YOU AND YOUR

ILEOSTOMY

Essential advice for before and after your operation

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INTRODUCTION

You have been given this booklet because it is likely that you are soon to have an ileostomy formed. The booklet has been written to help explain what an ileostomy is and what it will mean to you once you have had your operation. **We have separated the information into 4 sections:**

- SECTION 1: **INFORMATION TO READ PRIOR TO YOUR SURGERY**
- SECTION 2: **HELPFUL INFORMATION FOR YOUR RECOVERY PERIOD**
- SECTION 3: **ADJUSTING TO LIFE WITH YOUR ILEOSTOMY**
- SECTION 4: **OTHER HELPFUL ADVICE**

Everyone is different and will want to read what they feel is most useful to them. We recommend you read the first section and perhaps have a look ahead to what you can expect when you wake up after your surgery. You may want to leave the remaining sections until you are at home and feeling a bit better. It is completely up to you.

The booklet has been written to help explain what an ileostomy is and what it will mean to you once you have had your operation.

This booklet has been written by a team of Stoma Care Nurses, who have many years of experience in looking after people living with an ileostomy.

There are a number of **Frequently Asked Questions,** which may not have been covered in the three sections of this booklet. These are included on page 58. If you can't find the answer to any of your own questions in the booklet, please contact your Stoma Care Nurse.

At the back of the booklet you will find a **Glossary of terms.** This includes a number of words, some of which are medical terms, along with their meanings. We have also included alternative words that you might hear to describe some of the terms.

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SECTION 1

YOUR STOMA AND SURGERY

Information to
read prior to your surgery

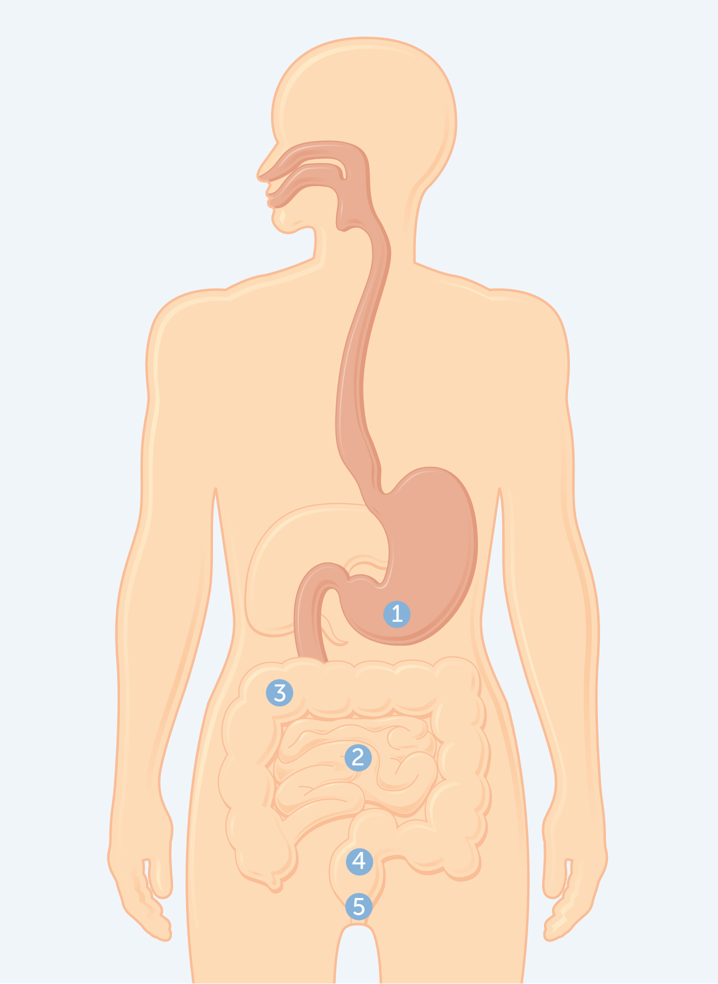
1. YOUR STOMA AND SURGERY

Your digestive system

Your digestive system, also known as the gastrointestinal system, is part of your body that absorbs and digests food, as well as eliminating the body's waste. Anything you eat or drink is chewed in your mouth before travelling down your esophagus into your stomach where the food is further broken down by gastric juices. This is then pushed along your digestive system into the small bowel, where the digestion and absorption process continues and your body obtains the necessary nutrients it needs. The waste from this process, along with any fluid, moves into the large bowel. This is then absorbed, turning the waste material into a solid stool. The solid stool is then stored within your rectum and excreted via the anus when appropriate.

The digestive system

Stomach ①
Small bowel (ileum) ②
Large bowel (colon) ③
Rectum ④
Anus ⑤



1. YOUR STOMA AND SURGERY

What is a stoma?

Stoma is a Greek word meaning 'opening' or 'mouth'. There are generally three types of stomas:

- ▷ **Colostomy:** from the large bowel
- ▷ **Ileostomy:** from the small bowel
- ▷ **Urostomy:** urinary stoma

A stoma can be either temporary or permanent, depending on the reason for its formation.

An ileostomy is usually on the right-hand side of your body, but in some circumstances may be formed on the left-hand side.

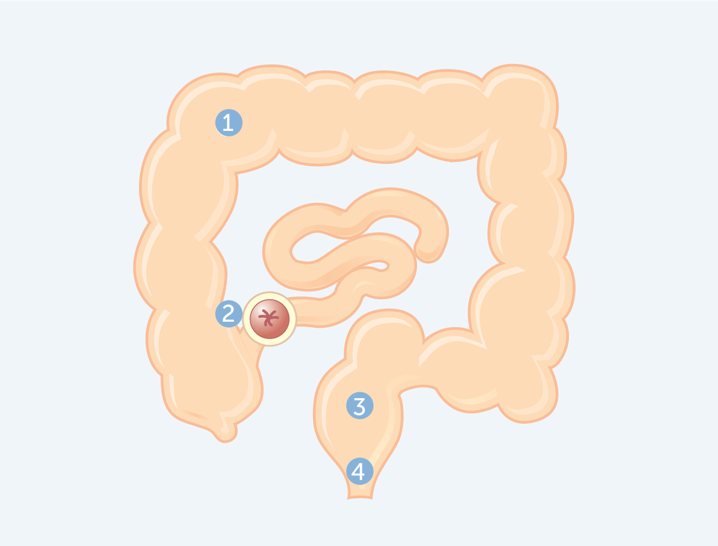
What is an ileostomy?

An ileostomy is a surgically created opening from your small bowel to the surface of your abdomen. An ileostomy provides a new path for waste material to leave your body after part of the bowel has been removed. It can produce output varying from liquid stool to a thick, porridge-like consistency.

You will either have an end ileostomy or a loop ileostomy.

End ileostomy

This is formed when all or part of the large bowel and/or the rectum are removed. Part of the small bowel is brought out to the surface of the abdomen to create a stoma.



The bowel and where an end ileostomy may be formed

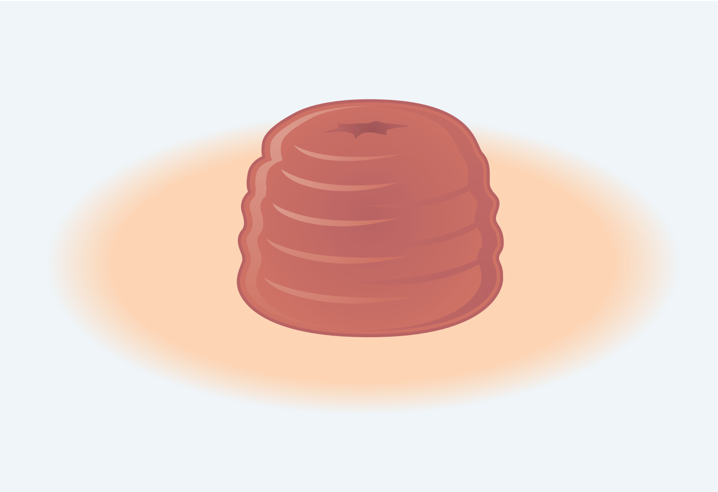
End ileostomy

① Large bowel (colon)
② Ileostomy
③ Rectum
④ Anus

1. YOUR STOMA AND SURGERY

An end ileostomy can be temporary, but is generally permanent. If a temporary end ileostomy is created, a diseased section of large bowel is removed, but the remaining bowel cannot be re-joined at the same time as it is unsafe or inappropriate for your surgeon to do this at this time.

