StoCare®
Quality without compromise

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, 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.

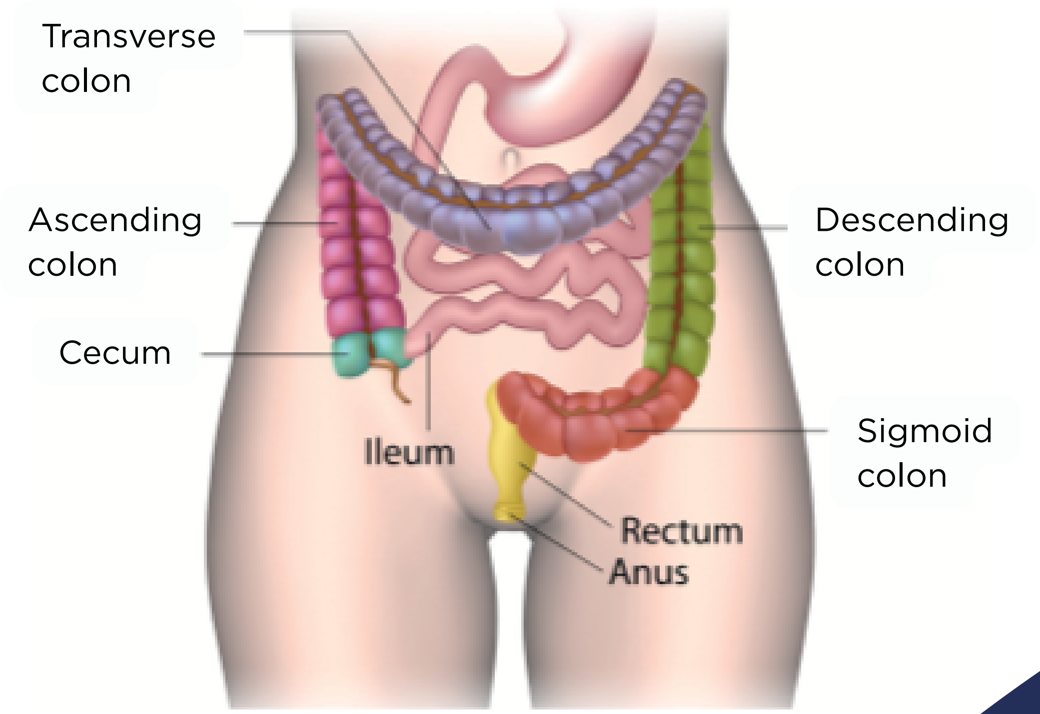
Every person is different and you will find that certain information is more relevant to you. This booklet has been divided into four sections in order for you to find any specific information or advice with ease:

- ✓ 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 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, usually on the right hand side. This means that poo leaves the body through your ileostomy, instead of going to the toilet as you did before. You cannot control or feel your stoma.

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:

- CANCER
- INFLAMMATORY BOWEL DISEASE
- BOWEL PERFORATIONS
- CONGENITAL ABNORMALITIES

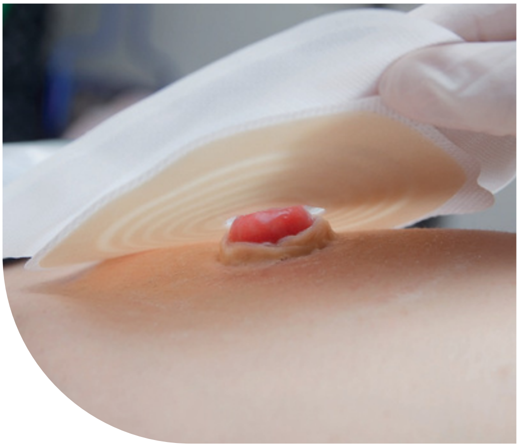
& MUCH MORE

Ileostomies can be formed during planned or emergency surgeries.

WHAT IS A STOMA?

The word ‘stoma’ is derived from 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. Anyone of any age can have one.



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 supplies like stoma bags and medical adhesive remover to take home and familiarise yourself with. This is your chance to ask any questions or bring up any worries you might have.

When you wake up, you will be wearing a transparent drainable bag, so you and your nurse can monitor your new stoma. To begin with, your nurse will empty your bag for you until you feel well enough to do it yourself. You will then start learning how to care for your own ileostomy. It might help to have a family member or friend present so they know how to help you at home.
Your ileostomy will work with a watery fluid 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

An ileostomy bag or pouch is designed to be placed over your stoma in order to collect your poo. It is attached to the skin around the stoma using an adhesive.

