

# LIVING WITH YOUR ILEOSTOMY



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With thanks to Bo Yeung,  
Bladder, Bowel and Stoma Clinical Nurse Specialist  
for her assistance with this booklet.

## INTRODUCTION

This booklet is designed to help you understand your ileostomy. It will explain what an ileostomy is and provide you with advice and support for before and after your surgery. It is normal to feel anxious before your surgery. But remember, there are thousands of people every year who are on the same journey.

### For a lot of people, an ileostomy is a life-saving procedure.

Every person is different and you will find that certain information is more relevant to you. This booklet has been divided into four sections in order for you to find any specific information or advice with ease:

- ✓ Before surgery
- ✓ After surgery
- ✓ Life with your stoma
- ✓ Follow up care and advice

This information is for guidance and does not replace advice given by your healthcare professional.

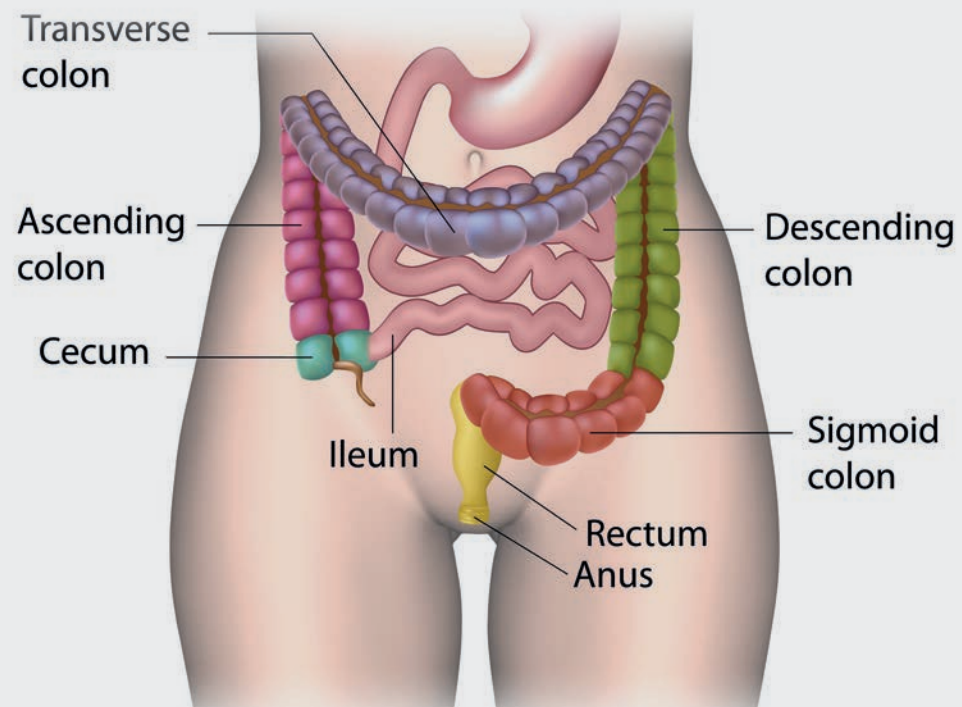




## YOUR SURGERY & STOMA

### YOUR DIGESTIVE/ GASTROINTESTINAL SYSTEM

Once you've eaten, your food begins a journey through a series of hollow organs joined in a long twisting tube from your mouth to your anus. The food travels down your oesophagus (throat) into your stomach where it is absorbed by enzymes, before moving into the ileum (small intestine) to be digested. All the necessary nutrients to keep you healthy are absorbed and the remaining waste is moved into the colon (large intestine), which will store the stool within your rectum until bowel movements allow it to be excreted via the anus.



### WHAT IS AN ILEOSTOMY?

An ileostomy is a surgical operation which brings part of your small intestine (ileum) through your abdomen to the surface of your tummy to form a stoma. Waste material then leaves your body through your stoma. An ileostomy is usually situated on the right side of your abdomen.