> *However, it may be possible to re-join your small bowel in the future, and this can be discussed with your surgeon.*



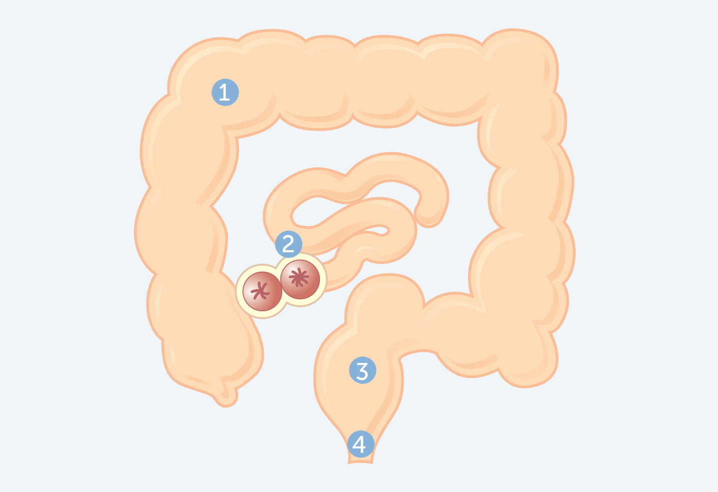
End Ileostomy only has 1 opening

1. YOUR STOMA AND SURGERY

Loop ileostomy

A loop ileostomy is usually created to protect a surgical join in the large bowel or to divert the flow of stool from an obstruction. It is formed when a loop of the small bowel is brought to the surface of the abdomen and opened to form a stoma. This can be temporary or permanent. A loop ileostomy can also be formed to protect the join following reconstruction surgery, such as an Ileo-anal pouch.

A loop ileostomy has two openings; only one of these will pass stool. The other may produce mucus.



A diagram of the bowel and also where a loop ileostomy may be formed

Loop ileostomies

① Large bowel
② Ileostomy
③ Rectum
④ Anus

Loop Ileostomy has 2 openings

1. YOUR STOMA AND SURGERY

Why am I having an ileostomy?

Your operation may need to be performed for a variety of reasons and your Surgeon and Specialist Nurse will explain these to you. There are a number of different diseases and conditions that can result in the need for an ileostomy, such as:

- Ulcerative Colitis
- Crohn's Disease
- Diverticular Disease
- Fecal incontinence
- Cancer
- Trauma
- Familial Adenomatous Polyposis
- Radiation damage
- Congenital abnormalities

Before surgery

You will have the opportunity to meet with the Colorectal Surgeon and Specialist Nurse on one or two occasions before your surgery. This is usually in clinic or at your pre-operative assessment appointment where you will be told about all aspects of your surgery, given written information and most likely be shown ileostomy products for you to consider. You will be able to take samples home, so that you can familiarize yourself with items you may be using. During your pre-operative appointments you should have time to ask questions and discuss any aspect of your care. You might want to start making a list of things to discuss prior to your appointments to take with you so that you do not forget to ask anything.

> *It is a good idea to take a member of your family or caregiver with you to your pre-operative appointments, as there is a lot of information to take in.*

The stoma care nursing team will be key throughout your journey and will be available to advise and support both you and your family/caregivers.

Where possible, your Stoma Care Nurse will involve you in marking the ideal site for your ileostomy as a guide to the surgeon, taking into consideration your individual needs. However, at the time of surgery, it may not always be possible to put the stoma in the exact position your Stoma Care Nurse has marked.

1. YOUR STOMA AND SURGERY

What will my ileostomy look and feel like?

Your ileostomy should protrude from your abdomen, like a spout, and this can vary depending on how it is formed by your surgeon. It will be soft to touch, pinkish-red in colour and moist; rather like the inside of your mouth. There is no sensation in the stoma, so it is not painful. However, it has a rich blood supply and it is normal for it to bleed a little from time to time, especially when cleaning. Your ileostomy is likely to be swollen at first and will take a few weeks to reduce in size. There will be small stitches around the edge of your stoma, which will either be dissolvable or your Stoma Care Nurse will remove them 1-2 weeks after your operation.

End ileostomy

Loop ileostomy

SECTION 2

AFTER YOUR SURGERY

Helpful information
for your recovery period

2. AFTER YOUR SURGERY

Waking up after your surgery

When you wake up after your operation, you will feel tired. It is possible that you may experience a range of emotions during this time and for some time afterwards. This will vary as we are all different.

> *Remember that it may take a while for you to recover, both physically and emotionally.*

Initially you will be wearing a drainable bag, which will most likely be transparent or have a viewing window, so that your nurses can check on the colour and size of your stoma easily. The nurses will empty your bag until you are feeling well enough to do this yourself.

You may have drips and drain tubes attached to your body, but there is no reason to be alarmed – this is quite normal. These will all be removed when appropriate and with very little discomfort.

Drainable bags

2. AFTER YOUR SURGERY

When will my ileostomy start to work?

Your ileostomy will usually start to work shortly after your operation, and the output will be watery and green/yellow in colour initially. This will start to thicken to a brown, porridge-like consistency when you start to eat normally. Your output will stay like this as it is no longer passing through the large bowel, where fluid is reabsorbed to create a formed stool.

You will have no control over when your ileostomy works and may not be aware of it happening. Your ileostomy may produce wind, sometimes noisy!

All of this is normal and is to be expected.

It is recommended that people with an ileostomy wear a drainable bag, which would need emptying approximately 6-8 times in 24 hours. It is important to empty your bag regularly, to ensure that it does not get too full. If a bag is full, it can be more difficult to empty and may also be more noticeable under clothes. Most people will change their drainable bag every 3-5 days, but it is up to you.

You may still feel like you need to go to the toilet via your anus if your rectum has not been removed. This is perfectly normal. When you do sit on the toilet you may well pass some old stool and/or possibly some mucus.

If you have had your rectum removed and anus closed, there is a possibility you may experience 'Phantom Rectum'. This is a sensation of wanting to open your bowel in the usual way. It may help to sit on the toilet until the sensation has passed.

2. AFTER YOUR SURGERY

Wearing a stoma bag

There are a variety of different bags for you to choose from, and you can try a one-piece or two-piece product to see which type suits you best. It is your choice which bag you use. Your Stoma Care Nurse will usually show you options to help you decide which is the most suitable for you. There are a range of different sizes which are designed to be worn under your normal clothes. Drainable bags have integral filters to allow wind to flow from the bag very gradually. The filter also contains a charcoal material which will absorb any odour. Bags are waterproof, so you can choose to have a bath or shower with it on or off. It is up to you, but remember, you will have no control over when your stoma is likely to function.

> *After a while, you will establish a routine for changing your pouch and it's a good idea to keep this as simple as possible.*

Your stoma will work at different times of the day; for instance, it could be active shortly after a meal. It may be easier to change your bag at an inactive time.

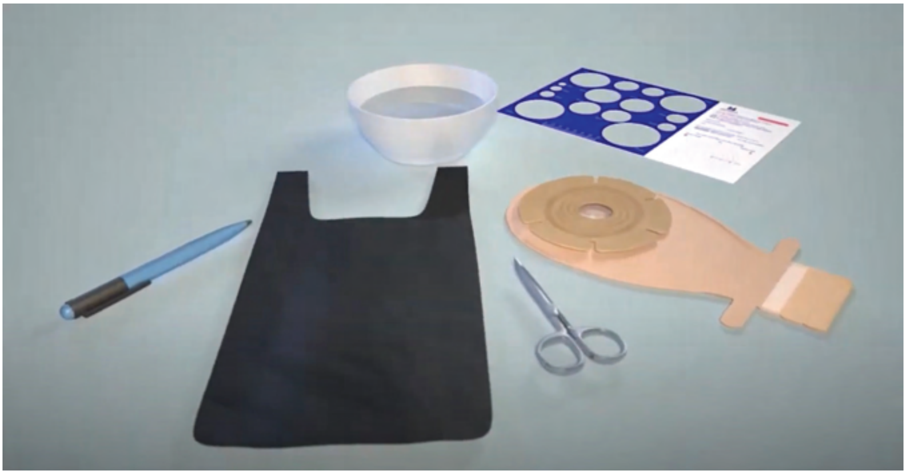
One-piece and two-piece bags

Changing your stoma bag

Ensure you have everything to hand before changing your bag:

