to should you feel you need to. We'll cover the 'most asked' questions from what to eat through to what to wear and what you can do (which is, spoiler alert, anything you want, really).

We hope that this guide gives you the confidence to live your life to the fullest with your new stoma friend.



What is a stoma?

A stoma is an opening on the abdomen that allows urine and/or faeces to exit the body. A stoma is created by bringing a section of your bowel to the surface of your stomach, which can be made from either your large intestine (colon), small intestine or connected to your urinary system.

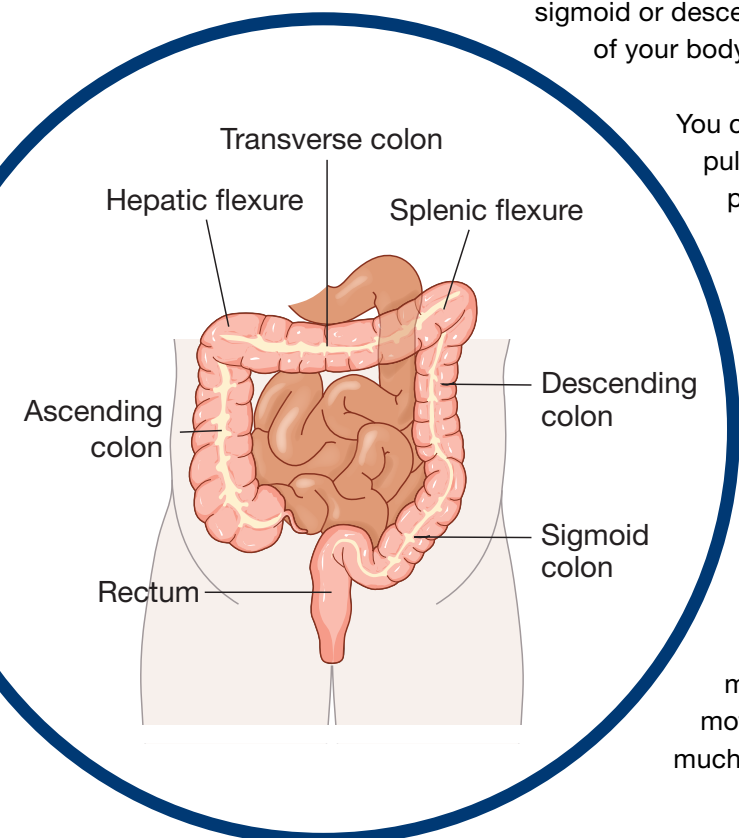
Your stoma may lay fairly flat to the body or protrude out like a spout. Some people even say a stoma resembles the shape, colour and size of a strawberry! Your waste is then collected in a stoma bag that attaches to your skin. There are no nerve endings in a stoma so you shouldn't feel any pain but you may feel sensations from the surrounding area. A stoma can be temporary or permanent.

What types of stoma are there?

There are three main types of stoma.

Colostomy

This is an opening that has been created from your colon (large intestine) and the most common type is a sigmoid or descending colostomy and is usually sited on the left hand side of your body.



You can have an end colostomy where one end of the colon is pulled through and sewn to the abdomen, these are usually performed if the stoma is to be permanent and the bowel below the stoma has been removed. For example a Hartmann's procedure.

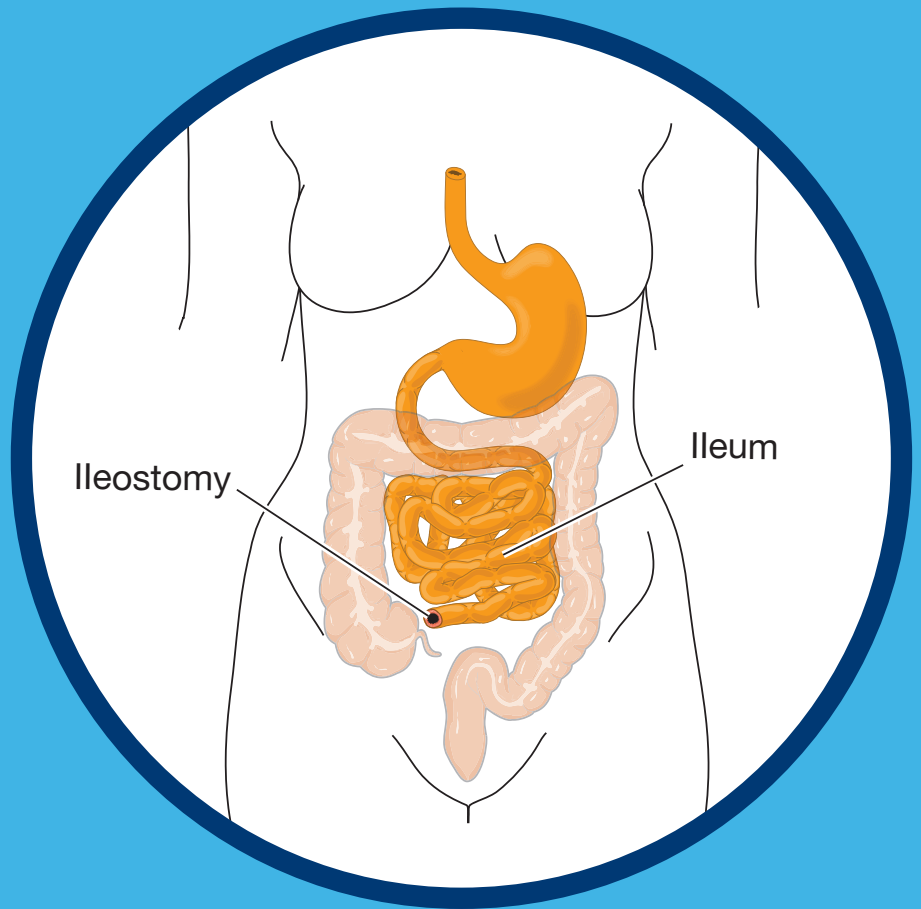
Or you can be given a 'loop colostomy', in which a loop of the colon is pulled through and sewn to the abdomen. This form of stoma will have two openings, one which allows waste to filter and the other part will be connected to the inactive part of the bowel and may produce mucus. This type of stoma is usually temporary as it is easier to reverse.

