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HEALTHCARE  
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making life better



# Ileostomy

Pelican Healthcare & Respond  
Prescription Dispensing Service,  
a partnership that works for you



Pelican Healthcare, award-winning providers of ostomy products, and Respond, award-winning prescription dispensing service, a perfect partnership that works for you.

We're dedicated to improving the quality of life of the ostomate and continence community throughout the UK.

We have teamed up with our brand ambassadors and Community Stoma Care Nurses, to bring you informative and helpful ostomy advice booklets, covering some frequently asked questions and concerns.

If you have any further questions please contact your stoma nurse, who will be able to advise you further.

*there for you...*



BRITISH HEALTHCARE TRADES AWARDS 2018  
NHS DAC PATIENT SERVICES

**Winner**

Hearing that you need stoma surgery will most likely be very difficult and will leave you with many questions. However, you are not alone; each year in the UK thousands of people like you go through stoma surgery and are supported, like you will be, by a team of healthcare professionals.

There will be lots of information and guidance available and this may feel overwhelming, so please do not hesitate to ask your nurse any questions you have.

If your operation is planned, you may have the opportunity to decide on a suitable location for your stoma with your nurse. Your nurse will take into account factors such as lifestyle and clothing and by agreeing a location for your stoma in advance, this should help you continue with the activities you enjoy and the clothes you like to wear post-recovery.

You will have the opportunity to practice applying and removing a stoma bag before your operation. This will give you an idea of what to expect, and to practice changing your stoma bag. Your stoma nurse will be able to answer any questions you may have.

This booklet will cover all you need to know prior to the operation and early days of recovery.

We hope that the following hints and tips will help you.



## Meet our ambassador, Ant

Hi, my name is Ant and I have had an ileostomy for almost 3 years now. The journey to getting my stoma started 14 years ago. I was diagnosed with Ulcerative Colitis after suffering with all the usual symptoms one can expect when they are diagnosed with a form of IBD. Initially my ulcerative colitis was managed through medication, however after numerous prescriptions and trials with different medications, I decided to have my large bowel removed as nothing seemed to be working. It took me a long time to come round to the idea of having surgery. In the beginning my consultants never discussed the option of surgery with me, but after connecting with some inspiring people through social media (including some of the ambassadors in the Respond and Pelican family) it confirmed to me that surgery would be the best way forward.



Post-surgery life is great. I did worry that having a stoma would limit me in my ability to do everything as I once did before. But I haven't had any limitations in anything that I do. I can go to the gym, play sports, eat all the foods I used to love (with some minor exceptions) but nothing is holding me back. I look back now and think 'how on earth did I manage' when I was constantly running backwards and forward to the toilet, keeping down a full time job and exercising as much as I did now. It highlights how unwell I was before and what a brilliant option having a stoma has been for me. I can't imagine my life without my bag.

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# *before your surgery*

"Get some test stomas/sample bags if you can! They were a great help for me to visually see and understand what a bag would be like. I would also prepare for the recovery to be longer than you think."

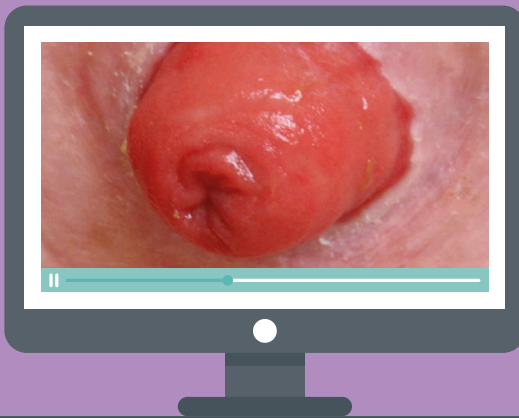
## What is a stoma?

A stoma is a surgical opening that is created to allow faeces to exit the body before it reaches the rectum. It can be either permanent or temporary.

The stoma will be pinkish-red colour, similar to the inside of your mouth, and will be soft and moist.

There are no nerves in a stoma so there are no sensations when touching it. Everyone's stoma is different in size and shape.

A stoma bag (or sometimes known as a stoma pouch) is then placed over your stoma to collect the waste, which would have previously passed through the anus.



Scan the QR code or visit  
**[respond.co.uk/ileostomy-preop](https://respond.co.uk/ileostomy-preop)**  
to watch the full video.