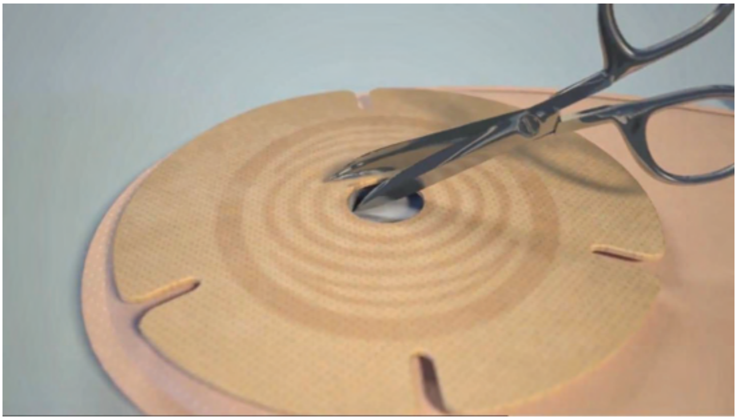
- ▷ A clean stoma bag
- ▷ Scissors and template (if required)
- ▷ Dry wipes or plain kitchen roll (not cotton wool or tissues)
- ▷ Warm water
- ▷ Disposal bag
- ▷ Adhesive remover (if required)

TIP: It is advisable to wash your hands before and after changing your appliance.



To change your bag

- ▷ Draw the template of your stoma onto the adhesive of the bag, then cut it out.

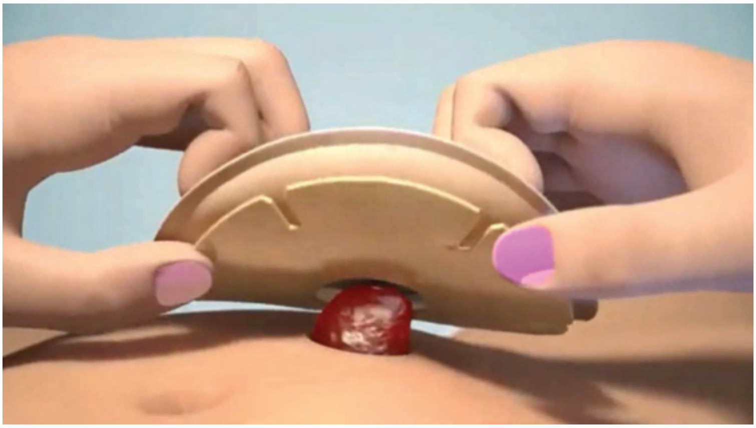


Cutting the hole

TIP: It is most important that this hole fits snugly around the stoma to prevent the risk of leakage and irritated skin. Your Stoma Care Nurse will show you how to do this and it will become easier with practise. However, if you would like your bags to be cut to size, this will be possible once the initial post-operative swelling has reduced.

2. AFTER YOUR SURGERY

- Close the outlet of the new bag so it is ready to apply.
- Drain the bag you are wearing into the toilet.
- To empty your drainable bag:
  - Once you are in your preferred position for emptying the bag, undo and unroll the outlet to open it.
  - When empty, clean the outlet with toilet tissue or a dry wipe.
  - Roll the outlet back up to its original position and secure.
  - Some bags allow you to tuck the outlet up into the bag for extra discretion.



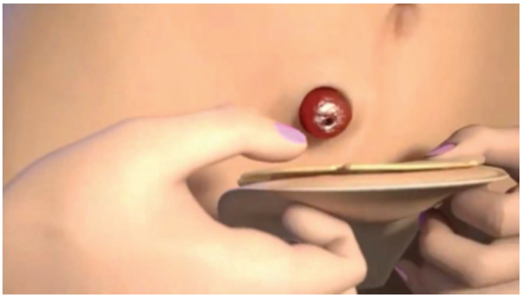
Bag removal

- To remove the bag carefully release the adhesive, working from the top down whilst supporting the skin (if you choose to use an adhesive remover, spray a small amount as you peel away the adhesive to help with removal).
- Once removed, fold the adhesive section of the used bag to seal.
- Place your bag into a disposal sack.
- Use dry wipes (kitchen roll is an alternative) and warm water to clean around the stoma. Place these in the garbage bin (do not put them in the toilet as they may block it!)
- Ensure the skin around the stoma is dry.
- Remove the backing film from the adhesive of the new bag.

TIP: To clean your stoma and skin, water is considered adequate and acceptable. However if you prefer to use soap, a simple non-perfumed, non-moisturised soap should be used. Ensure that it is rinsed away before drying your skin to prevent irritation.

Peel

- Fold the top half of the adhesive back, then position it around the stoma, working from the bottom and smoothing upwards with your fingers. Take time to ensure there are no creases in the adhesive and use the warmth of your hands to mould the bag to your skin, making sure it is well stuck!
- Securely close the disposal sack and put in the normal household garbage bin. DO NOT flush a used bag down the toilet, as it will cause a blockage.



Position

Press

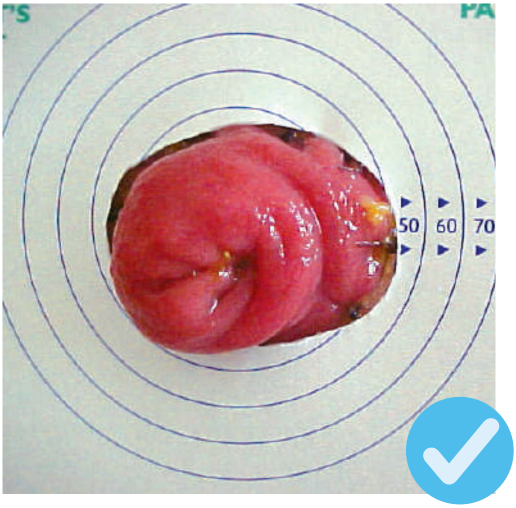
2. AFTER YOUR SURGERY

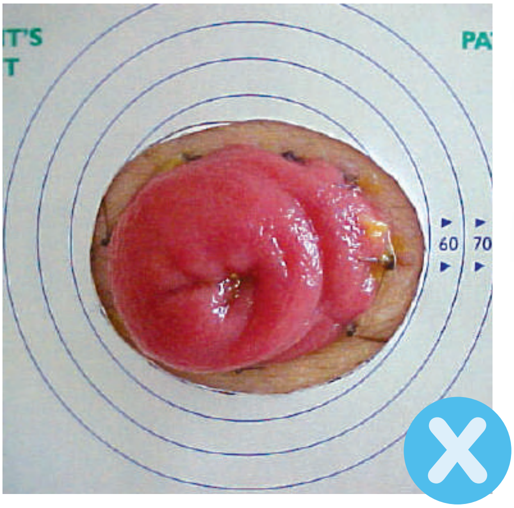
Caring for your skin

Caring for your skin is an essential part of looking after your ileostomy.

Immediately after your surgery, your stoma and surrounding skin may look swollen and even a little irritated. This is all to be expected post operatively and with good care it should improve in appearance over time.

You may find that your product requirements may alter due to the changes in your stoma size and shape. Your ileostomy template will alter and should be checked at least weekly for the first 8 weeks, or particularly if lots of healthy skin can be seen through the hole.





The area of skin around your stoma needs ongoing care and attention to prevent and reduce the risk of soreness.

If you start to develop sore, irritated or even broken skin, do not delay in contacting your Stoma Care Nurse for appropriate advice on treatment and the need for alternative products.

2. AFTER YOUR SURGERY

Aim to keep your skin in optimum condition by considering:

- Good nourishment and hydration – take time to look at the section in this booklet about food and drink that aid healing and promote hydration.
- This could be an excellent opportunity to stop smoking – smoking effects how nutrients and oxygen might get to your skin and so results in a drier, dull skin that is at more risk of breakdown.
- Regular exercise increases your body's metabolism and encourages oxygen to reach your skin cells quicker and in greater supply.
- Care for your skin on a daily basis; keeping it clean and moisturised as adaptation to life with a stoma depends largely on the health of the peristomal skin (skin around your stoma).
- Remove any hair from the skin around your stoma. This is so the adhesive does not pull at the hair shaft causing inflammation and trauma to the skin. How often you need to remove hair from around your stoma is very individual, and you will get to know when removal is necessary.