The output from your stoma can vary from a liquid to a semi formed consistency e.g. porridge. However, the output from your stoma can change depending on your diet and volume of fluids. You will receive plenty of dietary advice before and after your surgery but it is recommended that you stick to a low fibre and low residue diet.

Your ileostomy may be temporary or permanent. For some people, it is possible to have another surgical procedure to reverse their ileostomy. You will need to discuss this with your surgical team.

### TYPES OF ILEOSTOMY

**END ILEOSTOMY** - This is formed when the colon (large intestine), or part of the colon is removed and the end of the ileum (small intestine) is brought through the abdomen to form the stoma. An end ileostomy may be temporary or permanent depending on the medical reason for your surgery.

**LOOP ILEOSTOMY** - This involves a loop of the ileum being brought through the surface of the abdomen. The looped ileum is then opened up and stitched to the skin to form a stoma, giving time for the diseased part of the colon to heal. A loop ileostomy is usually temporary and may be reversed at a later date.

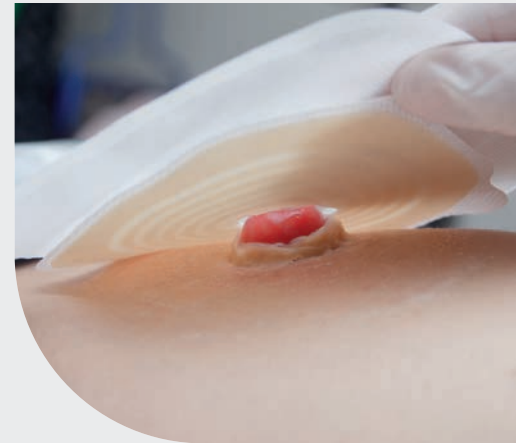
### REASONS FOR AN ILEOSTOMY:

- TRAUMA
- CONGENITAL ABNORMALITIES
- CROHN'S DISEASE
- RADIATION DAMAGE
- BOWEL CANCER
- INHERITED DISORDERS
- ULCERATIVE COLITIS
- BOWEL PERFORATIONS

### WHAT IS A STOMA?

The word 'stoma' is derived from the Greek, meaning 'opening' or 'mouth'.

Your stoma will look red, feel moist and be unique to you. No two stomas are the same. It may protrude from your abdomen or lay flat. It may also have dips, creases or folds depending on your body shape. Your stoma has no nerve supply so can feel no pain.



### PREPARING FOR YOUR SURGERY

You will be provided with information on all aspects of your surgery by your colorectal surgical team. You may have a few appointments prior to surgery. This may include a preoperative assessment. During one of your meetings, your nurse will determine where the stoma will be placed for you to easily take care of it yourself. This is called 'Stoma Siting'.

You will be provided with plenty of written information about the type of surgery and stoma you will have. You will also be given samples of adhesive remover and stoma bags to take home and familiarise yourself with. This is your chance to ask any questions or bring up any worries you might have.

## AFTER SURGERY CARE

When you wake up you will be wearing a transparent drainable bag, so you and your nurse will be able to monitor your new stoma. To begin with, your nurse will empty your bag for you whilst you recover from surgery. They will also assist you until you feel confident enough to empty it yourself. You will then start learning how to care for your own ileostomy. Your ileostomy will work with a fluid watery output, which may become more like a paste over time. Don't be alarmed if you experience wind, this is normal and will decrease over time!

## WEARING A STOMA BAG

The type of bag you use may change over a few weeks as your stoma changes, but this is something that you and your stoma nurse will decide upon. A stoma bag, or pouch, is designed to be placed over your stoma in order to collect any bodily waste products. There are different types of bags: one-piece, two-piece, drainable and closed. You may find that a drainable bag works best for you as the output from your stoma will be loose or in liquid form. This means that you may have to empty your bag more frequently throughout the day. However, your Stoma Care Nurse will help find the type and size of bag that best suits you.