There are many different types of bags: one-piece, two-piece, drainable and closed, to name a few. Ileostomy patients tend to use a drainable bag as the output from ileostomies is loose or liquid and very active. This will enable you to **empty** your bag frequently throughout the day (the number of times varies depending on your diet, lifestyle, etc.), without having to take the bag off and replace it with a new one every time. Your stoma nurse will help you determine what type and size of bag you should wear.

How often you **change** your ileostomy bag is up to you. Every two or three days is a good benchmark to aim for, as it allows you to check the condition of your skin while protecting it from frequent adhesive removal, which can irritate it. It is recommended that you use a medical adhesive remover to limit damage to the skin around your stoma (peristomal skin) and make changing your bag easier.

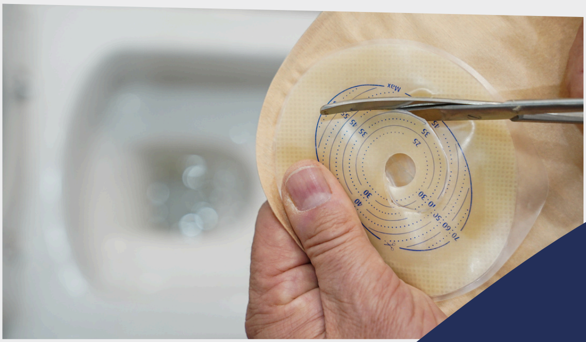
Stoma care products are specialised products that are available by prescription through home delivery services and some pharmacies.

AFTER SURGERY CARE

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 baseplate) fits around it. This is called the ‘template’ and will help prevent leakage and irritation to your peristomal skin. For ileostomies, the template should be cut to fit so no skin is left exposed.

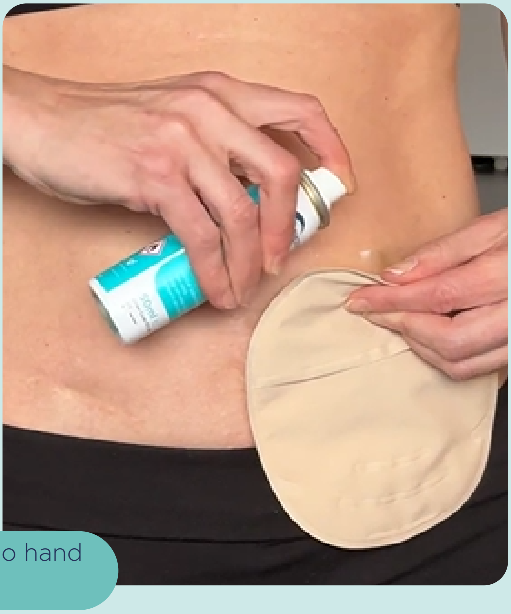
Initially you will be shown how to cut your stoma bag template. Once your stoma has settled in size (which can take a few weeks to months) you will be able to request pre-cut stoma bags.

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 (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 disposable bag.
- Carefully wipe any stool or fluid from the stoma and surrounding skin with a dry wipe.



BE PREPARED: Ensure you have everything to hand before beginning to change your bag.

- Do not apply any creams or lotions to your stoma unless advised to do so by your stoma nurse.

- Clean the skin with a wet wipe.

- Dry your skin.

- Cut the flange of your new bag so that it fits accurately around your stoma.

- Apply a medical barrier film spray or wipe (follow the manufacturers instructions).

- Remove the backing film on the new bag.

- Position the flange around your stoma and gently smooth it upwards, avoiding any creases in the flange.

- Finally, place your hands on top of your stoma bag and hold for 30+ seconds to ensure the bag is well stuck to your skin.

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

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 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.

Follow the instructions given to you by your surgical team and stoma care nurse, which could include physiotherapy advice.

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.

PERISTOMAL SKIN CARE

It is important to keep the skin around your stoma (peristomal skin) clean and healthy. Healthy skin provides a natural barrier against irritation and infection. Your peristomal skin should have an appearance similar to the surrounding abdominal skin. Here are some top tips to avoid skin damage:

- Stay hydrated.
- Change your bag as soon as possible if it has leaked.
- Remove hairs from around the stoma to prevent the adhesive on the bag from pulling on body hairs and causing pain/inflammation.
- Ensure that your stoma bag template is measured correctly.
- Clean the skin gently, avoid any irritants (perfumed soaps, lotions, wipes containing alcohol, etc.) and do not scrub.
- Ensure the skin is completely dry before replacing your pouch.
- Using a medical adhesive remover reduces the risk of skin damage when removing a bag, as can using a protective barrier film spray or wipe before applying a new bag.

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, you can reintroduce different types of food. Many people with a stoma can eat anything they like without restrictions - your best bet is to just try it. It's a good idea to keep a food diary and note down any symptoms that occur. Try every food at least twice to notice patterns, as there is a chance it was a one-off or caused by other factors.