TIP: *To remove the hair around your stoma you might find it helpful to use a plastic deodorant lid or empty toilet roll cardboard to place over the stoma, for protection, and shave around it. If you experience sore skin, please refer to page 48.*

SECTION 3

LIVING WITH A STOMA

Adjusting to life with your ileostomy

3. LIVING WITH A STOMA

AVOIDING A HERNIA

There are steps you can take to help prevent a hernia, and it is important to be aware of these after your surgery. There are exercises you can do to help prevent a hernia: please speak to your Stoma Care Nurse about these. For more information on what a hernia is: please see page 49.

Early days at home

When you are first discharged from hospital you will feel tired and find everyday tasks such as having a shower exhausting. This is normal and will improve over time. You should not need to stay in bed when you get home, but you will need plenty of rest, and should make time for a nap during the day.

You may experience some pain and discomfort initially whilst recovering from your surgery. This is a normal part of recovery and you may need to take regular pain relief. There is no need to suffer! Avoid tight fitting clothing during this period as your abdomen may be sore and swollen.

It is normal to feel emotional after major surgery, so don't worry if you have 'down' or 'teary' days to begin with. Talking to family and friends can be helpful – don't feel you need to cope alone. Your Stoma Care Nurse is there to support you, and there are patient support groups who can help too.

Don't be frightened to ask for help.

Changing your stoma bag will be slow at first, but with practice and as you gain confidence, this will become part of your normal daily routine.

Tips for early recovery

- It is advisable to go for a short walk daily.
- You should be able to manage stairs.
- Spread tasks over the day and rest in between, but remember you are likely to feel more tired as the day goes on.
- Do not lift anything heavier than a half-full kettle.
- You will be able to make small light meals.
- You must not drive in the early days after your surgery because you are still sore and may have restricted movement. Certain medication can affect your ability to drive.

Tips for ongoing recovery

Over the next few weeks, increase the amount of activity that you are doing as your body allows.

- Continue to rest when you get tired.

- Continue to avoid heavy lifting due to the risk of developing a hernia. If you do need to lift; keep the objects close to your body, bend knees and wear a light support garment. Your Stoma Care Nurse will be able to advise you.
- Household activities such as ironing can be done sitting down.
- Continue to walk on a daily basis, going further over the weeks.
- Avoid stretching up to reach high cupboards.
- You should be able to drive after 3–6 weeks, depending on your type of surgery but you MUST check with your insurance company.
- Continue the abdominal exercises you were taught in hospital.

3. LIVING WITH A STOMA

Obtaining your supplies

You will be discharged from hospital with ostomy supplies and any additional equipment you will need. You can obtain additional samples, if needed, by contacting Westech Health Care Ltd and specking with one of our trained specialists. Westech can also help you find a local retailer that will be convenient for your product purchases.

Ostomy Coverage

There are four different types of coverage avenues that can be utilized based on qualifications and location. See links below for more information.

1. Federal Programs
   - A. Interim Federal Health Program
   - B. Disability Tax Credit
2. Indigenous Services Canada – Non-insured Health Benefits
3. Vertrans Affairs Canada
4. Provincial and Territory Programs

Helpful Links

- British Columbia – BC Fair PharmaCare
- Alberta – Alberta Aids to Daily Living
- Saskatchewan – Saskatchewan Aids to Independent Living
- Manitoba – Ostomy Manitoba
- Ontario – Assistive Devices Program
- Quebec – Ostomy Appliance Program (OAP)
- New Brunswick – Health Services Ostomy / Incontinence Program
- Nova Scotia – Nova Scotia Pharmacare
- Prince Edward Island – Prince Edward Island Pharmacare
- Newfoundland and Labrador – Newfoundland and Labrador Prescription Drug Program (NLPDP)
- Northwest Territories – Health and Social Services, Extended Health Benefits
- Nunavut - Extended Health Benefits
- Yukon – Yukon Health Care Insurance Plan (YHCIP) Chronic Disease and Disability Benefits

3. LIVING WITH A STOMA

Eating little amounts and often will help regulate your output.

Diet and hydration

After your surgery you may find your appetite is reduced, but it is still important to eat little and often to help your recovery. You should be able to eat normal foods and return back to the food you enjoyed before your surgery. You may find that some foods can upset your stoma but this may be a one off and we would advise you to try them again in a couple of weeks. Certain foods will alter the consistency of your output, therefore what you eat plays an important part in controlling the output. You should aim for a porridge-like consistency, which can be easier to manage. Some foods can cause blockages, so should be avoided or eaten with caution.

Dietary tips for the early days

You are likely to have lost weight following your surgery. It is important to increase your intake of calories, fat and protein to aid your body's healing process. In addition to your normal diet, you should look to include the following foods:

- Full fat milk and cheese
- Double cream (add to soup, mashed potato and puddings)
- Snack on biscuits and cakes
- Foods high in protein each day such as fish, tender meat and eggs
- Drink regularly to avoid dehydration

Ongoing dietary advice

- Eat and drink regularly
- Include fruit and vegetables daily
- Have foods high in protein each day such as meat, fish, eggs, cheese, milk or yogurt
- Include carbohydrates with each meal such as bread, potatoes, pasta, rice and breakfast cereals
- Include milk and dairy foods two to three times per day as they are rich in calcium – choose lower-fat varieties as a healthier option
- Experiment and try everything in small amounts, gradually increasing quantities. If something disagrees with you, avoid it for a couple of weeks and then try a small amount again

People with an ileostomy will experience the same common digestive issues that they may have had before their surgery, such as wind, odour and loose output.

Maintaining hydration

Maintaining adequate hydration is important for everyone. It is advisable to drink 6–8 glasses/mugs of fluid a day, but limiting caffeine.

Loose output

This can be caused by many things including diet, medication and your emotions. Common foods that can cause loose output:

- Green vegetables
- Spicy foods
- Alcohol
- Raw fruit
- Fruit juices
- Wholemeal varieties of foods

Cooking fruit breaks down the fibre in it, so you could try stewing fruit.

Solutions to thicken output

- Starchy foods such as: white rice, pasta, white bread and potatoes
- Ripe banana
- Marshmallows or jelly babies
- Live yogurt
- Cheese
- Noodles
- Tapioca and other milk puddings
- Smooth peanut butter

If you take anti-diarrheal medication, such as Imodium, ask your Doctor for tablets or syrup rather than capsules, as these may not be broken down in the small bowel and so may have a limited effect. If you experience loose/higher output that is unusual for you, please contact your Stoma Care Nurse for advice.

Dehydration

Dehydration is a condition that occurs when the loss of body fluids, mostly water, exceeds the amount that is taken in. When we lose too much water, our bodies may become out of balance or dehydrate. Severe dehydration can be life threatening. If your output loosens and you find you are emptying your bag more frequently, you may be at risk of dehydration. Please contact your Stoma Care Nurse if you are at all concerned.

Sign & symptoms of dehydration

- Increased thirst
- Dry mouth
- Weakness/headache/lethargy/tiredness
- Confusion, sluggishness, or fainting
- Decrease urine output
- Dark coloured urine

3. LIVING WITH A STOMA

Salt helps your body to absorb fluid and keep hydrated so it is advisable that you include an extra teaspoon of salt in your diet every day to help prevent dehydration, unless you have been advised to avoid salt or limit your intake because of another underlying medical condition. If this is the case please discuss with your Stoma Care Nurse and/or GP.

Tips to avoid dehydration

If you experience any of the symptoms of dehydration, firstly be aware of your daily fluid intake (see top of page 30), but you could also try any of the following:

- Salty foods such as Bovril or Marmite; either spread on toast or as a drink
- Salted crisps
- Full sugar fizzy drinks (allowed to go flat)
- Isotonic sports drinks

Treatment of dehydration

- Contact your GP, Stoma Care Nurse

Food blockages

Some foods can swell in the bowel and may cause a blockage. This will cause your ileostomy to stop working normally. You should seek urgent advice from your Stoma Care Nurse or GP if you think this may be happening to you.