Your stoma will be individual to you and will need to be measured so that the part of the appliance which goes against the skin (the flange or base plate) fits around it. This is called the 'template' and will help prevent leakage and irritation to the skin surrounding your stoma (peristomal skin). For ileotomies, the template is cut to fit so no skin is left exposed. Initially you will be shown how to cut your stoma bag template.

Once your stoma has settled in size (which can take a few weeks to months) you will be able to request pre-cut stoma bags. It is recommended that you use a medical adhesive protect or remove spray to limit irritability to your peristomal skin and make changing your bag easier. Your Stoma Care Nurse can advise you on this.

Stoma care products are specialised products that are available by prescription through home delivery services and some pharmacies.

You will be provided with 2 weeks supply of products and follow up advice before you are discharged from hospital.



# CHANGING YOUR STOMA BAG

- Wash your hands.
- Ensure clothing is out of the way and you have easy access to your stoma.
- Use a medical adhesive remover to release the adhesive barrier if advised to do so by your Stoma Care Nurse (follow the manufacturers instructions).
- Remove the stoma bag from top to bottom by gently peeling back the flange.
- Once the stoma bag is removed, fold the adhesive section in half to seal it.
- Place the stoma bag into a disposal bag.
- Carefully wipe any output or fluid from the stoma and surrounding skin with a dry wipe.



### BE PREPARED:

Ensure you have everything to hand before changing your bag.

- Do not apply any cream or lotions to your stoma unless advised to by your Stoma Care Nurse.
- Clean your skin with a wet wipe.
- Dry your skin.
- Cut the flange of your new bag in order for it to accurately fit around your stoma.
- Use a medical barrier spray or wipe to protect your skin from irritation if advised to do so by your Stoma Care Nurse (follow the manufacturers instructions).
- Remove the backing film on the new bag.
- Position the flange around your stoma and gently smooth it upwards.
- Avoid any creases in the flange.
- Finally, place your hands on top of your stoma bag and hold for 30+ seconds to ensure your bag is well stuck to your skin.



Eventually you will become comfortable with wearing and changing your stoma bag and it will become routine for you.

## LIFE WITH YOUR STOMA

### EARLY DAYS

It is normal to feel anxious, a little sore or tired after surgery. Remember to give your body time to recover both mentally and physically. It may take a while and you may experience a range of emotions, but there will be plenty of people there to support you.

Once discharged from the hospital, you may find it difficult to do simple things, such as showering and changing. Don't worry, this will get easier over time and is completely normal. You should not feel the need to be bedridden all day. Getting up and walking around is very beneficial for your recovery as it will help with your blood circulation.

As expected with all surgeries, you may experience some slight pain and discomfort. If you feel the need to take some pain relief follow the advice of your Stoma Care Nurse who will advise you on how to manage any pain and provide support and guidance on the tablets you have been prescribed. Don't suffer in silence!

Follow the instructions given to you by your surgical team and Stoma Care Nurse.



### DRIVING

Your surgeon will advise you as to when you can safely return to driving. In some cases, you may need to report your surgery and treatments to your insurance company and seek advice.

### DAILY CHECKLIST

- Get up and walk around regularly.
- Take time to nap or rest when tired.
- Take your time returning to any strenuous tasks such as mowing the lawn or using a vacuum cleaner.
- Be aware of the increased risks when lifting heavy objects as this could cause a hernia.
- Take pain relief medication as recommended by a healthcare professional to ease discomfort.

## SKIN CARE

It is important to keep the skin around your stoma clean and healthy. Healthy skin provides a natural barrier against irritation and infection. The peristomal skin should have an appearance similar to the surrounding abdominal skin. Using a medical adhesive remover reduces the risk of skin damage and soreness.

Following assessment, if required, you may need to use a protective barrier spray, wipe or cream to help treat any skin damage and promote stoma skin care.