With a colostomy you will generally pass formed bowel motions similar to how you would have naturally passed motions. Output from a colostomy can often be predictable, much as it was before surgery.

Ileostomy

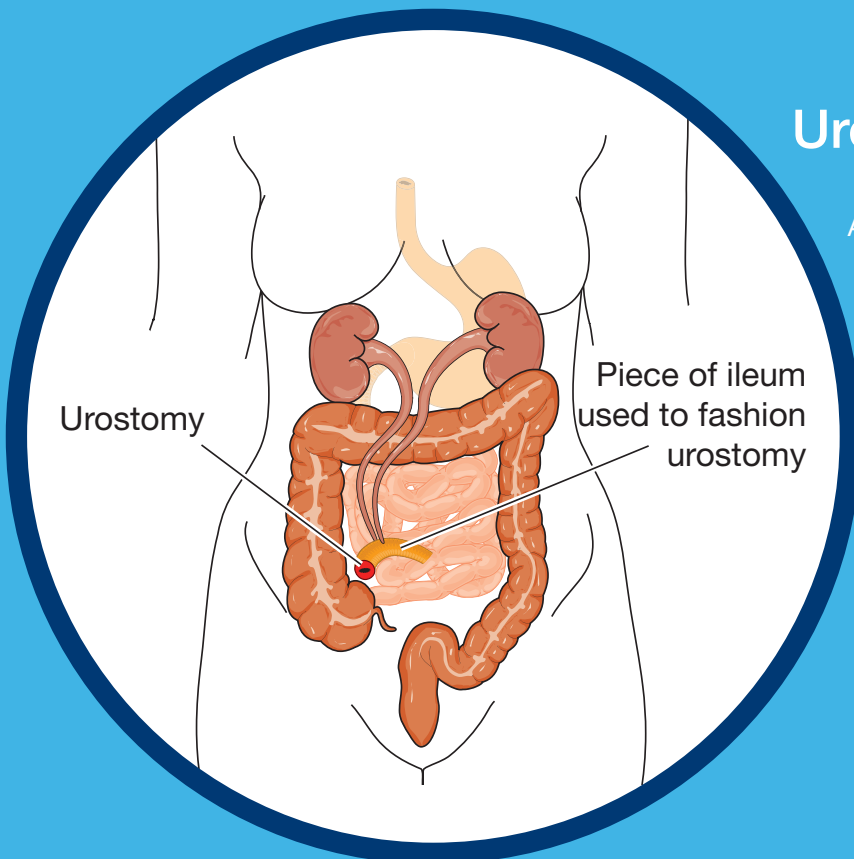
This is an opening that has been created using the ileum, the end of your small intestine. This type of stoma is commonly formed if you need to either completely rest your colon or if you have had your colon (large intestine) removed due to disease.

You can have an **end ileostomy** or a **loop ileostomy**. The output from an ileostomy will be liquid as the small intestine doesn't absorb fluid in the same way as the colon.



Urostomy

A urostomy or ileal conduit can be created if the bladder needs to be removed due to disease or injury. This is formed by taking a section of the small intestine and attaching it to the ureters at one end and bringing the other end out onto the abdominal surface and sewing it into place. This will form a channel that will allow the kidneys and ureters to drain urine into. A bag will need to be worn over the stoma as there will be no control.



What are the most common reasons for having a stoma?

The most common reasons are due to bladder or bowel injury or disease including -

Bowel Cancer

This is a cancer that originates in the colon or rectum, it is also known as colon cancer, rectal cancer or colorectal cancer.

Generally cancers that are found low in the colon or rectum may require a temporary or permanent stoma.

The symptoms of bowel cancer are a change in bowel habit either constipation or diarrhoea that lasts for more than three weeks, blood in the stool, a persistent pain in the abdomen, feeling more tired than usual, losing weight.

Inflammatory Bowel Disease (Crohn's Disease/ Ulcerative Colitis)

This is a chronic autoimmune condition that mainly attacks the digestive system, causing painful inflammation and ulceration. With Ulcerative Colitis, it is the large intestine that is affected and with Crohn's Disease, any part of the digestive system can become affected from the mouth to the anus. There is no known cure for this condition at present and symptoms can include bloody diarrhoea, stomach cramps, weight loss and fatigue. Some people may also experience inflammation or arthritis in their joints as part of the condition.