An ileostomy is a **surgical procedure** which involves removing or bypassing the whole of the **large intestine/colon** and diverting the small intestine through an opening in the abdomen

Ileostomists generally change their bag every **2-3 days**



It can be **temporary** or **permanent**



## What is an ileostomy?

People living with an ileostomy generally wear **drainable bags** and empty this bag **several times a day**



It is used to treat many conditions including **colon** or **rectal cancer**, **ulcerative colitis**, **Crohn's disease**, **Familial Adenomatous Polyposis**, **intestinal birth defects** and **other intestinal damage**



Stool output is similar to that of a **porridge consistency**



An ileostomy is normally on the **right side** of your **abdomen**



## Glossary of Terms

**Colon** is part of the large intestine. It passes waste (stool or faeces) to the rectum.

**Rectum** is the last part of the large intestine and stores stool until it is evacuated.

**Crohn's Disease** is an inflammatory bowel disease that causes chronic inflammation of the gastrointestinal tract which is the passageway of the digestive system that leads from the mouth to the anus.

**Ulcerative Colitis** is a long-term condition in which the innermost lining of the colon and rectum become inflamed and develop tiny sores or ulcers.

**Familial Adenomatous Polyposis** is an inherited disorder in which many polyps (usually hundreds to thousands) form on the inner walls of the colon and rectum.



## What will an ileostomy bag look like?

You will have some choice about the type of bag you would like to use. Here is an example of an ileostomy bag that is worn following ileostomy surgery. Feel free to ask questions to your healthcare provider about your options.

Drainable bag



## Before your surgery

Before surgery, members of the medical team, which includes your surgeon, and your specialist stoma nurse will help to prepare you and advise you about your operation.

You will discuss with your surgeon the type of stoma which is best for you and whether the stoma is going to be permanent or temporary. The procedure involved will be carefully explained and you will also have the opportunity to voice concerns or ask any questions.

Due to the wealth of information that you will be given, it is quite likely that you will not be able to take it all in at first. Your stoma care nurse will be on hand both before and after surgery to help you through it. Your stoma care nurse will want to know as much as possible about your lifestyle and needs and based on this your nurse and surgeon will recommend the best position for your stoma.

It is perfectly normal to be anxious before surgery, your medical team will be on hand to answer any questions and offer advice.

## Packing for your stay in hospital

To make sure your stay in hospital is as comfortable as possible you might want to think about packing the following:



A supply of night clothes



A comfortable dressing gown and slippers



Plenty of clean underwear, including socks



Comfortable day clothes



A small hand towel



Sanitary products



Razor and shaving products



Comb or hairbrush



Any medication you normally take, and a list of doses of each medicine



Books and magazines (and reading glasses if required)



Toiletries – soap, toothbrush, toothpaste, shampoo, deodorant



# *after your surgery*

"Immediately after you are going to feel tired, drained of energy and probably in a lot of pain. So take your time, celebrate the small wins as the road to recovery is a long road. When you get home, you can start adjusting to stoma life in your environment. Put supplies where you need them and if things aren't feeling great, speak to your stoma nurses."



## Waking up with your stoma

Whether you are expecting it or not, waking up for the first time with a stoma may be daunting. You are likely to feel uncomfortable and sore, but staff will give you medication to ease the soreness. Your stoma will be swollen initially, this is normal and will reduce in size in a few weeks.

The surgery you have gone through may affect you both physically and emotionally and it may take time to come to terms with the major changes to your body, but this is completely natural.

During the first few days after your surgery, you should expect to feel tired and emotional, and you may also find your body image and confidence has been affected. These feelings are normal and are natural responses to dealing with the stress of your illness and surgery.

At no point should you be afraid to open up about how you are feeling to your partner, family, or close friends. Acknowledging these feelings will help you emotionally and aid your recovery.

## Your first bag

When you wake up from your surgery it is likely that the bag you are wearing will be clear. This is so the nurses can monitor your stoma during the first few days of your recovery.

Your stoma may not function for the first few days after your operation, which is perfectly normal. Your nurse will begin teaching you how to change your bag even if the stoma is not active.

The thought of changing your bag yourself might be frightening, but the nurses will spend as much time with you as you need until both you and they are confident that you can change your bag independently.

## Your stoma care routine

Dealing with managing your stoma on top of recovering from major abdominal surgery will likely leave you feeling frustrated and worried about coping. It is completely natural to feel this way and being open about these feelings is important in helping you to overcome them.

Initially, your stoma care routine will be slow, which is to be expected, but with patience and practice you will become quicker and more confident.

Be mindful not to rush yourself. Take your time to understand what works best for you individually and you will soon develop the routine that is right for you.