- Ensure that your stoma bag template is measured correctly as this can rub on your surrounding skin.
- Remove hairs from around the stoma to prevent the adhesive on the bag from pulling on body hairs and causing pain/inflammation.
- Stay hydrated! You will receive advice regarding the amount of fluid you should be drinking based on the volume and consistency of your stoma output and how often your bag needs emptying over 24 hours.
- Maintain an active lifestyle. This may be a struggle after surgery but just start slowly. Even light exercise is good for your overall well-being.

If you notice any changes to your stoma or peristomal skin e.g. swelling, redness, lumps or a rash, do not hesitate to contact your Stoma Care Nurse or GP. Especially if the problem persists or gets worse.



## DIET & FLUIDS

After your surgery, you may feel that you have lost your appetite or that your diet has become restricted. Patients who have undergone an ileostomy are usually advised to follow a low fibre, low residue diet to help maintain a good output and reduce the risk of blockages in your bowel. As you recover and over a period of time you may be able to reintroduce food groups that include vegetables and fruits that you like. Don't panic, you will be able to enjoy all your favourite foods again when you recover. Patience is key...

Slowly begin eating foods that are high in calories and protein such as eggs, cheese, fish, meats and legumes. You should also start eating carbohydrates such as breads, oats, pasta and potatoes (no skins).

You may experience common digestive problems such as wind, odour and a more liquid stool output as you re introduce some foods but you can self-monitor any changes and discuss these with your Stoma Care Nurse. You are unlikely to experience constipation when you have undergone an ileostomy. However, some foods may alter the consistency of your output.

Find some dietary recommendations for these conditions below.



### WIND

- ✓ Eat natural yoghurt, low fibre foods, kiwis, ginger & peppermint.
- ✗ Avoid chewing gum, eggs, fizzy drinks, beans, lentils, long gaps between meals & straws.



### ODOUR

- ✓ Natural yoghurt & peppermint can reduce odour.
- ✗ Fish, asparagus, eggs, beans & onions can increase odour.



## LIFE WITH YOUR STOMA



### FOODS THAT THICKEN STOOL

Yogurt, pasta, noodles, smooth peanut butter, white bread, rice and bananas.

Are you drinking enough?