Signs and symptoms

- Your output will decrease, stop altogether or may contain large amounts of watery fluid
- You may experience pain
- You may feel or be sick
- Your abdomen may swell
- Your stoma may swell and look bigger
- You may experience reduced wind or it may stop altogether

Tips to avoid food blockages

It is important to chew your food really well. The following foods are known to increase the risk of food blockages, so extra care should be taken:

- Nuts
- Coconut
- Celery
- Mushrooms
- Sweetcorn
- Raw fruit skins
- Bean sprouts and bamboo shoots
- Dried fruit such as currants and raisins
- Popcorn

Treatment of food blockages

If you suspect a food blockage, stop eating solid foods. You could also try the following:

- Increase your fluid intake
- Take pain relief
- Massage your abdomen
- Go for a walk and move around

Wind

Sometimes certain foods can give you wind. The following foods may increase wind:

- Cabbage
- Beans/lentils/pulses
- Cauliflower
- Sprouts
- Spicy foods
- Onions
- Fizzy drinks
- Chewing gum

Leafy green vegetables can cause more wind in the early days. Try root vegetables such as carrots, parsnips and sweet potatoes.

Solutions to reduce wind

- Avoid talking and drinking whilst eating and keep your mouth closed whilst chewing
- Avoid drinking with a straw
- Eat regularly and avoid long gaps between meals
- Allow fizzy drinks to go flat
- Try drinking peppermint drinks such as cordial or tea
- Eat live yogurt – The natural kind seems more effective
- Keep mobile
- Avoid smoking and chewing gum

Odour

The following foods can sometimes cause odour:

- Fish
- Eggs
- Onions
- Cabbage
- Garlic
- Asparagus

Solutions to reduce odour

- Eat live yogurt
- Peppermint oil capsules
- Peppermint cordial, diluted to taste
- Peppermint tea

If you have any concerns about the effect of your diet or medication on your ileostomy, please seek the advice of your Stoma Care Nurse or GP.

Training and exercise

In hospital

You may be seen by a physiotherapist who will work with you on exercises you can do to support your stoma **health and strengthen your abdominal muscles. Take your time and know your limits.** The best exercise immediately following surgery is to get up and walk. You may need the help of a Nurse or Physiotherapist at first but this should become easier. Getting out of bed is also advised to reduce the chance of a chest infection. You may be taken for a stair assessment prior to discharge.

⚠

Continue with the abdominal exercises you were shown in hospital.

In the early days

It is important to keep mobile when you return home, and walking is ideal, but remember – however far you walk you will need to get back again. You may find it helpful to set yourself realistic goals that gradually increase over time. Listen to your body and if it feels too much, don't do it!

Ongoing exercise

After stoma surgery it is important that you get back to a healthy lifestyle as soon as you feel able. Your recovery period may vary and will depend on your age, type of surgery, level of fitness before surgery and time spent in hospital. Strengthening your abdominal muscles is beneficial for your general recovery. Swimming, walking, yoga and pilates will help to do this, but stop if it hurts.

Whatever activities you enjoyed before your surgery, you should be able to get back to once you have recovered. Speak to your Stoma Care Nurse or Surgeon before starting anything strenuous. It is also advisable to speak to your Stoma Care Nurse about a support belt before returning to any exercise and activities. This will support your abdominal muscles, helping to prevent the development of a hernia around your stoma.

If you go to a gym, it is advised to see or speak to a personal trainer before commencing activities as they should be able to offer a tailored exercise programme.

Activities such as gardening and golf can be commenced again but it is advisable to wear a support belt when doing these.

Ensure that you drink plenty of fluids when exercising to avoid dehydration.

3. LIVING WITH A STOMA

If you have recently had surgery, check with your consultant or GP prior to booking your holiday to ensure you are able to travel. You should seek medical approval for the trip if you have been in hospital during the last 6 months.

Travel

Planning your holiday

If you are planning your first trip, it is only natural that you may be feeling apprehensive about travelling for the first time following your operation. It is sensible to start with short trips away from home to build up your confidence. Once you feel reassured, and as your confidence builds, you can start to venture further afield.

Plan ahead

- Make a checklist of equipment you need to take with you.
- Go through your bag change routine to remind yourself of exactly what you use.
- Calculate the number of bags you would normally need for each day of your holiday – and double it, with a few extras! The change in climate and environment may mean more bag changes are needed.
- Having extra supplies can only add to your peace of mind.
- It may be useful to take different size bags with you for different activities. Most companies make a range of different size bags. You may want a larger capacity for a long flight, or a smaller bag for swimming. Ask your Stoma Care Nurse for advice.
- In general, it is advisable to keep most of your supplies in your hand luggage so that it remains with you at all times and is within easy reach. However, in case your hand luggage is misplaced, extra supplies should be kept in your suitcase or companion's luggage as a precaution.
- A separate small travel kit containing items needed for a bag change should be kept close at hand to make visits to the toilet simple and discreet.

Travel insurance

When you have decided on your destination, it is recommended that you have adequate travel insurance. Below are some useful links for more information on Travel Health Insurance from the Government of Canada.

- Well on Your Way - A Canadian's Guide to Healthy Travel Abroad
- Health cards - Canada.ca

3. LIVING WITH A STOMA

Air travel

Remember that the International Air Transport Association (IATA) regulations forbid passengers to take dangerous items on board an an aircraft and scissors should be packed in checked luggage. Restrictions also apply to carrying liquids on board. Check with your airline a fewweeks before departure. When booking or checking in try to choose anaisle seat near the toilet. When you check in at the airport, make sure you arrive early to accommodate any unexpected delays. Air travel can make some people a bit 'windy'. It is a good idea to avoid foods which you know may cause excessive wind; have frequent small meals for 24hrs prior to flying; and try to avoid spiced or fatty foods and fizzy drinks.

Your hand luggage may be searched at the airport. If you are unable to speak the language, you can obtain travel cards which are printed in several languages and explain the reason why you are carrying your equipment and about your condition.

General travel

When traveling it is advised to pack twice as many supplies and accessories that you will need and to precut your flanges. Scissors will be required to be packed in any checked baggage. It is best to continue with the products you are using now and not try a new system before or on your holiday. Do keep a small travel bag with you at all times with extra supplies in case of delays and separation from your main baggage. It can be useful to have a Travel Card that indicates special screening requirements and or a simple explanation of your condition. See below links:

- OCS Travel Card: ostomycanada.ca
- SecuriCare Stoma and Continence Travel Certificate: securicaremedical.co.uk
- Free Ostomy Travel Card for Hassle-free Security Check [16 Languages]: farmoderm.it

Some airports are now offering a distinctive lanyard to passengers with a hidden disability or medical condition. This allows travellers to discreetly identify themselves to staff to ensure tailored help and support can be offered throughout their journey. For more information visit www.hdsunflower.com/ca.

3. LIVING WITH A STOMA

Road travel

If you are travelling by road, try to plan your breaks around places that have adequate toilet facilities. Most roadside cafes, restaurants, service stations and hotels have toilet facilities. Do not be afraid to ask if you need to use them.

Food and drink

When abroad, the general advice on food and drink is the same for anyone:

- Be wary of the water supply in some countries
- Use bottled water or boiled water, including when cleaning your teeth and your stoma
- Avoid food that has been standing for long periods
- Don't have ice cubes in drinks
- Wash salads and fruit before eating them

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If you have an ileostomy, Loperamide (Imodium) capsules may not be absorbed adequately as they are designed to be absorbed in the large bowel. 'Imodium Melts', which you place on your tongue, or 'Imodium Elixir', which is obtainable on prescription from your GP, will be utilised better.

Tummy upsets

A change in climate, water or food can upset your bowels, so be prepared. As a precaution for diarrhea, it is advisable to take with you (Imodium) which slows down the bowel's activity, and sachets of rehydration powder, which easily dissolves in water to replace lost body salts, reducing the risk of dehydration.

These medications are available on prescription or over the counter from the pharmacist or local supermarket. Always read the instructions very carefully before taking these medications. If your symptoms do not settle after 24 hours, seek medical advice.

Fluids

Drink plenty of fluids. In hot, humid countries, we perspire much more and need to replace lost body fluids. This applies to all the family, not only those with a stoma. Make sure you have plenty of fluid stops and always carry a bottle of water. Sports drinks are excellent for combating dehydration. Allow fizzy drinks to go flat first, to reduce wind. Remember that too much alcohol will accelerate dehydration as well as giving you a hangover in the morning – so don't overdo it!