Diverticular Disease/ Diverticulitis

This is a condition that affects the colon by causing small bulges or pouches to develop in the intestine. These pouches can become inflamed and infected and this is known as diverticulitis. In severe cases this inflammation can cause a perforation to the bowel. You are more likely to develop diverticular disease if you don't have enough fibre in your diet. Symptoms of diverticulitis include pain in your abdomen (usually on the left side), diarrhoea or constipation, bloating and excess wind, high temperature, vomiting, and bleeding from your rectum.

Bladder Cancer

This is a cancer that originates in the bladder or bladder lining. If the cancer found is fairly small and localised then they may be able to treat the tumours and keep the bladder intact but sometimes it is necessary or best advised to have the bladder removed to prevent a recurrence. In these instances a stoma will be formed as a method to drain urine from the body. Symptoms of bladder cancer include blood in the urine, which is usually painless.

Perforation of the bowel through trauma

Perforation is a hole that forms somewhere in the gastrointestinal tract, usually as a result of injury or from severe disease. A perforation can cause severe abdominal pain and can become life threatening if the contents of the bowel leak and cause infections such as peritonitis.

Other symptoms of a perforated bowel include a high temperature, chills, a fast heart rate, feeling dizzy and weak, shortness of breath and passing less urine and/or stools. This condition is considered a medical emergency.





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Section **one**

The right bag for you

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The right bag for you

What type of bag should you use?

Having the right bag is as individual as the person wearing it. There are many things to take into consideration such as whether your output is formed or loose, body shape, stoma size, any skin sensitivities and even what type of clothes you like to wear. It is also down to what feels good for you.

In general terms, most people with a colostomy produce formed stool and will wear a closed bag, which will need to be changed between one to three times a day. Those with an ileostomy will wear a drainable bag, which can be emptied regularly throughout the day and changed between every three to seven days, and someone with a urostomy will wear a bag with a drainable tap on the end so that urine can be regularly drained from the pouch and will be fully changed around every three days.



Types of bag

There are many types of different bags, which have been detailed below. It is advisable to trial different types of bags to find one that you feel comfortable and confident wearing. You don't have to settle just for the one you are given straight out of surgery.



Closed bags

As the name suggests, these bags have a closed bottom and are most suited to those who pass formed stools. These bags will need to be changed as soon as the bag becomes around a third full, which on average is between one and three times a day. They usually come in three different sizes mini, midi and maxi, What size you wear is down to personal preference and based on how much output you usually pass.



Drainable bags

These bags will have an opening that allows loose stools to be drained out and emptied into the toilet. They will then normally have a velcro or clip mechanism to fold the flap section and keep the bag secure. Generally those with an ileostomy will wear this kind of bag although some people with a colostomy prefer wearing these bags as the baseplates tend to be stronger and more durable. Again you can get these in three sizes, mini, midi and maxi to suit.



Urostomy bags

Urostomy bags are similar to drainable bags except they have a little plastic tap on the end to allow urine to drain from the bottom.



One piece bags

These types of bags have an all-in-one baseplate and bag. They are the most commonly used and are liked as they generally sit flatter to the body and are less fiddly to put on around the stoma.



Two piece bags

These types of bags have a separate baseplate and a bag that either clips or sticks using an adhesive directly onto the baseplate. This type of bag is useful if you suffer from skin problems and you don't like to keep removing the baseplate. You can simply unclip the bag section and replace with a new bag.



Convex bags

These types of bags are suitable for those who have a retracted stoma and find that wearing a flat baseplate causes leaks. The convex opening moulds into the gaps and gently forces the stoma forward. A convex bag should only be worn after a consultation with a stoma nurse as wearing a convex bag when not needed can cause damage to the skin.



Concave bags

These types of bags are suitable if you have a hernia or any creases or outward areas around the stoma that you need your baseplate to mould around. Again it is best to consult with your stoma nurse before changing to this bag type to make sure it's appropriate for you.



Measuring your stoma and cutting your bag

One of the most important and basic tasks in looking after your stoma is to ensure that your bag is cut to the correct size and shape of your stoma. You can check the size of your stoma by using one of the template guides that are usually found in your box of stoma supplies. The template should fit snugly around your stoma without cutting into it. If you leave too large a gap around the edges this can lead to output reaching the skin and causing skin irritations, which can lead to your bag not sticking to your skin effectively.

You can choose to either cut the bags yourself, most stoma bag suppliers will be able to send you a special pair of stoma scissors to cut your bags with, or your stoma nurse may give you a set in hospital to take home with you or you can send your template to your supplier and they will cut the bags to fit you. Some people prefer to do this themselves, especially if they have a more oval shaped, rather than circular stoma.



Remember to measure your stoma regularly as it's size can fluctuate, especially after the first three months of surgery. Any changes to your weight can also affect the size of your stoma. Your stoma can also shrink or increase in size whilst it's functioning so it's worth taking this into consideration when measuring for your bag.

Support and additional products for your bag

There are many different products available to help you feel more confident and secure with your stoma along with support belts and underwear, which may help prevent you from developing a hernia or help support a hernia if you already have one. Most of these products are available on prescription or are offered as a complimentary item by your stoma bag supplier.

Complimentary items

Your delivery company may offer some or all of these as part of their home delivery service.



Wet wipes

Useful to carry around when out and about to wipe off excess output from the end of a drainable bag. They're not normally recommended for use around the stoma as they can cause irritation and affect how well your pouch sticks.



Dry wipes

These can be dampened to clean around the stoma and then used to dry the area around the stoma before attaching a new bag.



