

pelican
HEALTHCARE
respond
making life better



Urostomy

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, Laura

My name is Laura MacKenzie, I am 46 years old and live on the West Coast of Scotland with my husband, Iain.

I was diagnosed with late state, muscle invasive squamous cell carcinoma bladder cancer in September 2017, with the only symptom of passing faeces in my urine the month before. (Looking back I had also lost weight but as I had been actively trying to lose weight, didn't think too much of that).

I went through every imaging and diagnosing test possible and while chemo pre-surgery was considered, there was no time for that so they had to move straight to surgery. I only knew two days pre-op that my op could go ahead when a second PET scan confirmed the cancer had not spread out within the pelvic area. If it had spread, the operation could not go ahead, and limited palliative care options were available.

5 years on, I am still cancer free and signed off by medical team. Generally I manage well with my two stomas. I do have a retracted urostomy which can cause me issues but with my Eakin Paste and Pelican Convex Platinum Urostomy bag, I can keep it in check. Stoma surgery has allowed me to still be here. My surgery saved my life.



Contents

Before your surgery	06
What is a stoma?	07
What is a urostomy?	08
What will a urostomy bag look like?	09
Before your surgery	10
Packing for your stay in hospital	11
After your surgery	12
Waking up with your stoma	13
Your first bag	13
Your stoma care routine	14
Going home with your stoma	15
Disposal of used stoma bags	15
Driving	15
Clothing	16
Going back to work	17
Exercise	18
Lifting	18
Nutrition	19
Holidays	20
Travelling	20
Further advice from Laura	21
Your ostomy care information	22



before your surgery

"If you get the chance, reach out to someone who has been through the surgery."

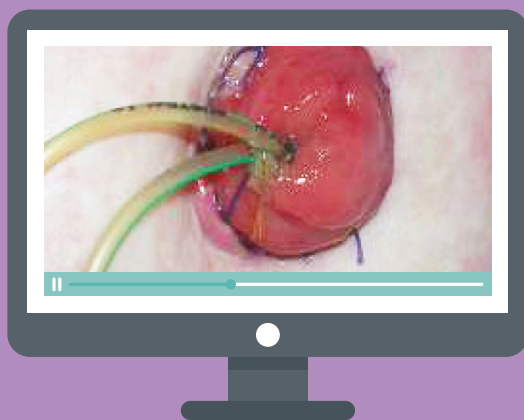
What is a stoma?

A stoma is a surgical opening that is created to allow faeces or urine to exit the body before it reaches the rectum or bladder. 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 is then placed over your stoma to collect the urine, which would have previously passed through the urethra. A urostomy is also known as an ileal conduit.



Scan the QR code or visit
respond.co.uk/urostomy-preop
to watch the full video.



A urostomy is a **surgical procedure** which diverts the normal flow of urine from the **kidneys and ureters** into a surgically created stoma

Urostomists generally change their bag every **1-3 days**



It is **permanent** and **not reversible**



What is a urostomy?

1

2

3

4

5

6

7



It is used to treat **Bladder cancer or a defect or problem with the urinary system** which needs to be removed or bypassed



A urostomy is normally on the **left side** of the **abdomen**



The flow of urine output is **continuous**



People living with a urostomy wear urostomy bags, which need emptying **several times a day**

Glossary of Terms

Cystectomy is the name of the surgery to remove the bladder.

What will a urostomy bag look like?

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

Infused with
Vitamin E



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

"Never let your stomas hold you back. Surgery is tough and the recovery is too. Take things step by step, master changing your bag(s) with the support of your stoma nurse. You very much can get back to a normal life. I work full time in a senior position and love to travel long haul for my holidays from Scotland to the Caribbean and the Indian Ocean. With some preparation, anything is possible."

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 Urostomy Association. Their information is listed below:



Freephone	01386 430140
Email	info@urostomyassociation.org.uk
Website	urostomyassociation.org.uk

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

Respond Blogs



To read, scan the QR code or visit 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.

