

Starting Your Journey





CONTENTS

- 4 WHAT IS A STOMA?
- **10 PLANNING FOR SURGERY**
- 12 WAKING UP WITH A STOMA
- 16 YOUR STOMA CARE ROUTINE
- 20 GOING HOME WITH A STOMA
- 24 YOUR RECOVERY

Having a stoma should not prevent you from enjoying life. With guidance and support from your healthcare professional you should be able to return to doing all the things you enjoyed before your 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.

If your surgery is planned then you should be able to agree on a site for your stoma.

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



Colostomy

A colostomy is normally situated on the left-hand side of the body, and used to divert the faecal flow away from the anastomosis or injured area. If possible the surgeon will simply remove the diseased part of the bowel and join the two remaining healthy parts of the colon back together. If this is not possible, a colostomy is performed.

The faeces from a colostomy are usually firmer than that from an ileostomy. This is because the large bowel is still intact, and absorbs water which is passed through the stomach.



Loop Colostomy

Created by bringing a loop of the bowel through an incision in the abdominal wall.



End Colostomy

Commonly formed following rectal or anal cancer. Can be temporary or permanent.

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An ileostomy is an opening from the small bowel, allowing faeces to leave the body without passing through the large bowel. This will usually involve the removal of the entire colon, and is normally situated on the right-hand side of the body.

The faeces from an ileostomy is more liquid, as there is no bowel to act as a distribution point for liquid intake. Therefore it is important that an ileostomate maintains a high level of hydration.



Loop Ileostomy

Created when a loop of the small bowel is brought out as a stoma but the colon and rectum are not removed. Usually only used as a temporary measure.



End Ileostomy

Constructed when the colon has been removed usually due to inflammatory bowel disease such as Ulcerative Colitis or Crohn's Disease.

Urostomy

An urostomy is when a passageway is made for urine to pass from your kidneys to the outside of your abdomen.

The most common type of urostomy is an ileal conduit which involves a piece of small intestine being removed and separated from the gastro-intestinal tract. One end of the ileum is closed while the other end becomes the stoma.

The conduit acts only as a passageway and does not store urine and so urine will constantly flow into the pouch.



Picture above is post operative with stents in place.



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 daunting, 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. Taking into account things like your lifestyle and clothing, siting your stoma will mean that after your recovery you will be able to continue enjoying the activities and wearing the clothing you are used to.

There should also be the opportunity to practise wearing a pouch before your operation. This will give you an opportunity to practise applying and removing pouches.

PLANNING FOR SURGERY

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
- Books and magazines (and reading glasses if required)
- Toiletries soap, toothbrush, toothpaste, shampoo, deodorant
- 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



WAKING UP WITH A 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 and your stoma will be swollen initially. This is expected after major surgery so please do not worry.

The surgery you have gone through will 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, Stoma Care Nurse (SCN) or close friends. Acknowledging these feelings will help you emotionally and aid your recovery.

As well as family and friends, please remember that your Stoma Care Nurse is also there to help and support you.

Robert's Story

I was admitted to hospital with severe abdominal pains in December 2014. After a CT scan revealed a blockage in my intestine, the surgeon explained the procedure for the operation and I went to the operating theatre early on Christmas Eve morning!

Waking up, I felt very woozy and was covered in tubes and bandages. The colostomy pouch just seemed part of it. I never expected it to be part of my life for the next two years. At first the pouches kept leaking and soiling my bedclothes: how could I ever lead a normal life if this kept happening?

Fortunately the wonderful stoma nurse found a different pouch that gave a better fit. She brought along a huge bag full of bits and pieces. When she left, I said "You've left your bag behind!" She said "It's yours now!" That was when it really dawned on me that my life had changed.



Read other ostomates' stories, experiences and useful advice at pelicanhealthcare.co.uk

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Your first pouch

When you wake up from your surgery it is very likely that the pouch 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. Once your stoma becomes active your nurse will begin teaching you how to change your pouch.