Disposal bags

Scented disposable bags have been designed for the hygienic and convenient method of ostomy and appliance waste disposal. Available in a pack of 30.



Bed pads

These can be placed over bed sheets to help protect against any accidental leaks that may occur.



Hand sanitiser

Discreet pocket size pump spray, ideal when on the go. Kills 99.99% of germs in the first 30 seconds. No alcohol formula and kind to hands. 50 mls.



Scissors

Curved scissors for cutting your bags or pouches at home or when away on holiday. Bullen Healthcare offers a cutting service as part of our Home Delivery Service.

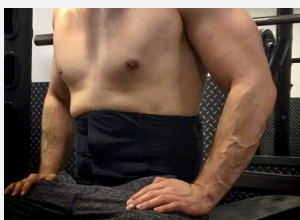
Also available on prescription

These additional products may be available on NHS prescription. Please speak to your GP or Stoma Care Nurse to see if they are available in your area.



Barrier Products

Barrier products can come as a spray, wipe or cream and are designed to leave a protective layer on your skin to help prevent output from irritating your skin. A spray is much more cost effective than wipes. Trio Elisse is the only patented skin barrier as it not only protects the skin, but actively soothes red and irritated skin.



Support garments

Support garments available include wraparound belts and high waisted briefs, boxers and vests tops with a support panel. There are different levels of support ranging from light to firm.



Adhesive remover sprays/wipes

These are ideal in helping to remove your bag without tearing or causing any soreness or damage to the skin. There are many different adhesive removers available - some with a fragrance to remove any smells during a bag change.



Flange extenders

These come in two different shapes normally straight or curved and can be wrapped around your existing baseplate for added protection if you find you have gaps in your baseplate due to natural skin dips or scarring.



Stoma paste

This is the stoma equivalent of polyfilla! The paste fills in any gaps between your baseplate and skin, which creates a seal and stop any output from reaching the skin.



Stoma barrier rings/seals

These are seals that mould around your stoma to protect the skin from output. There are different types available including hydrocolloid rings that absorb any moisture from under the ring and help to promote healing and silicone rings that are designed to stretch and fit into any creases or dips around your stoma.



Ostomy odour drops

Adding these drops can help to reduce odour from the bag when emptying. There are a range of scents available, which can help mask the smell or you can get unscented odour eliminators such 'Na'Scent', which eliminates the smell completely.



Stoma bag gelling agents

Adding in a sachet of an ostomy gelling agent can help to absorb liquid output making it easier to empty and less likely to leak from the pouch.

Testing new products

Please seek advice from your stoma nurse before trialling any new bags or additional products.

If you are not happy with the bag that you are using or are experiencing any issues such as leaks or sore skin, it is ok to seek advice from your stoma nurse and/ or supplier and try out samples of other bags to see if they are a more comfortable fit for you. By letting your stoma nurse and/or supplier know what your issues are, they will be able to recommend suitable alternatives to you. You can usually order samples of bags online to try, alongside samples of a supporting additional product such as adhesive spray removers and baseplate extenders. If your GP or stoma nurse agrees that you need this new product then it will usually get added to your prescription.

It is important to have a check up with your stoma nurse before trialling any convex or concave products to avoid any injury to your skin.



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Section **two**

How to look after your skin with a stoma

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How to look after your skin with a stoma

Having healthy peristomal skin is vital to ensure that your stoma bag sticks effectively to your skin. One of the most common complications for people with a stoma is having sore, irritated, red and broken skin. There are many reasons why your skin may become sore. The most common reason is output coming into contact with the skin. Allergies to the bag adhesive and fungal skin infections are other issues.

Not only is having sore and broken skin uncomfortable and painful but it can also affect how your bag sticks to your skin, which in turn creates a vicious cycle of leaks and further broken skin. It's important to get any damage under control as quickly as possible in order to prevent this cycle from happening. Below are some easy ways to help prevent and treat peristomal skin irritations.

If your skin irritation is severe and does not improve after a few days then you should make an appointment to see your stoma nurse for treatment.



Making sure your bag fits properly

One of the most basic ways to help keep your peristomal skin healthy is to make sure that you have measured and cut your bag correctly to ensure that the bag fits snugly around your stoma (without cutting into your stoma) to help avoid output from reaching the skin and causing soreness.

You can measure your stoma by using the templates provided in your box of stoma bags. Remember to measure your stoma regularly as it's size can fluctuate, especially in the first three months after your surgery. Any changes in your weight can also affect the size of your stoma. You may also find that your stoma shrinks or increases when it is functioning so it also worth taking that into consideration when measuring for your bag.



Additional products for your skin

There are additional products that you can try to help prevent or relieve any skin irritations, these include:



Barrier sprays / creams

Applying a barrier spray or cream to the skin under your bag can help prevent any skin irritation caused by the adhesive. Your stoma nurse will probably first recommend a spray as they are easier to apply. If you do use a cream, apply a thin layer to the peristomal skin, allow the cream to sink in and dry before attaching your bag. It is important to only use a small amount of cream as using too much can prevent your bag from sticking.



Stoma paste

This is the stoma equivalent of polyfilla! The paste fills in any gaps between your baseplate and skin, which creates a seal and stop any output from reaching the skin.



Stoma barrier rings

These are seals that mould around stoma to protect the skin from output. There are different types available including hydrocolloid rings that absorb any moisture from under the ring and help to promote healing and silicone rings that are designed to stretch and fit into any creases or dips around your stoma.