Storage of stoma products

If you are holidaying in a hot climate, your stoma bags should not be allowed to get too warm. It is advisable to keep your appliances in a cool bag or box and choose the coolest part of your accommodation to store them.

Swimming

Most people are apprehensive when going swimming for the first time. Some people are worried that the water will affect the adhesion of the bag. Your stoma bag will be very secure while you're swimming. Once the bag is wet, the adhesive tends to become 'tacky' and sticks even better. If you want to change your bag after swimming, you may find the adhesive is still 'tacky' and, when you try to remove it, it may peel off like chewing gum and leave residual adhesive. It may be better if you dry the bag well and leave the bag for a few minutes. The adhesive should then return to normal.

You may want to change your bag to a smaller size for swimming and going to the beach. Don't be afraid to go sunbathing while you are abroad, either. If you like spending a lot of time in the sun, it is best to ensure your bag is covered as the plastic of the pouch magnifies the heat. Chlorine found in swimming pool water and salt from sea will dry out the adhesive on your pouch, so it may be advisable to change the bag more frequently.

Swimwear

The type of swimwear that can be worn depends on your personal preferences and the position of your stoma.

Female

- If you are happy to wear a bikini – great!
- If you choose to wear a more discreet bikini style, a high-legged style may cover your stoma. A good swimsuit lining or double layer fabric will support your abdomen and help hide the bag
- When choosing swimwear, try and choose a boldly patterned costume which will camouflage any bulges
- You could choose to wear a sarong on the beach and at the side of the pool. It can be easily removed when you fancy a dip

3. LIVING WITH A STOMA

Male

- If you are happy wearing your Speedos – great!
- Alternatively, swimming shorts are a good choice as they can be worn above the stoma and are generally loose fitting. Choose a swim-short with a mesh lining which will support your bag.

Remember

- *Holidays are to be enjoyed!*
- *Plan ahead*
- *Relax and enjoy your trip*

Useful websites

The following companies produce swimwear for ostomates:

Simply Swim: www.simplyswim.com
Vanilla Blush: www.vblush.com
Comfizz: www.comfizz.com
Siil Ostomy: www.siilostomy.com

3. LIVING WITH A STOMA

Coping with the emotional challenges of having a stoma

Your stoma may have been formed for a variety of reasons including cancer, trauma or inflammatory bowel disease. The reason your surgery was necessary may have a bearing on how you adapt to life with your stoma. Some people will see their stoma as a welcome relief after many years of experiencing a reduced quality of life, as a result of their illness. Others may feel a sense of loss and look to their stoma as something they do not wish to have. This is a common and understandable reaction.

Learning to cope with your stoma emotionally as well as practically will not come to you overnight. We all learn to accept changes in our lives at different speeds and for some this will take longer than others.

It is important to know that you may go through periods of sadness and grief, and feel anxious at times. Don't be too hard on yourself, allow your emotions to surface. It is OK to feel angry, sad or want to cry.

It is helpful to talk about these feelings with anyone who you feel comfortable with; your partner, family, friends or your Stoma Care Nurse. They will be there to offer support and help along the way. There are also support groups and associations offering help and advice from people who are already living with a stoma.

Who should I tell?

You may be anxious about how other people will treat you now you have a stoma. Only you can decide who to tell and when. Some individuals choose to tell family and friends from the beginning and this can help with adapting to life with a stoma.

3. LIVING WITH A STOMA

Sex, intimacy and relationships

Initially you will be recovering from your surgery and getting used to the practicalities of living with a stoma so may not feel ready to be intimate. This is fine – give yourself time to recover from surgery first. Speak openly with your partner regarding your feelings and experiences as they may be more anxious about it than you. Promote intimacy through closeness, holding hands and kissing. The main thing to remember is to try to relax and feel comfortable.

Some types of surgery can impact on an individual's sexual function. This could be due to physical changes to this area of your body, or you are simply just not ready yet. You may need to experiment to find the most comfortable position for intercourse. You should discuss this with your Stoma Care Nurse when you feel ready, to find out what impact (if any) your surgery could have.

When the time is right

You do not need to wear a special bag for intimate times, but if you choose to there are smaller sized bags and caps available. If possible, change or empty your pouch before intercourse – having an empty bag will be more discreet.

Cummerbund (wide support bands) help to conceal and support the bag. Women may wish to wear lingerie and there are several companies that make a variety of underwear styles for women living with a stoma.

Women

Some women may experience loss of sensation, pain or dryness following some types of surgery. This can be helped with the use of lubricants, change of position and avoiding deep penetration. If you experience difficulties, your Stoma Care Nurse will be able to offer advice.

You should speak to your doctor regarding contraception if you require it, as it is still possible to conceive following stoma surgery. If you do want to become pregnant, please speak to your Consultant or GP as they are best placed to advise you. During pregnancy you may experience changes in the size of your stoma and consequently your template will require adjustment.

3. LIVING WITH A STOMA

Men

Men may experience difficulties in getting and maintaining an erection and ejaculation. This is because the nerves and blood supply involved with this may become bruised or damaged during surgery. This may improve with time, however if problems continue it is advisable to speak to your Stoma Care Nurse, as drugs and treatments such as Viagra, penile injections, implants or mechanical erectile appliances are available and can be very effective.

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Warning: *Intercourse via the stoma should never be attempted as this can be very dangerous.*

3. LIVING WITH A STOMA

Body Image

Whether male or female, we all have our own personal perception of our bodies – our likes and dislikes. Your surgery will involve a physical change to your body and this may, in turn, affect how you feel about yourself. This is normal and it may take time to adjust to these changes.

Regardless of surgery, we all come in different shapes and sizes and often find it comforting and helpful to talk about our body image worries.

"Your stoma is a small bit of your overall body and it's important to remember that and not let it dominate everything – it will from time to time – but don't let it all the time."

Carole living with a stoma

Clothing choices and tips

When it comes to choosing clothing, people have very individual styles and preferences.

> *There is no reason why you can't wear a variety of different clothing that is comfortable and fashionable.*

The most important rule with clothing, is to ensure that belts or waistbands are not worn over your stoma or restrict the bag too much.

There are specialized stoma underwear, swimwear and clothing companies that produce clothing for people with stomas but this is not necessary to purchase or wear – your usual clothing should be suitable. If you wish to buy new clothing because your size or body shape has changed, high street stores have a variety of styles and trends to suit.

You can wear anything you like, but here are a few suggestions that may help you to choose your clothing.

Women

- Vest tops
- Camisoles
- Tunics
- 1-piece swimwear or tankini
- Sarong
- High waisted trousers or skirts
- Maternity tights, jeans, jeggings

Men

- Vests
- Boxers
- High waisted trousers
- Braces
- Swimming trunks

Useful websites

The following companies have been recommended by ostomists:

Grandmas Hands: www.grandmas-hands.com
Awesome Ostoschels www.awesomeostoschels.ca
Bravery Bag Covers (Kids): www.braverybagcovers.com
Yummie: www.yummie.com
Ana Alternative: www.alternativeana.com

Suggestions from people living with a stoma:

Women

"In the early days after your surgery opt for loose tops and palazzo type pants, baggy leggings that are kind to your waist area. If you have to buy new stuff get some colourful things as you'll be looking and feeling washed out."

"Dresses giving very tight silhouettes are not a good idea but A-line or those with ruches can work wonders and make you feel good wearing them. Boden have some great A-line dresses ."

"Layering is great. Kettlewell have lots of lovely fluid colourful cascading wraps to wear over tops and an excellent top called a 'Tasha' top that looks good on absolutely everyone."

"Experiment – big scarves, pashminas, soft fabrics are kind. Draw attention to great legs, nice neck lines, earrings, snazzy shoes and boots ."

"Opt for patterned support swimwear with ruching. Not only will you look good, you will feel more confident in water with the added support that nothing is coming adrift. Fantasie, Fiftyplus and Simplyswim have good ranges. Pareos and kaftans are useful too."

"Trousers or leggings with a deep waistband are the most comfortable as they don't cut across my ileostomy. The same goes for underwear: a deep lace band at the top also holds the pouch in place ."

"I go swimming but don't think there is any need to buy special swimwear – either go for a tankini top and straight leg bottoms, with support pants underneath or an ordinary swimsuit with 'tummy control' panels for support, maybe in a patterned fabric. If you angle the bag slightly towards the centre of the body when applying it doesn't show."