The thought of changing your pouch 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 pouch independently.

Before your operation your nurse should be able to provide you with a pre-operative pack that gives you tools and advice to practise applying and removing pouches.

If you would like to practise before your operation please request a pre-operative pack from your Stoma Care Nurse.









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 totally 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 practise 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 of 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 Colostomy UK, the Ileostomy Association and the Urostomy Association. You can find their contact details on the back cover of this booklet.

Brenda's Story

The first time I changed my pouch I was terrified but I gave it a try and I coped! I was really nervous for the first few changes but gradually became more confident and after a while it became a habit. I think the main thing at the start is to allow lots of time, never rush, and just take as long as you need.

It took a few weeks to get into some kind of a routine, and I was overly careful in case I was doing it incorrectly, but when I needed advice my nurses were a great help.

I'm now much quicker at changing my pouches and I have settled on a routine that works for me.



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Changing your pouch - tips

Your nurse will give you lots of advice about changing your pouches, but the following tips may also be useful:



Tips

- Be prepared; have everything you need to change your pouch to hand before you start.
- Be gentle removing your pouch as the skin around your stoma may be tender or sore.
- Adhesive removers (such as Release) help to remove the pouch gently and protect the skin around your stoma.
- Wash your stoma slowly with warm water and dry-wipes.
- It is not uncommon for a stoma to bleed if rubbed too firmly because it contains sensitive blood vessels.
- Many users find barrier sprays/wipes (such as Protect Plus) effective at protecting the skin around their stoma.
- Warm the skin protector of your new pouch in your hands before you apply it. This will help it stick more quickly.



GOING HOME WITH A STOMA

The operation you have had 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.

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 living with a stoma concerned about wearing their current clothes, there is a wide range of ostomy-friendly clothing and support garments available online. To find out more about HiLINE support wear please call Respond Healthcare on 0800 220 300 0800 028 6848 (N.Ireland) www.respond.co.uk

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.

Exercise

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

It is really 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 really 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.

Tips

For your safety, always take a mobile phone when you leave the house.

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. To encourage your recovery, a varied diet that includes each of the different food groups in moderation is the best option.

Keeping hydrated is also a really important part of the recovery process so be sure to drink plenty of fluids. Please be mindful not to drink too much before meals as this can curb your appetite.

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.





YOUR RECOVERY

You will probably be daunted by the prospect of recovering from your surgery and managing your stoma at the same time. Please be reassured that feeling this way is totally natural.

The information in this booklet is intended as a guide; your recovery is unique to you and how you feel each day after your surgery. You know your body best and you should always do what is best for yourself.



Tips

If you have any questions before your surgery or during your recovery please do not hesitate to contact your nurse.



AWARD-WINNING STOMA & CONTINENCE SUPPORT SERVICE

At Respond, we know stoma and continence care can be challenging. That's why we are proud to have been awarded NHS DAC Patient Services Award at the British Healthcare Trades Awards 2018.

The award recognises feedback from nurses and the exceptional customer feedback in our annual NHS Patient Satisfaction Survey.



BRITISH HEALTHCARE TRADES AWARDS 2018 NHS DAC PATIENT SERVICES

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To find out more about our award-winning delivery service and how we make life better Call **0800 220 300** Call **0800 028 6848** (N.Ireland) or visit **respond.co.uk**

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Useful Contacts

Colostomy UK

Email: info@colostomyuk.org Tel: 0800 328 4257 www.colostomyuk.org

Ileostomy Association

(Ileostomy and internal pouch support group) Email: info@iasupport.org Tel: 0800 0184 724 www.iasupport.org

Urostomy Association Email: secretary.ua@classmail.co.uk Tel: 01386 430140 www.urostomyassociation.org.uk

For complimentary samples call us now on **0800 318 282** www.pelicanhealthcare.co.uk

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