Top tips for skin irritations

Some of our experienced ostomates offer up their best advice when it comes to clearing up skin irritations around the stoma.

It is important to speak to your stoma nurse for advice before implementing any of these tips.



Gaviscon liquid

It may sound strange but this heartburn medication can also calm sore peristomal skin. The liquid has an alkaline base to neutralise acid and can soothe any redness and reduce itching.

Calamine lotion

Calamine lotion is well known to be a good soother during an outbreak of chickenpox but this lotion can also help cool and soothe red and irritated peristomal skin. Simply apply a small amount onto the skin around the stoma and leave to dry. Once the lotion has dried you can then reapply your bag.





Aloe vera

Aloe vera is a plant extract that is usually used to cool sunburn and reduce redness. This natural ointment can easily be found in your local chemists or some supermarkets and can be used to help cool down irritated skin. Again, apply a small amount to the skin around the stoma, allow the cream or ointment to dry and then reapply your bag. Make sure that you are not allergic to aloe vera or related plants before applying.

Sudocrem

Most of us will have a tub of this antiseptic cream around the house to treat any scrapes, cuts or as a nappy cream. Apply a small amount around the stoma and this cream can soothe any irritation, heal any sore areas and put a protective layer between your skin and bag to prevent any further soreness.

Make sure you allow the cream to dry before reapplying your bag.



Air time

If you are able to, remove your bag for a small portion of your day to allow your skin to breathe and recover. It is a good idea to have some dry wipes and a small refuse bag handy in case your stoma becomes active.



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Section **three**

Common stoma issues



Common stoma issues

Pancaking

Pancaking is a common issue that many people with a stoma experience. It is when output sits around the top of the stoma bag instead of falling to the bottom. This can cause output to get trapped and start to push the baseplate of the stoma bag away from the skin, which can then lead to leaks and sore skin. There are a couple of reasons why pancaking may happen...

1 Stoma bag filter

The filter on a stoma bag can create a vacuum sucking out all the air and leaving the sides of the bag stuck together. You can alleviate this by applying a sticker over the filter (these can be found in the box your stoma bags came in) to stop air in the bag from being released. Some people also add in a little piece of scrunched up tissue to keep the sides of the bag open. You could also grease the inside of your bag with a little olive oil or baby oil to help the output down to the bottom of the bag.

2 Sticky output

If your output is quite firm and sticky then this can cause it to stick around the top of the bag. To alleviate this problem, you may need to make a few dietary changes to loosen up your output so that it slides down into the bag. It is worth trying to increase your fluid intake as this can help to create the right consistency. Increasing your fibre intake can also help with this issue. If dietary changes have no effect, then your doctor may be able to prescribe a small dose of a laxative to help. Please check with your GP or stoma nurse before making any dietary or medication changes, especially if you have a related bowel condition.

Ballooning

Ballooning is when wind that passes out of the stoma cannot escape through the filter of the stoma bag and inflates the bag. Occasionally the force of the pressure can cause the baseplate to loosen and lift. Generally ballooning occurs if the filter on the bag gets blocked.

The filters can get blocked if they get wet so it is worth covering your filter with a sticker (these can be found in the box your stoma bag comes in) when bathing, swimming or showering or changing your bag after it gets wet. If you find that you experience a lot of wind and ballooning, then you should check your diet to see if you can reduce your intake of certain foods such as alcohol, fizzy drinks and spicy foods, garlic, onions, brussels sprouts and cabbage. Making sure that you eat at regular times, avoid getting hungry, eating slowly and chewing your food well can also help reduce wind. Some people also find that peppermint oil capsules help and these are available on prescription or over the counter.



Controlling odour

In general, you shouldn't really notice any odour from your stoma bag unless you are changing or emptying your bag as the filter on your bag should be able to effectively deal with this. If you do notice any odours whilst you are wearing your stoma bag then it is a good idea to change your bag to see if this helps as the filter may have failed. Some bags are also more effective at filtering odours than others so it's also worth testing other bags if you find that you experience odours on a regular basis.

To control odours when emptying your bag, you can use ostomy odour drops that mask odours or a product such as Na'Scent which eliminates the bacteria that causes odours. These are usually available on prescription. Some people also use a product that you spray directly into the toilet before emptying to disguise any odours.



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Section **four**

Where to get help & support for your stoma



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Where to get help and support for your stoma



Booking an appointment with your stoma nurse

If you have any concerns about your stoma or are suffering from any complications such as sore skin, excessive amounts of leaks or you suspect you may have a hernia then you can call your stoma nurse and they should be able to make you an appointment to visit them. If it has been several years since your last visit you may also need a referral from your GP for the appointment. Your first point of action should be to phone your local stoma nurses office and they will guide you on how to make an appointment.

Your stoma supplier advisor

For any small niggles like a small amount of irritation on your skin and not finding a comfortable fit with your bag then your stoma supplier advisor may be able to offer you help with any products or new bags that are available on the market. They may also be able to offer you some advice on who to visit if you are looking for any stoma support wear on prescription.



Support groups

At times having a stoma can feel like an isolating experience and it can be helpful to talk to others who understand what you are going through and share stories and tips on how to navigate life with a stoma.



With the digital age it is now easier than ever to join a stoma support group and there are various closed groups on Facebook that you can join and talk to others about living with your condition.