"High waisted knickers, jeans and skirts are best for me. I like the skinny stretch jeans, but the boyfriend style is good too as they are roomy at the top then taper down. I wear these with a longer jumper or shirt over the top ."

"In the summer wear any tops or t-shirts with linen type trousers as they often have plenty of room for the bag to expand."

"Dresses with suitable styling, eg, gathers, loose waisted, fitted and flared can be more forgiving than skirts and tops ."

"Waistcoats, jackets, a loose cardigan or top – whatever suits the occasion, smart, sporty, casual worn over a more fitted top work well for me."

"Remember people aren't generally looking for a 'bump', it is more obvious to you because you know what's there ."

Men

"I find that a company called Chums supply trousers that have a high waist. They do cords and casual trousers with an elastic waist and I find they cover the bag well."

"I find there is a need to unload my pockets to reduce the supported weight. Because of the need to carry emergency supplies with me I use a leather reporter style "man bag ."

"I tend to wear patterned or striped shirts and jumpers which help to deflect the eye from any irregularities in body shape caused by the pouch. I also buy a larger than usual size around the waist so that it offers more space and for the natural folds of the material to distract the eye."

Medication

Some medicines are known to cause side effects and having an ileostomy does not exclude you from these. The symptoms will be exactly the same:

- Antibiotics can cause a change in the usual consistency of your output
- Iron tablets can cause black and sticky stools

Despite experiencing these symptoms, it is important to continue to take any prescribed medication and discuss any side effects with your GP.

Some medications, such as capsules/enteric-coated and slow release tablets, may not be absorbed in the small bowel and therefore will not be effective. Please discuss this with your GP or Pharmacist.

Chemotherapy

Chemotherapy is drug therapy and there are a number of different types that can be used to treat cancer. Some of these drugs can have an effect on your stoma and output. Speak to your Stoma Care Nurse or Oncology Nurse Specialist.

Problems you may experience with your stoma

Sore skin

Good skin care is vital to prevent sore skin. Sore skin is a common problem and is often seen but easily treated. There are a number of reasons why this may be happening. This isn't a complete list, so please contact your Stoma Care Nurse for further guidance if your symptoms persist.

- Ill-fitting bag:

  Following surgery you may find that your abdominal shape changes, especially if you gain or lose weight. This means the skin close to your stoma may not sit evenly against your bag, exposing healthy skin and allowing sore skin to occur or leakage to take place.

It is therefore important to regularly check your template size and suitability of your bag.

- Change in output:

  A change in output from your stoma could contribute to sore skin. It is essential that the adhesive wafer fits well to offer good protection to the surrounding skin.
- Trauma to stoma or skin:

  Your stoma and the surrounding skin is at risk of damage and so should be well cared for. An incorrectly sized template may rub and cause injury to the side of the stoma, which may include small ulcers. It may be that the shape of the stoma remains the same but the size has altered. Get into the habit of checking your stoma, template and surrounding skin regularly.
- Product sensitivity:

  Sensitivity to the adhesive on your bag is rare, but can occur even if you've been using it for a long time. It may begin as a slight irritation and become progressively worse if left untreated.
- Folliculitis:

  This is an inflammation of the hair follicles. It appears like small pimples, occasionally pus-filled, that can be painful and is often seen after shaving the skin around the stoma.

As soon as you notice any changes to the skin immediately around your stoma, please contact your Stoma Care Nurse for advice about treatment.

Muco-cutaneous separation

To form the stoma, the bowel will be stitched to the skin. Occasionally, following surgery the stitches and skin can separate. This can sometimes look unpleasant but, like any other wound, it will heal over time. It is important to contact your Stoma Care Nurse who can advise you on treatment to aid healing.

Pancaking

Pancaking is relatively uncommon for individuals with an ileostomy. Pancaking occurs if the internal layers of the bag stick together causing a vacuum which prevents the contents from dropping to the bottom.

Ballooning

Ballooning occurs when your stoma bag blows up with wind. This can cause the bag to come away from the body.

If you are using a filter cover, try removing it.

If your stoma bag has a filter and you are still experiencing problems, it may be that you are suffering from excess wind. Spicy foods, some vegetables (onions, cabbage, peas, and beans) and fizzy drinks have been known to increase wind, so try to avoid these.

Also avoid drinking with your meal as this can cause you to swallow excess air. Eating regular meals will reduce the build-up of wind.

Parastomal hernia

A hernia is seen as a bulge in the abdomen. Surgery causes a weakness in the muscle wall, which sometimes allows part of the bowel to protrude through it, causing the bulge under the skin. A parastomal hernia can occur at any time following your surgery and develops around your stoma. They can be more common depending on the following risk factors:

- Age
- Weight
- Strenuous or heavy lifting
- Smoking
- Multiple abdominal and/or emergency surgery

The parastomal hernia can vary in size from as small as a golf ball to as large as a football. There are numerous abdominal support garments that are helpful in concealing and supporting the hernia. It is recommended that you wear a light support garment as prevention. However, if you are partaking in strenuous activity, it is necessary to be measured for a more supportive garment. Your Stoma Care Nurse can arrange this for you.

In some people, the parastomal hernia will not cause any discomfort, but others may experience a dragging sensation, discomfort or pain. This will often depend on the size of the hernia and can be eased by wearing a measured support garment.

It is possible to have surgery to repair the hernia depending on the symptoms and effect on quality of life, but this will be assessed on an individual basis by your surgeon. It should be noted that there may still be a risk of another hernia developing following the repair.

Blockages

A blockage can be caused by:

- Food
- Adhesions: this is scar tissue caused by surgery
- Parastomal hernia

Retraction

This occurs when the stoma is below skin level. There are various reasons for this:

- Difficulties with stoma formation
- Weight
- Shape of the abdomen

If you have a retracted stoma, you may need to try a range of bags and additional products to find the most suitable for your stoma. Leakages are more likely, but the use of appropriate products will minimize this. Finding the ideal products may take some time but your Stoma Care Nurse will be able to offer advice on what is best for you.

Bleeding

The bowel has a very good blood supply, which is why the stoma is pink/red in colour. Whilst cleaning your stoma, a small amount of bleeding on the cloth is to be expected. However, if you see blood inside your bag and/or in your stool you should contact your Stoma Care Nurse or GP.

If you take anticoagulants such as Warfarin or Aspirin this may increase your risk of bleeding. If the bleeding is heavy, persistent or comes from the inside of the stoma you should seek advice from your Stoma Care Nurse or GP.

Prolapse

Sometimes the stoma can extend in length, similar to a telescope effect, and this is called a prolapsed stoma. Despite the prolapse, your stoma should continue to be a healthy pink/red colour. If this changes and becomes darker it is important that you seek urgent medical advice.

It is important to check your template frequently and it may be necessary to use a larger bag to accommodate the stoma.

Lying down may reduce the size of the prolapse, and may make it easier to apply your bag. In some cases the use of a support belt, applied whilst lying down, can be effective in managing the prolapse.

Your Stoma Care Nurse can advise you on the use of a support garment or belt.

Granulomas

Granulomas are red lumps that can appear on and around the edge of the stoma. They can be tender and may develop at any time.

Sometimes rubbing from the wafer or base plate can increase the risk of granulomas occurring. Bleeding can happen and may interfere with the bag adhesion. The template should be checked to ensure a good fit but do not cut the template larger to accommodate the granulomas as this may allow them to grow larger.

Ulcers

Ulcers can develop for a variety of reasons that may include medication, type of appliance and as a result of your original diagnosis. They can appear as broken, red, sore areas which may be painful. Ulcers are treatable and your Stoma Care Nurse can advise you following assessment.

Stenosis

Stenosis results in the stoma becoming very small and tight. The output from the stoma will become watery and intermittent. Following assessment, your Stoma Care Nurse may use a dilator to insert into the stoma and will request you continue to do this at home.

Necrosis

This is extremely rare. Necrosis occurs if the blood supply to the stoma is restricted. Initially the stoma will become a darker red/purple and may even turn black, which is an indication that the blood supply is impaired. It may also feel cold and hard to touch. It is vital that you seek urgent medical attention.

SECTION 4

OTHER HELPFUL ADVICE

Additional help and support

4. OTHER HELPFUL ADVICE

Support

Stoma Care Nurse

Your Stoma Care Nurse will support you throughout your surgery and recovery, and will continue to be there to offer advice in the future.