### FOODS THAT LOOSEN STOOL

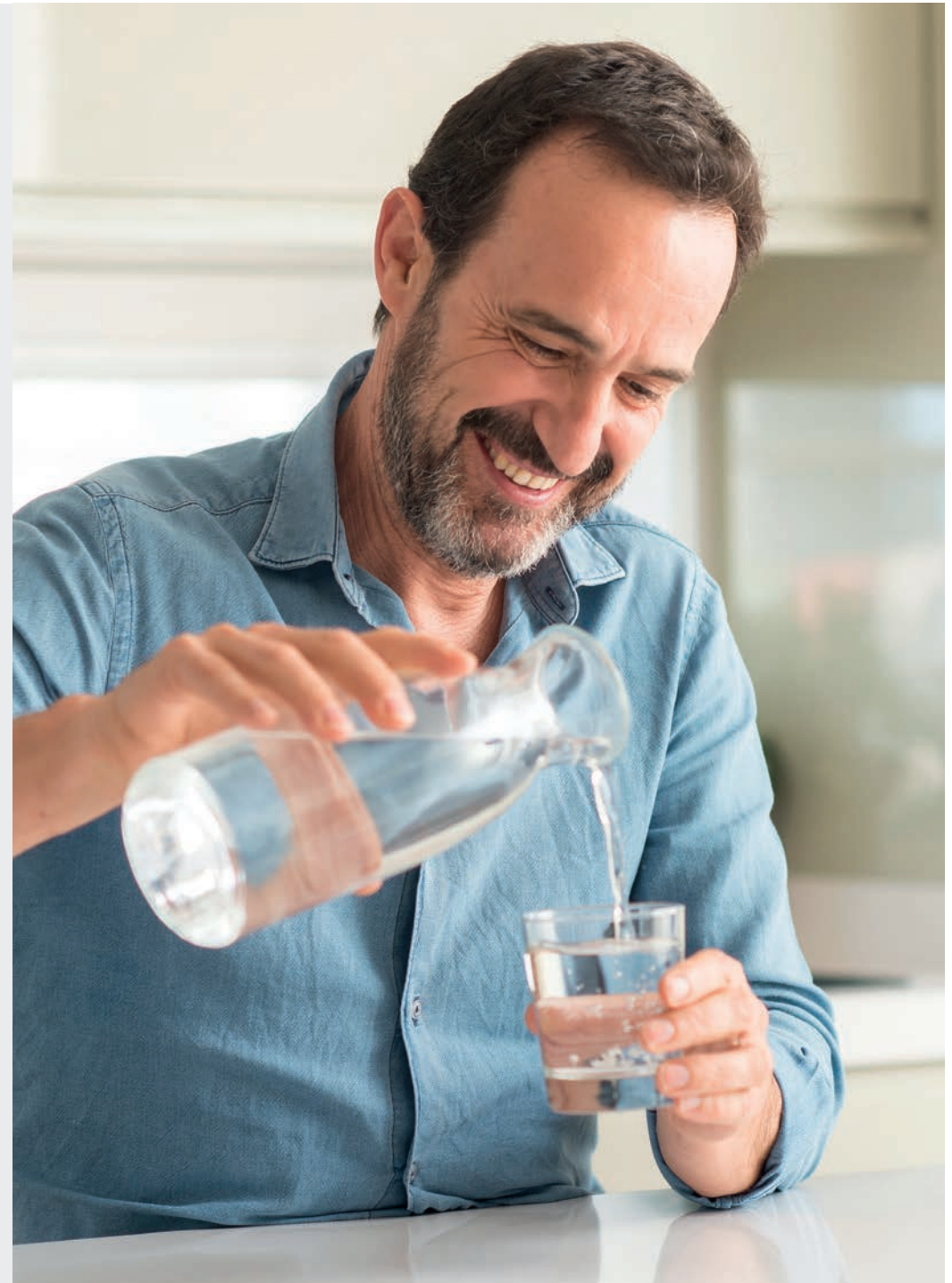
Raw fruit, raw vegetables, leafy greens, fruit juice, prunes, caffeine, alcohol.

Seek medical advice if diarrhoea lasts longer than 24 hours.

### FLUIDS

You are at greater risk of dehydration if you have had your colon (large intestine) removed. This is because the role of the colon is to reabsorb any remaining water and minerals back into your body. Your ileum (small intestine) does not absorb as much liquid as the colon. You may also experience a loose, liquid output for several weeks and therefore it is important to follow all dietary and fluid advice given. Signs of dehydration include a headache, dizziness, tiredness, a dry mouth, low urine output (which may be dark yellow), weakness/lethargy and confusion. If you think you are dehydrated, speak to your Stoma Care Nurse or GP who may recommend St Marks Solution or oral dehydration sachets that are available through pharmacies.

You may also be losing more salt than normal as you will be experiencing a loose, liquid output for several weeks. Talk to your Stoma Care Nurse or GP to discuss if you need to add extra salt into your diet.



ST MARK'S SOLUTION

St Mark's Solution may be recommended by your doctor if you are unable to absorb enough water, vitamins, minerals and other nutrients due to a high stoma output. This means you are at greater risk of becoming dehydrated and may be advised to drink between 1-3 litres of solution throughout the day.

Method for 1L of St Mark's Solution

Ingredients	Measurement
Glucose Powder	20g (6 teaspoons)
Table Salt	3.5g (1 level 5ml teaspoon)
Sodium Bicarbonate/ Sodium Citrate	2.5g (1 heaped 2.5ml teaspoon)

**A fresh solution should be prepared every day and thrown away after 24 hours.**

Tips and Advice

If you find the solution to be bitter or salty, try placing it in the fridge to chill it down, or freeze the solution and drink as a slushy.