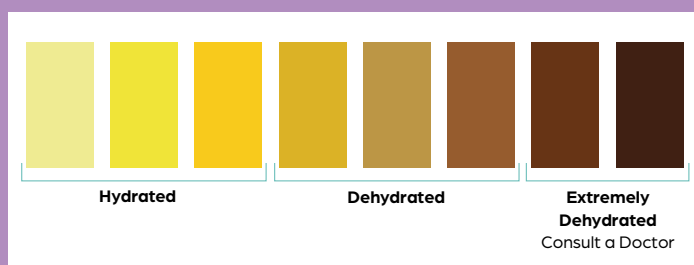
Nutrition

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

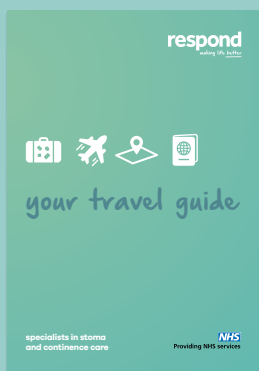
Holidays are good for us, and you can be confident of being able to enjoy one as soon as you feel ready to do so. Don't be tempted to travel too far too soon. Give your body time to recover and give yourself time to find out the effect of different foods on your shortened digestive system before you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

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

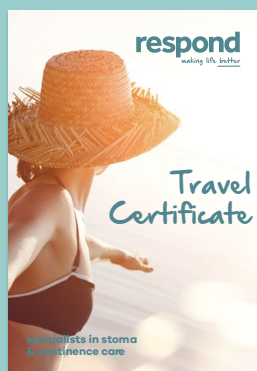
Travelling

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**



TRAVELGUIDE



TRAVELCERT

Further advice from Laura

I underwent a massively invasive 12-hour surgery known as a Total Pelvic Exenteration which is suitable in a very limited number of cases and usually used for recurring gynaecological cancers. In fact, to this day, through my own research and social media contacts, I have yet to meet anyone who had this surgery for primary, advanced, Bladder Cancer.

A total pelvic operation involves the removal of organs from your urinary, gastrointestinal, and gynaecological systems and results in the formation of two permanent stomas (a stoma is an opening in the stomach to allow for the removal of waste products from the body when organs normally providing this function are removed in part or in their entirety). I have a colostomy (faeces) and a urostomy (urine) – my "2 bags for life".

Living with two stomas is not always easy but they don't stop me doing the things I always loved, long haul travel, cooking and socialising with friends and more than that, they saved my life (without surgery I had only weeks to live).

With time you will become grateful for your stoma(s) whether or not they improved your life or saved them. The world as an ostomate, truly is your oyster.

Through social media I advocate for others with a stoma and/or who have stomas or bladder cancer to ensure the wider public stop the stigma associated with stomas and understand that bladder cancer is not just "an old man's disease".

I am also an Ambassador for Fight Bladder Cancer Charity and for Pelican and Respond Healthcare, which I find very rewarding.

If you have any questions, please reach out to me, @2bagsforlife



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 Laura... She's Family.

Laura is 45 and hails from the West Coast of Scotland. She has two stomas as a result of bladder cancer, and loves a holiday in the Caribbean.

"It's a really reliable service and I know I can get that personal touch."

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



Email
hello@respond.co.uk



Scan me
with your smartphone



Providing NHS services



Contact

Pelican Healthcare Ltd

Pelican Healthcare Ltd
Greypoint, Cardiff Business Park
Cardiff, CF14 5WF

0800 318 282
contactus@pelicanhealthcare.co.uk
www.pelicanhealthcare.co.uk

 PelicanHealthcare

 PelicanHealthcareLtd

 PelicanHealth

 Pelican-Healthcare-Ltd

Respond Healthcare Ltd


Respond Healthcare Ltd
Greypoint, Cardiff Business Park
Cardiff, CF14 5WF

0800 220 300 / 0800 028 6848 (N. Ireland)
hello@respond.co.uk
www.respond.co.uk

 RespondLtd

 RespondLtd

 RespondLtd

 Respond-Healthcare-Ltd



© Respond Healthcare Limited 2023
© Pelican Healthcare Limited 2023



BANDAUBROCHREV2