The three stoma patient charities in the UK are Colostomy UK support group, The Ileostomy & Internal Pouch Support Group (IA) and The Urostomy Association. The Ileostomy & Internal Pouch Support Group (IA) has forums on their website and the Urostomy Association has a members only Facebook group. There are many other Facebook groups that are usually run by other patients with a stoma or local support groups. Remember, that the information provided on these sites do not come from a clinical source, they are based on other patients experiences and opinions. It is important to always seek advice from your stoma nurse before acting on any information supplied by other patients.



You may also find there is support on different social media sites and find like-minded communities on Twitter and Instagram too. Charities like Bowel Cancer UK have large communities who all chat on Instagram and Twitter.

Please remember that you are a vulnerable person online and not everyone is who they say they are. Keep yourself safe by not revealing any details such as your address and date of birth. Do not give or receive any money or valuable items and avoid private messages with people you don't know well. We advise that groups are usually more suitable for those over 16 years old. If you have any concerns then report these to a group admin. It is your responsibility to keep yourself safe online.

If you prefer meeting people face-to-face or don't have internet access then there are several stoma support groups across the UK that meet up regularly. [Colostomy UK](#), [Ileostomy and Internal Pouch Association](#) and [Urostomy Association](#) all have a list of selected local groups across the UK on their websites. Contact the charities directly for further information.



Colostomy UK

www.colostomyuk.org

Helpline: 0800 328 4257 (24 hours a day)

info@colostomyuk.org



Ileostomy and Internal Pouch Association

www.iasupport.org

Freephone: 0800 018 4724

info@iasupport.org



Urostomy Association

www.urostomyassociation.org.uk

Telephone: 01386 430140

info@urostomyassociation.org.uk

Mental health and your stoma

Having stoma surgery doesn't just change you physically, it can also change you emotionally and this outlook may be positive or negative depending on your experiences. Some people with a stoma may find it difficult to come to terms with their surgery and their new physical appearance and may need further support.



Firstly, remember that it is ok to have down days or not feel ok with the experience you have gone through. There are ways to manage these feelings though.

It is important that if you are experiencing feelings of anxiety or depression and you feel that you are struggling to manage these that you visit your GP as they can help you with either self help tips, medication or refer you for counselling sessions to help you navigate your way through your thoughts.

Symptoms of anxiety include



- Feeling restless
- A churning feeling in your stomach
- Feeling sick
- Feeling light headed or dizzy
- Faster breathing and a thumping heartbeat
- Sweating or hot flushes
- Insomnia

Symptoms of depression include



- Feeling down, upset or tearful
- Feeling agitated or restless
- Feeling guilty, worthless or down on yourself
- Feeling isolated
- Feeling suicidal
- Not being able to sleep or sleeping more than usual
- Eating more or less than usual
- Losing concentration

Mind, the mental health charity have a wealth of resources and information about how to manage your mental health conditions. It is worth visiting their website www.mind.org.uk or if you want to chat you can call them on **0300 123 3393** or text **86463**.

Self care is a great starting point and is important for your mental health too. This could be something as simple as treating yourself, even if it something small like your favourite coffee, take the time to pamper yourself or remove yourself from the stresses of your day with activities such as meditation, colouring or a puzzle.

There are also some great apps available such as [Calm](#) and [Headspace](#) that can help you with specific moods such as if your feeling anxious, struggling with sleep or just feeling stressed.



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Section **five**

Guide to diet & exercise after a stoma surgery



Guide to diet & exercise after stoma surgery

What can I eat and drink after stoma surgery?

What to eat and drink post stoma surgery can be very confusing and there is a lot of information out there on what the 'rules' are for eating and drinking. The truth is everyone's tolerances are different and that there aren't any do's and don'ts when it comes to food. There is some general advice that you can choose to follow but normally it is recommended not to limit your food groups and only eliminate a food if you suffer any issues with it. For most, if you have a colostomy then your digestion will be near normal as before, unless you suffer from any surgical complications such as adhesions. If you have an ileostomy then you may need to be more aware of your nutrition and hydration levels.

It is important that you seek any nutritional advice from your stoma nurse, dietician or consultant.

Your diet straight after surgery



Many hospitals now follow an 'enhanced recovery programme', which includes encouraging patients to eat and drink as soon as possible after surgery and get up and move around. There is evidence to suggest that becoming mobile and getting back to your normal diet straight after your surgery encourages your bowel to heal and start functioning.

The myths and facts surrounding 'no-go' foods

You may have heard people talk about or have read online what someone with a stoma can and can't eat. We bust some of the common myths surrounding food and nutrition...



You can't eat raw vegetables, nuts and salads

It is not usually necessary to restrict your intake from these food groups. They are a good source of fibre and essential vitamins and minerals. Sometimes you may be advised to avoid high fibre foods if you are straight out of surgery or experiencing a 'flare' if you have inflammatory bowel disease. Your consultant or dietician will advise if you need to alter your diet.

You should avoid spicy foods

Spices are a good way to flavour your food and they also have a variety of health benefits. If you enjoyed eating spicy food prior to your stoma, there is no reason why you can't enjoy spicy food post surgery. It is all down to your individual tolerance.



You should avoid fizzy drinks

Although there are no nutritional benefits in drinking fizzy drinks, there is no reason why you can't enjoy them occasionally as part of a healthy, balanced diet. Some people may experience excess wind after consuming a fizzy drink.

It is difficult to eat in a restaurant with a stoma?