- Add a small amount of fruit juice or cordial to minimise bitterness.
- Try sipping the solution through a straw.

HYGIENE

After your ileostomy, you should be able to shower or bathe normally. It is your choice as to whether you want to wear your stoma bag. Water is considered appropriate to keep your stoma clean. However, you may also use soap too.



If you decide to use soap to clean your stoma, opt for a perfume-free and non-moisturised soap. Don't worry, water will not flow into your stoma. Soap should not irritate it in any way or cause any pain. Rinse soap off with water.



Water may disrupt the adhesion between your skin and stoma bag. Remember to always check your bag after showering or bathing to see if it is still stuck well to your skin.

CLOTHING

The main concern for most stoma patients is that their bag will be visible under their clothes and restrict their fashion choices. This is not the case. You can wear any clothes and dress to your personal preference. You do not have to wear 'baggy clothes' in order to disguise your bag. Today's bags are designed to be unrecognisable under clothes so unless you tell someone that you are wearing one, no one will ever know.



You will be able to return to your usual clothing once your swelling has settled.  
Jeans from Aura Clothing  
[www.aura.clothing](http://www.aura.clothing)

## LIFE WITH YOUR STOMA

### SWIMWEAR

When it comes to swimwear, some people may feel self-conscious about their body image after surgery. You shouldn't! You can still wear bikinis and one pieces with a stoma bag. There are also plenty of companies that produce swim wear for people that have undergone an ileostomy. If you wear your own swimwear, thicker fabrics will help disguise your bag. For females, high waisted bikinis don't only look fabulous but can also cover your stoma. If you prefer, a tankini top will also hide your stoma. For males, swimming shorts are ideal as they tend to have a higher waistline and will not rub against your stoma. However, if a pair of speedos are more to your taste then go ahead.

Some helpful swimwear websites:

[www.aura.clothing](http://www.aura.clothing)

[www.stomalight.com](http://www.stomalight.com)

[www.white-rosecollection.co.uk](http://www.white-rosecollection.co.uk)

[www.vblush.com](http://www.vblush.com)

### UNDERWEAR

Many people with a stoma feel that they are unable to wear their usual style of underwear. Don't let your stoma stop you from feeling sexy. You can still wear the same underwear as you did prior to surgery. However, if you find your old underwear uncomfortable, there are plenty of companies that sell specifically designed underwear for male and female patients. Not only is the underwear top of the range for your medical needs, but it is also very fashionable. Look around and see what suits the new you!

Some helpful underwear websites:

[www.white-rosecollection.co.uk](http://www.white-rosecollection.co.uk)

[www.vblush.com](http://www.vblush.com)

[www.cuiwear.com](http://www.cuiwear.com)



Printed Strappy Bikini from Aura Clothing.

## LIFE WITH YOUR STOMA

### EXERCISE & TRAINING

An ileostomy should not affect your ability to exercise in the long term. You should be able to enjoy the same activities as before.

After your surgery, you may be visited by a physiotherapist who will give you plenty of advice and assist you with walking. It is important that you move around your home and to try take a short walk daily. However, don't push yourself or do anything that you don't feel strong enough to do.



Ian returning to the sports he loves.

As time goes on and you begin to recover, you should be able to get back to a healthy lifestyle and engage in activities such as swimming, yoga, skiing, jogging and tennis (to name a few!). Many patients may need a support belt to protect from the development of a hernia. Speak to your Stoma Care Nurse for more information and advice.

Your age, fitness level prior to surgery, physical condition and surgery type will all become a factor in how quickly you can return to physical activity. Do not engage in any rough activities or try to lift weights until you are fully recovered as this can cause injury.