> *Don't be afraid to contact your Stoma Care Nurse if you have any questions.*

You can note the name and contact details of your Stoma Care Nurse below, so that you can refer back to them in the future.

My Stoma Care Nurse:..

Contact Details: ....

....

....

....

Visit Ostomy Canada Society: ostomycanada.ca

Ostomy Canada Society | Société Canadienne des Personnes Stomisées

Visit Westech Health Care: westechhealth.com

WESTECH HEALTH CARE LTD.

4. OTHER HELPFUL ADVICE

Other Organizations

There are a number of other organizations available to help and support you:

Ostomy Canada Society

☎ 1-888-969-9698
✉ Support@ostomycanada.ca
🖥 www.ostomycanada.ca
Peer Support Groups

NSWOC Canada

☎ 1-888-739-5072
✉ office@nswoc.ca
🖥 www.nswoc.ca
Find an NSWOC

Canadian Cancer Society

☎ 1-888-939-3333
✉ info@cancer.ca
🖥 www.cancer.ca

Colorectal Cancer Canada

☎ 1-514-875-7745
✉ info@colorectalcancercanada.com
🖥 www.colorectalcancercanada.com

Bladder Cancer Canada

☎ 1-866-674-8889
✉ info@bladdercancercanada.org
🖥 www.bladdercancercanada.org

Crohn’s and Colitis Canada

☎ 1-416-920-5035
✉ support@crohnsandcolitis.ca
🖥 www.crohnsandcolitis.ca

GI Society

☎ 1866-600-4875
🖥 www.badgut.org

Westech Health Care Ltd – Salts Healthcare Canada

☎ 1-844-323-0022
✉ info@westechhealth.com
🖥 www.westchhealth.com

Salts Healthcare UK

✉ hello@salts.co.uk
🖥 www.salts.co.uk

Canadian Digestive Health Foundation

✉ info@cdhf.ca
🖥 www.cdhf.ca

Vegan Ostomy

✉ info@veganostomy.ca
🖥 www.veganostomy.ca

Go Here App | Crohn’s and Colitis Canada

🖥 Washroom Locator App -
GoHere Washroom Access Program
crohnsandcolitis.ca

United Ostomy Associations of America UOAA

☎ 1-800-826-0826
🖥 www.ostomy.org

Friends of Ostomates Worldwide (Canada)

☎ 7-647-951-3940
✉ info@fowc.ca
🖥 www.fowc.ca

4. OTHER HELPFUL ADVICE

Canadian Cancer Survivor Network

☎ 613-898-1871

✉ info@survivornet.ca

🖥 www.survivornet.ca

Newbie Ostomy

🖥 www.newbieostomy.com

Ostomy Outdoors

🖥 www.ostomyoutdoors.com

The Great Bowel Movement

✉ info@thegreatbowelmovement.org

🖥 www.thegreatbowelmovement.org

Ileostomy & Internal Pouch Association

🖥 www.lasupport.org

Living with an Ostomy – HealthLink BC

🖥 healthlinkbc.ca

Living with an Ostomy - Alberta

🖥 myhealth.alberta.ca

Living with an Ostomy - Saskatchewan

☎ 0800 090 2309

🖥 saskhealthauthority.ca

Manitoba Ostomy Program – Shared Health

🖥 sharedhealthmb.ca

Supporting Adults Who Anticipate or Live with an Ostomy

🖥 RNAO.ca

Association québécoise des personnes stomisées

☎ 1-418-815-7723

🖥 www.aqps.org

🖥 www.stomies.ca

Patient Education Resources – Nova Scotia Health

🖥 nshealth.ca

Ostomy Care – Western Health NL

🖥 www.westernhealth.nl.ca

Local Support Groups

Note the details below for safe keeping.

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4. OTHER HELPFUL ADVICE

Frequently Asked Questions (FAQs)

If you are worried about anything before or after your operation, please consult your Stoma Care Nurse who will be happy to help you. Below are some brief, but useful, answers to a range of common questions.

I find odour a problem with my stoma, what can I do?

Most stoma bags are now designed with integral filters, so odour should not be apparent apart from when you are emptying or changing your bag. However, deodorising air fresheners are readily available in supermarkets.

Can I bath/shower without the bag on?

It is entirely up to you. Whether you find bathing or showering most convenient, both can be done either with your bag on or without it. However, you will have no control over when your stoma may work, so it could work during your bath or shower if you choose to leave your bag off.

Who can I ask for advice?

Your Stoma Care Nurse will continue to be available should you have any problems with your stoma, or if you need help or advice.

How often do I need to see my Stoma Care Nurse?

After you have recovered and are feeling more confident with your stoma care routine, you will not need to see your Stoma Care Nurse as often. However, it is advisable to see your Stoma Care Nurse for an annual review.

Top tip – some people find that an Extra Strong Mint placed inside their bag helps to effectively mask odour.

4. OTHER HELPFUL ADVICE

Glossary of terms

Abdomen:

The part of the body that contains the pancreas, stomach, intestines, liver, gallbladder, and other organs. This may also be referred to as: “tummy,” “belly” or “stomach.”

Adhesive:

The sticky part of a one-piece bag that sticks to your abdomen. This may also be described as: “wafer,” “flange,” “base plate” or “hydrocolloid.”

Anus:

The natural exit where stool leaves the body.

Bag: (External): A term used to describe a stoma appliance worn over a stoma to collect urine or stool/output.

Ballooning (of stoma appliance):

Occurs when a pouch that is being worn fills up with wind.

Baseplate:

The part of a two piece system that sticks to the abdomen. This may also be described as “wafer,” “flange,” “base plate” or “hydrocolloid.”

Cancer:

A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

Chemotherapy:

A drug treatment for cancer.

Colitis:

Inflammation of the large bowel (colon).

Colon:

Large bowel, consisting of caecum, ascending, transverse, descending and sigmoid colon.

Colorectal:

Referring to the colon and the rectum.

Colostomy:

An opening from the colon to the outside of the body. A colostomy provides a new path for stool to leave the body after part of the colon has been removed.

Congenital abnormalities:

A birth defect or abnormality existing at or before birth.

Convexity:

A specialist shape of wafer with an outward curve. The convex shape is most often used with a retracted or flush stoma.

Crohn’s disease:

An inflammatory bowel disease affecting any part of the gastrointestinal tract, from mouth to anus.

Diarrhea:

Loose, watery stool.

Diverticular Disease:

A condition where small sacks or pouches form in the wall of the large bowel.

Diverticulitis:

When the small pouches or sacks mentioned above become inflamed or infected.

Hydrocolloid:

The sticky part of your bag or base plate.

4. OTHER HELPFUL ADVICE

Ileostomy:

An opening from the small bowel or Ileum to the outside of the body.

Ileum:

The final and longest segment of the small bowel.

Inflammatory Bowel Disease:

A broad term used to describe the three conditions, Crohn's Disease (CD), Ulcerative Colitis (UC), and Familial Adenomatous Polyposis (FAP or Gardeners Syndrome).

Loop Stoma:

A loop of bowel is brought out through a surgical opening made in the abdominal wall.

Mucocutaneous junction:

Sutured join of any stoma between the bowel and the skin.

Muco-cutaneous separation:

Breakdown of the suture line between the bowel and the skin securing the stoma to the abdominal surface.

Oncologist:

A specialist doctor who is trained in diagnosing and treating cancer.

Oncology Nurse Specialist:

A nurse who specialises in oncology and sees patients following a cancer diagnosis.

Ostomist/ostomate:

A person who has a stoma.

Ostomy:

A surgically created opening.

Parastomal:

Around/behind the stoma.

Peristomal skin:

The area of skin immediately surrounding the stoma.

Rectum:

Lowest part of the large bowel ending in the anus (bottom).

Stoma:

Stoma is a Greek word meaning 'opening' or 'mouth'. There are generally three types of stomas:

- Colostomy: from the large bowel
- Ileostomy: from the small bowel
- Urostomy: urinary stoma

A stoma can be either temporary or permanent, depending on the reason for its formation.

Stoma Care Nurse:

A nurse trained in the care and support of people with ileostomies, colostomies and urostomies.

Ulcerative Colitis:

A disease that causes long-term inflammation of the lining of the large bowel.

Urostomy:

A urinary stoma.


COFFEE

Notes

Notes

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