Most restaurants will happily cater for those who have any specific dietary requirements so finding something you can eat and drink shouldn't be a problem. Most people will find that once they recover from stoma surgery that they can enjoy a healthy and varied diet. If you feel nervous or anxious about finding a toilet when out, it can help to plan your trip in advance and call the restaurant ahead to answer any questions you may have.



On the next page are examples of foods that may alter alter your output. Remember, that this is only a general guide and not everyone will experience any side effects from different foods. These are not relevant for someone with a urostomy.

Foods that thicken your output

If you are suffering from loose stool and you are looking for foods that help thicken up your output then the below food groups may help:



- Jelly babies
- Marshmallows
- Bananas
- Rice
- Pasta
- Mashed potato
- Toast
- Porridge
- Peanut butter
- Apple sauce

Foods that loosen your output

These food groups are more known to have a laxative effect and cause loose stools. If you are suffering from diarrhoea, look to see if you are eating any of the food groups below in high quantities.



- Fruits, vegetables and salads
- Alcohol
- Fizzy drinks
- Chocolate
- Fruit juice
- Fish
- Spicy food
- Nuts
- Caffeine
- High fibre food such as bran
- Foods high in saturated fat/processed or fast foods

Foods that can cause excess wind

If you suffer from excess wind, it can help to limit foods that are known to produce excess gas, which include:



- Onions
- Garlic
- Fizzy drinks
- Fish
- Beans and pulses
- Cucumber
- Peas
- Kale, broccoli, cauliflower, sprouts, cabbage
- Alcohol
- Chewing gum

Avoiding dehydration with an ileostomy



If you have an ileostomy and you have had your colon removed then it can be difficult to maintain a good level of hydration as it is your colon that absorbs fluid back into the body. It is important that as well as being hydrated that your body has the right balance of electrolytes (vitamins, minerals, salts etc) and water alone is not always enough to maintain this. A good way to replace these is by drinking rehydration sachets that are designed for after a bout of diarrhoea such as Dioralyte as these replace the salts and minerals needed by the body.

You should discuss with your stoma care nurse or surgeon before you start taking Dioralyte or St Mark's Solution.



St Mark's Solution

There is also a way to make your own rehydration drink and this is known as St Mark's Solution. This is a specially formulated drink which is high in salt to help your body absorb fluid and reduce losses from your stoma.



The electrolyte mix needs to be made up freshly every day. To do this you need to measure out the following powders:

- 20g (six level 5ml spoonfuls) of Glucose
- 2.5g (one heaped 2.5ml spoonful) of Sodium Bicarbonate (baking soda)
- 3.5g (one level 5 ml spoonful) of Sodium Chloride (salt)

This needs to be dissolved in 1litre of cold tap water. It is recommended that you drink 1litre of the electrolyte mix each day. You can buy the ingredients (powders) from any pharmacy and some supermarkets or you can obtain them on prescription from your GP. They are cheaper to buy than to get through a prescription if you pay prescription charges.



Exercise and fitness with a stoma

Getting back into exercise - where to start

Firstly it is important to check with your doctor that it is safe for you exercise after your surgery. It is best to avoid any heavy lifting or strenuous exercise for the first 12 weeks post surgery but it doesn't mean that you can't be active. Gentle exercise will help improve blood flow throughout the body and this in turn will help to promote healing.



Walking

Going for walks around your local area is a good place to start post surgery. You could begin by walking for 30 minutes each day and then build up from there. Not only is walking good for you physically but the fresh air will help to clear your mind and boost your mood.

Swimming

Swimming is another good exercise for someone with a stoma to begin with. It's a good overall cardiovascular exercise that works all muscle groups but the water offers you extra support. It is perfectly safe to swim with a stoma bag. If you are worried about your bag leaking or falling off in the water then you could add flange extenders around the edges to help you feel more secure. Stoma bags are designed to withstand water so you shouldn't experience any problems.





Gardening

Once you're feeling well then getting back into the garden is a great form of exercise and works many of the muscle groups. It's a good idea to wear support when you are gardening and to do some little and often to avoid injuring yourself.

Pilates and Yoga

These two types of classes are very good at rebuilding your core strength and your balance. Yoga also has an element of relaxation to it and promotes overall wellness and a sense of calm and will help to improve anyone suffering with a low mood.



Exercises that can help strengthen your core and prevent a hernia

Colostomy UK have published a guide with a range of exercises that you can perform to help strengthen your back and stomach muscles and improve your posture and core. Performing these exercises regularly could also help to prevent a hernia from developing. [Click here](#) for more information on these exercises.

Wearing support during exercise

Once you are fully recovered from your surgery there's no reason why you can't get back to all the activities you loved before, whether they were team sports, visiting the gym or dance classes. It is important to have the right support and protection for your stoma if you are doing any exercise.



Support garments

Support garments available include wraparound belts and high waisted briefs, boxers and vests tops with a support panel. There are different levels of support ranging from light to firm.



(www.respond.co.uk)

Stoma guard

These are a protective shield or cup that fits over your stoma and are particularly useful if you play contact sports. They usually attach to a stoma belt.

Chair yoga sessions



Colostomy UK are committed to getting ostomates back into exercise with their active ostomates programme and one of the things they do is offer chair yoga at a variety of ostomy events up and down the UK. This is a really gentle form of exercise suitable for all ostomates of all abilities. To find out where there next chair yoga session is, contact [Colostomy UK](#).