For further tips and advice on returning to training after your surgery visit the Ileostomy & Internal Pouch Association at:

<https://iasupport.org/>

### WORKING & TRAVELLING

#### WORKING

Your doctor will advise you as to when you should return to work. Your ileostomy shouldn't limit you at work and you should be able to do everything you used to do. Make sure you take spare supplies to work with you and you'll be back to your routine in no time!

#### TRAVELLING

If you feel slightly nervous about travelling after your surgery don't worry, it's completely normal. You'll gain your confidence back in time. But until then, maybe start with short-haul destinations. There is plenty of advice available to help you plan your travel. For more information on all aspects of stoma care, including travel advice visit

<https://iasupport.org/>

If you are obtaining your stoma supplies from a DAC-Dispensing Appliance Contractor then they will be able to provide travel advice and travel cards.

Your Stoma Care Nurse can advise what you will need to take with you. It is recommended that you pack extra supplies, better to be safe than sorry! Remember to pack some supplies in your hand luggage so they are readily available to you. If you run out of extra stoma bags whilst abroad, ileostomy products can be bought in selected medical retailers globally.



### BODY IMAGE & EMOTIONS

No two people in this world are the same, and we all perceive our own bodies differently. With today's influx of social media, we also tend to compare our own bodies to other peoples. Having a stoma will change the physical state of your body, temporarily or permanently. This may alter the way you see yourself. Take all the time you need to adjust to your physical changes. Remember that you have potentially undergone lifesaving surgery and you are a survivor.

Do not let your stoma define or control you. You may feel emotional and down some days but just remember you're not alone. Thousands of people have an ileostomy every year and will be going through the same feelings as you.



Photo from Purple Wings Charity.

Talk to the people around you about any body image worries you might have. Discussing your feelings with your close friends and family can help.

You can also talk to your Stoma Care Nurse or GP.

### SEX & RELATIONSHIPS

A big worry for many people after surgery is that their new stoma will interfere with their intimate relationships. During recovery, you will be getting used to your new stoma and may not feel ready to engage in any sexual activity. Make sure you voice your worries to your loved one so they are able to understand. Chances are they are just as anxious as you.



It is important that your partner understands that sexual activity will not harm you or your stoma. If you have undergone extensive surgery, you may experience pain. Ladies may also experience dryness after surgery. If this is the case, try using a lubricant or changing position to determine what is most comfortable and pleasurable for you and your partner.

You and your partner will still be able to conceive after stoma surgery.

Speak to your oncologist if you have any fertility questions before starting any cancer treatments. However, if you don't want to conceive you should speak to your doctor regarding contraception after surgery.

### MEDICATION

As with all medication, you should expect to experience possible side effects. Certain medicines may affect the consistency, colour and odour of your stools but this will depend of what type of ostomy you have had and the medications you are taking.

Medicines such as antibiotics can cause your stools to become loose or cause diarrhoea whereas over the counter medicine can cause both constipation and diarrhoea. If you are taking any supplements after surgery, your stools may become dark and sticky.

Always read your medicines guidance information.



Ensure you communicate any side effects with your healthcare professionals.

### CHEMOTHERAPY & RADIATION



Many people have to undergo surgery to battle cancer. This may mean you need further treatment to stop the spread of cancer cells to other parts of your body (chemotherapy) or to target the cancer cells themselves in the area from which they originated (radiotherapy).

Your oncologist and specialist nurse will support you and discuss all this information with you during your visits to hospital.



Visit [www.macmillan.org.uk](http://www.macmillan.org.uk) for more information and advice regarding chemotherapy drugs and their side effects.

### PROBLEMS YOU MAY ENCOUNTER

#### SMELL

Many people worry about their ileostomy output causing their external bag to smell. This should not be a problem as modern day stoma appliances include charcoal air filters which should neutralise the smell. However, if you find your pouch smelling, speak to your Stoma Care Nurse to help look for a solution.