Your nurse will be able to answer all your questions so please don't be afraid to ask, no matter how insignificant you think your question is.

You will also get great help and advice from the IA Support Group. Their information is listed below:



Ileostomy & Internal Pouch  
Association

**Freephone**

0800 018 4724

**Email**

[info@iasupport.org](mailto:info@iasupport.org)

**Website**

[iasupport.org](http://iasupport.org)

## Going home with your stoma

The operation you will have involves major abdominal surgery and as such, you should make sure you give yourself enough time to recover. Generally, it takes around 8–12 weeks, but every person is different, and you should not try and do too much before you are ready.

In your first weeks at home, you should focus on resting and getting your strength back gradually. Accept offers of help from family and friends, allow yourself to nap when you need to, and listen to your body if you feel tired.

## Disposal of used stoma bags

Empty the contents of your bag down the lavatory and if possible, rinse it before disposal. Your stoma bag and any other used items, wipes, etc. must be placed inside a plastic bag, sealed, and put into the dustbin.

## Driving

Following your operation, it is important that you check with your GP or consultant before you start to drive again. It is also important to check your insurance policy as conditions may vary depending on your insurer.

Do not drive until you have been given the authority to do so. Failure to comply with this advice may invalidate your insurance and could also be harmful to your recovery.

## Clothing

After your operation, your abdomen will likely feel tender so you might be more comfortable initially in loose-fitting clothes. Once healed you should be able to wear your regular clothes as normal.

For anyone who is living with a stoma and is concerned about wearing their current clothes, there is a wide range of ostomy-friendly clothing and support garments available on prescription and to buy online.

# Let's Talk...



### Pelican Podcast

Let's Talk... dives into the lives of inspiring ostomates as they open up about living with a stoma. Hosted by Louise, an ostomate herself and a Pelican ambassador, she navigates a range of stoma-related topics with other ostomates, who share their stories with the aim of helping those who may feel isolated, alone or not understood during their stoma journey.

**Listen to the podcast by scanning the QR code or search "Pelican Let's Talk..." into your chosen Podcast platform.**

### Blog Posts

Our ambassadors regularly write blog posts where they write about living life with a stoma, with the aim of raising awareness and providing an insight into stoma life.

### Pelican Blogs



To read, scan the QR code or visit [pelicanhealthcare.co.uk](https://pelicanhealthcare.co.uk)

### Respond Blogs



To read, scan the QR code or visit [respond.co.uk](https://respond.co.uk)



## Going back to work

Depending on the type of operation you have had and whether you need to have any further treatment, you will probably be fit to return to work between 6 and 12 weeks after surgery. Having a stoma should not restrict the type of work you do.

Before returning to work, you might want to talk to your employer about the possibility of a 'return to work programme.' This could include staggered hours or going back to work on a part-time basis for a while. No one at work needs to know about your stoma; 'to tell or not to tell' is your personal choice. However, being open and honest is often the best policy as trying to hide something can be very distressing. There is no need for you to feel embarrassed, just plan beforehand who you are going to tell and how much you want them to know.

Keep a supply of your stoma care equipment at work and try to eat regularly during the working day.

If your job involves lifting heavy objects, consider wearing a support belt. This may help to prevent a hernia from developing around your stoma.

## Exercise

When you're feeling strong enough, gentle exercise is a really good way of aiding your recovery.

It is important that you do not attempt to do too much too soon, but a short walk, even just around the house or garden, will be beneficial to you.

As your strength returns, consider setting yourself a target of doing a little more each time. Please remember that however far you go you will also have to get back, so do not tire yourself out by walking too far!

Walking with a friend is advised as not only does it make the walk more interesting, but it is safer, especially should you feel unwell. If you do go out walking alone then be sure to let someone know where you are going and how long you intend to be out.

You may want to take a spare bag or some supplies with you, and for your safety, always take a mobile phone when you leave the house.

Specially designed abdominal exercises will strengthen your tummy muscles. However, before starting any abdominal exercises, you must first speak to your consultant surgeon, stoma care nurse or GP.

## Lifting

During recovery you should avoid any unnecessary lifting. However, if you do need to lift anything then you should place your feet shoulder width apart with one foot in front of the other, keep your back straight and bend your knees.