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Section **six**

Travelling with a stoma



Travelling with a stoma

One of the most common questions that ostomates ask about involve travel, in particular, flying abroad and how to manage your stoma in a hot foreign climate. Having a stoma doesn't limit your ability to travel but it may just take a little extra forward planning.

The myths and facts around travelling with a stoma

1



Will my bag 'inflate' on the plane?

The cabin pressure on a plane shouldn't have any effect on your stoma or inflate your bag.

Will I get through security with my bag?

Most security personnel are trained to deal with passengers who have an invisible illness or disability such as an ostomy. If the airport has a body scanner then your stoma bag will show up, but the normal scanners should not pick it up. but should they wish to examine you then you are able to request that they do so in a private room. If you have any questions at all then it is best to contact 'special assistance' at the airport you are travelling through.

2





3

Can I swim with a stoma?

Yes! You can swim in the sea or in the swimming pool with a stoma. Your bag shouldn't have any issues withstanding the water but if you are worried at all then pop on a couple of flange extenders around your bag for extra security.

Will the heat affect my bag?

It shouldn't do, but some people find that the heat can sometimes affect the adherence of the bags so you may need to change it more often than if you were at home.

Some people also find that the change in climate, food and drinks can also upset their tummy for a few days so it's best to be prepared.



4

How many supplies should I take with me?

We would say that it is worth taking at least double the supplies that you would normally use on a daily basis. This is to take into consideration that a hot climate can sometimes affect how well your bag sticks to your skin and so can any lotions or oils that come into contact with your bag. Some people may also find that a change in diet and drinks can also cause a tummy upset so having extra bags will cover you for this issue. Remember that your supplier may need a couple of weeks to deliver your order so make sure you order your holiday supplies in plenty of time.



How to obtain extra medical allowance for a flight

Contact the 'special assistance services' number with the airline that you are flying with. They will be able to advise you if they offer any additional hand luggage to take medical equipment on board. Most airlines will make some allowance. It is down to the individual airline whether they charge for this extra hand luggage or whether they provide it for free.

Taking supplies and prescription medications on a flight

While the liquid restrictions for hand luggage is under 100mls, for essential medication you may carry more than 100mls providing you have the relevant documentation from your doctor. Airport staff may need to open the containers to screen the liquid at security.

It is worth contacting your airline if your medication involves needles and syringes as each individual airline will have their own set of rules of how these need to be stored and administered if required during the flight.

Most airlines will request you to carry a copy of your prescription and/ or a doctors note covering the medication. You may find it's easier to take adhesive remover wipes rather than sprays and pre-cut your stoma bags to avoid needing scissors.



Invisible disabilities sunflower lanyard scheme



The sunflower lanyard scheme is being rolled out across the airports and is designed to discreetly make airport staff aware that you are travelling with a hidden disability. This may then prompt staff to offer you extra assistance to make sure that travelling through the airport is as stress free as possible. It is not there to let you queue jump and will not get you through security any quicker. Staff may offer you extra help with your luggage and offer you assistance to help you on board your flight. Contact special assistance at the airport you are travelling through to see if they support the sunflower lanyard scheme.

Obtaining a RADAR key

If you are travelling around the UK then you can purchase a [RADAR key](#) for around £3, which opens around 9,000 accessible toilet facilities around the UK. [The Irish Wheelchair Association](#) have their own version of the key for Ireland and in Europe there is the [Euro WC key](#), this mainly unlocks facilities in Germany, Switzerland and Austria.





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Section **seven**

Clothing & your stoma

Clothing and your stoma

Clothing is a big part of everyday for pretty much everyone. They can be used to express your mood, express your personality and even your level of professionalism. Many people with a stoma worry that having a stoma means that they need to completely alter their wardrobe. Gone are the days of tight fitting outfits, or are they?



What to wear to your pre stoma siting appointment

If your surgery is elective (planned), then you will be invited to a pre surgery appointment and as part of this visit you may see your stoma nurse to be marked up for your stoma. It is a good idea to wear your favourite pair of jeans/trousers/skirts etc so that your stoma can be sited with these in mind. All stoma nurses will offer this service and it will give you a little extra confidence that you will still be able to wear the clothes you love post surgery.

Don't let your stoma hold you back

Don't let your stoma change your style, if you wore closely fitted clothes before your operation, you will be able to do the same post surgery. Many people continue to wear the same underwear as they did before their surgery, however some people prefer high waisted underwear or a support vest/belt which can help to smooth down the appearance of the bag under your clothing. The stretch of the underwear should still allow space for your bag to continue functioning as it should. Specialist stoma underwear can be purchased online and certain types may also be available on prescription.

If you like wearing tight skinny jeans, then you might want to opt for a style with an elasticated waist or size up for extra space for your bag. High waisted designs are great as they hold in and cover over a stoma bag.



Stoma bag covers

If you worry about your bag being seen then why not decorate it to match your personality? There are many small businesses online who make personalised stoma bag covers or you can have a go at making your own.

Can we help?

Why not give us a call today and speak to one of our friendly personal customer advisors and find out more about how Bullen Healthcare can help you get on with life with a stoma without any worries.

Call us on

Freephone 0800 031 5401

Visit us at

www.bullens.com/stoma-guide

Useful Links

Ileostomy and Internal Pouch Support Group

www.iasupport.org

Colostomy UK

www.colostomyuk.org

Urostomy Association

www.urostomyassociation.org.uk