#### BALLOONING

Ballooning is a common issue that many patients who have undergone an ileostomy experience. Just like it sounds, your stoma bag fills with wind which may cause your bag to come loose from your body. If you suffer with excess wind, speak to your Stoma Care Nurse about changes you can make to your diet or lifestyle. Alternatively, you can remove your filter cover to release any air.

#### PAINFUL SKIN

Possibly the most common problem stoma patients encounter is sore skin. There are many causes of this including output from your stoma coming into contact with exposed skin, a poorly fitted bag, incorrect template sizing, skin reactions or sensitivity to any products and folliculitis (usually caused by shaving).

Speak to your Stoma Care Nurse if you experience sore skin. They may recommend certain products to reduce skin irritability.

## SUPPORT

Your Stoma Care Nurse is there to provide you with support and advise you on what products you should use to use to care for your stoma after surgery and beyond.

Stoma care products are available on prescription through home delivery companies and some pharmacies.

Certain services will be included when you are supplied with stoma bags and adhesive products. These include pre-cut templates (once your stoma has settled), disposable bags, dry wipes and other products on request if required.

You can use the form below to keep a record of useful telephone numbers, recommended supplies and where to order them from.

Date of surgery:
Type of stoma:
Stoma size & shape:
Bag pouching system:
Nurse recommended products:
Delivery company name:
Delivery company address:
Delivery company phone number:

## WHO SHOULD YOU CALL?

Stoma Care Nurse Name:
Stoma Care Nurse phone number:
GP name:
GP phone number:

If you experience any of the following:

- Severe pain
- Skin irritation
- Pouch leakage
- Bleeding of your stoma
- Blood in your stools
- Rash
- Lumps or bulges on your peristomal skin
- Persistent diarrhoea
- Persistent constipation
- Vomiting

Contact your Stoma Care Nurse or GP as soon as possible.

## GLOSSARY

### Adhesive:

The sticky part of your bag that sticks to your skin to help your stoma bag feel secure.

### Anus:

The external opening where the gastrointestinal tract ends and stools exit the body.

### Bag:

Also referred to as a 'pouch' which is connected to the end of an abdominal stoma.

### Cancer:

A term used to describe a collection of related diseases caused by the uncontrolled division of abnormal cells in the body. These cells spread into surrounding tissues and can travel through the blood or the lymph system to form new tumours.

### Chemotherapy:

A cancer treatment which uses cytotoxic drugs to disrupt the division of cells.

### Colon:

A term used to describe the large intestine extending from the cecum to the rectum.

### Constipation:

Difficulty emptying the bowels due to hardened faeces.

### Diarrhoea:

Frequent passing of stools that are in liquid form.

### Flange:

Also referred to as the 'base-plate' which adheres to the peristomal skin in order to attach the bag to the body. It also protects the skin from coming into contact with bodily waste.

### Folliculitis:

A term used to describe a common skin disorder where small pus-filled bumps appear on the skin. Usually caused by shaving and can cause irritability around the stoma.

### Ileostomy:

A surgical operation where part of your small intestine is brought through your abdomen to the surface of the stomach to form a stoma.

### Ileum:

The final section of the small intestine.

### Large intestine:

Another term for the colon or last section of the gastrointestinal tract.

### Output:

Faecal matter or 'poo' discharged from the bowels as waste material.

### Peristomal skin:

The skin surrounding the stoma.

### Rectum:

The final section of the large intestine before the anus where stools are stored.

### Small Intestine:

The part of the gastrointestinal tract between the stomach

and the large intestine where the majority of digestion and absorption occurs.

### Sphincter muscle:

A circular muscle surrounding an opening that maintains constriction of natural bodily passage. A stoma does not have a sphincter muscle.

### Stoma:

An artificial opening derived from the Greek meaning 'mouth' or 'opening'.

### Stoma Care Nurse:

A senior registered nurse trained in the care and support of stoma patients.







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A page with 28 horizontal ruling lines, evenly spaced, for writing.



## StoCare®

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