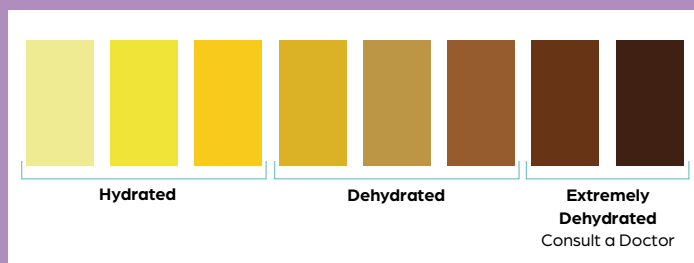
## Nutrition

An important part of the recovery process after major surgery is making sure you eat and drink enough to help your body repair itself.

You might not feel up to eating much initially, but smaller meals and snacks eaten regularly throughout the day will give your body the nutrition it needs to aid your recovery.

Building up your appetite gradually is much kinder to your digestive system in the early stages of recovery. A varied diet that includes each of the different food groups in moderation is the best option. Please be mindful not to drink too much water before meals as this can curb your appetite.

Keeping hydrated is also an important part of the recovery process so be sure to drink plenty of fluids, especially water. Many people get dehydrated by not drinking enough fluid or by losing fluids and not replacing them. Good hydration is important for all age groups and is something everyone needs to consider.



Please see the hydration colour chart which can be used to help you check for signs of dehydration.

If left untreated, dehydration can become severe. Please consult your stoma nurse or healthcare professional if you have any concerns, and check out our wide range of support literature, such as our nutrition advice booklets, for further information on staying healthy after ostomy surgery.

## Holidays

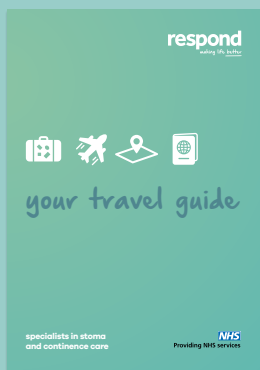
Holidays are good for us, and you can be confident of being able to enjoy one as soon as you feel ready to do so. Don't be tempted to travel too far too soon. Give your body time to recover and give yourself time to find out the effect of different foods on your shortened digestive system before you go globe-trotting.

Comfort and a bit of luxury not too far from home will boost your confidence to go further afield next time.

## Travelling

Having a stoma should not prevent you from travelling, either for business or pleasure. Whenever you leave the house, always make sure you have a small supply of all the items you need for changing.

For more information and advice get in touch to request your handy travel guide brochure and certificate, or download them on our website at **[respond.co.uk/lifestyle](https://respond.co.uk/lifestyle)**



TRAVELGUIDE



TRAVELCERT



## Further advice from Ant

I had my stoma surgery before the first lock down, in 2020. I was in hospital for several weeks before being able to go home. I had a few complications, which meant I had to have my stoma refashioned, which was a second small operation a few weeks later, however my life has been completely transformed because of my stoma. I have my quality of life back, I am no longer on any medication and I can finally move forward with what I want to achieve. I have never been happier! Hopefully this small booklet of hints and tips will be of use to you, but as always, if you have any questions then please reach out to me, @ibdlife.

I also love being able to travel. I travel quite a lot with my work and have always enjoyed going on holidays. I did worry that I would have issues when going in and out of airport security, or I would struggle with my appliances whilst sunbathing, but none of these worries were justified. I go through security like normal, you can even get passenger assistance if you want and get additional luggage for your medical supplies. I can still go exploring, enjoy all the foods of different cultures and cuisines and my bag is absolutely fine. I even remember saying on holiday to my partner, 'This food would have made me so ill before my surgery, I AM GOING TO GET SECONDS!'



## Your ostomy care details

Please use this page to make a note of all the important details regarding your stoma, such as your stoma nurse's name and their contact details, and any products you use!



**Stoma Nurse:** .....

**Hospital:** .....

**Telephone number:** .....

**Stoma type (loop or end):** .....

**Date of surgery:** .....

**Surgeon/Consultant:** .....

**Your home delivery service:** .....

**Contact details:** .....

**Your stoma products:** .....

.....

.....

.....

.....

# This is Keith... He's Family.

**Keith** has been an ostomate for 10 years.  
He loves the new Pelican ModaVi bag, he is  
a bus driver for First Cymru Buses and loves  
to bake in his spare time.

*"Everything is on time, everything is in  
perfect condition, I am one happy ostomate."*

Joining Respond has never been so easy,  
get in touch today and let us do the rest!  
**#JoinTheRespondFamily**



Phone  
0800 220 300  
0800 028 6848 (N.Ireland)



Online  
[respond.co.uk](https://respond.co.uk)



Email  
[hello@respond.co.uk](mailto:hello@respond.co.uk)



Scan me  
with your smartphone



**Providing NHS services**



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