You may experience common digestive problems such as wind, odour and a more liquid stool output as you reintroduce some foods. 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

✓ Natural yoghurt, peppermint drinks, eating regularly, letting fizzy drinks go flat and not drinking through a straw can reduce wind.

✗ Beans, peas. sprouts, cabbage, onions, leeks, lentils, spicy food, fizzy drinks and chewing gum can increase wind.

ODOUR

✓ Natural yoghurt & peppermint can reduce odour.

✗ Fish, asparagus, garlic, eggs, beans, cabbage, sprouts and onions can increase odour.

FOODS THAT THICKEN STOOL

- Starchy food such as white bread, white rice, pasta, noodles or peeled potatoes
- Easy to digest fruit such as ripe banana, melon, peaches, mangoes or tinned pears
- Natural yoghurt
- Milk puddings
- Smooth peanut butter
- Apple sauce

FOODS THAT LOOSEN STOOL

- Raw or undercooked fruit or vegetables
- Prunes/figs
- Wholemeal/wholegrain products
- Spicy food
- Fatty/greasy food
- Alcohol
- Caffeine

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.

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 nurse or GP who may recommend St Marks Solution (see page 18) or oral dehydration sachets that are available through pharmacies.

You may also be losing more salt than normal. 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. The means you 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 it 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 enough 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 dry your peristomal skin well if you remove your bag or check your bag after showering or bathing to see if it is still securely in place.

CLOTHING

The main concern for many 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.

Some high street brands such as Debenhams, Marks and Spencer and Primark stock clothing ranges specifically designed for stoma bag wearers.

Jessica Women's Ostomy Swimsuit from whiteroseostomy.co.uk

Swimwear

When it comes to swimwear, some people may feel self-conscious about their body image after surgery. You shouldn't! There are plenty of companies that produce swimwear for ostomates. If you wear your own swimwear, thicker and patterned 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.

Websites where you can buy ostomy underwear and swimwear include

www.whiteroseostomy.co.uk
www.vblush.com
www.cuiwear.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. 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.

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 **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 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.

Here are some quick tips for travelling with a stoma:

- Go through your bag change routine and make a list of everything you use.
- Calculate how many supplies you will need and pack plenty of extras, including different bag sizes.
- If flying, keep your stoma supplies in your hand luggage so it is not lost and you have them to hand should you need them.
- Carry your stoma supplies with you in a dedicated, easy-to-carry bag for quick and easy changes.
- You may want to download a travel certificate in the local language to explain your condition.
- For travelling in the UK, you can use a radar key to easily access disabled toilets.

For more information on all aspects of stoma care, including travel advice, visit www.stocare.co.uk/stoma-advice-and-support

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.

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. They may be able to help you find a local stoma support group.

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. Sometimes, stoma surgery can affect the nerve endings and blood supply to the penis, resulting in erectile dysfunction; speak to your stoma nurse about this. Also, J-pouch or Barbie butt surgery will impact your ability to have anal sex.

Stoma surgery should not affect your ability to conceive. If you don’t want to conceive you should speak to your doctor regarding contraception after surgery.

Speak to your oncologist if you have any fertility questions before starting any cancer treatments.

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 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. You can purchase gels and sprays to neutralise odour.

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. This might happen because the filter on your bag is not working as it should. Protect it from getting wet by using the filter cover when washing or swimming. You can release air from your ileostomy bag by ‘burping’ the bag in a controlled manner from the bottom. If you suffer with excess wind, speak to your stoma care nurse about changes you can make to your diet or lifestyle.

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).

HERNIAS

Stoma surgery can weaken the muscle that was cut, making it susceptible to a parastomal hernia. This is when a section of the intestine pushes through the muscle in the same area as the stoma and presses against the skin. This results in swelling around the stoma, which can get bigger over time. Parastomal hernias rarely cause complications. However, you should contact your stoma nurse if you suspect you have one, especially if you are experiencing pain. They will assess how serious it is and advise you how to manage it. They may suggest that you wear a support garment. If it is very painful, is becoming so large that it is unmanageable or has caused a complication such as strangulation or obstruction, surgery to repair the hernia may be considered.

Speak to your stoma nurse if you experience sore skin or frequent leaks. They may recommend products to help such as barrier films or a stoma seal.

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 ‘baseplate’ 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.

NOTES

MORE FROM STOCARE

Discover more free stoma advice and support on our website
www.stocare.co.uk/stoma-advice-and-support

CONTACT US

☎ 01772 620014
✉ info@rhodeshealth.co.uk
@stocaresocial

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