YOU AND YOUR **UROSTOMY**

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 a urostomy formed. The booklet has been written to help explain what a urostomy 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 UROSTOMY**
- 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 a urostomy 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 a urostomy.

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 54. 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

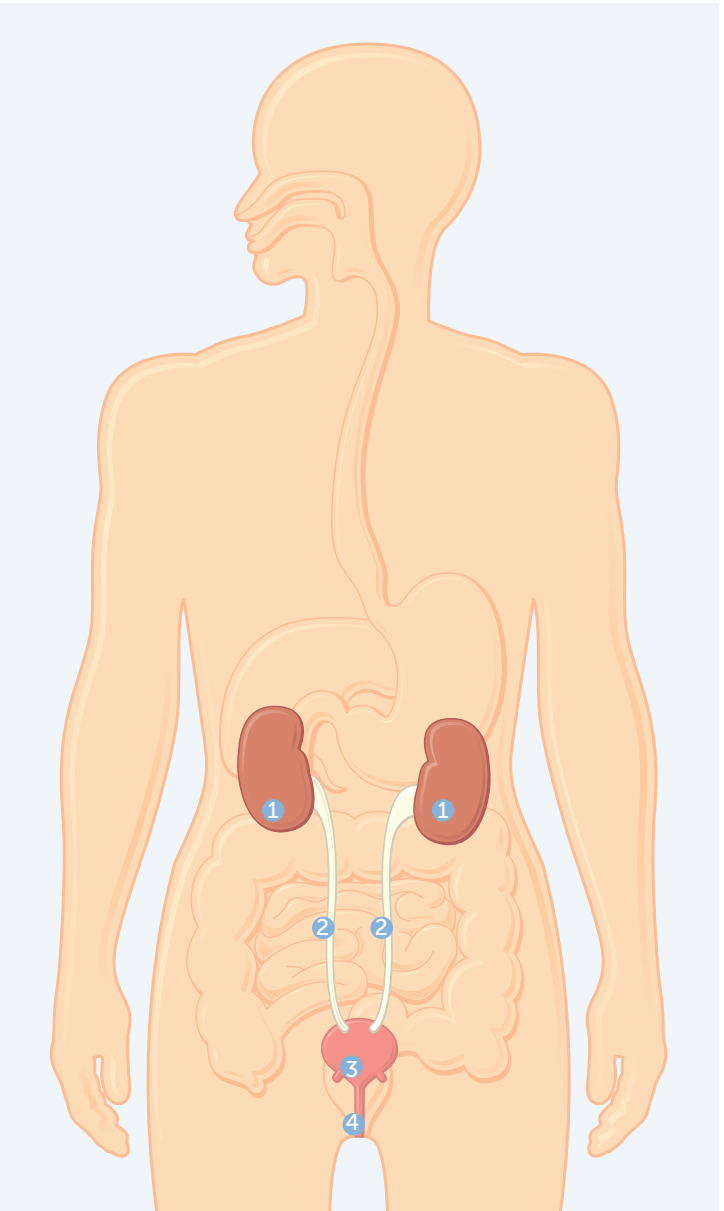
1. YOUR STOMA AND SURGERY

Your urinary system

The urinary system consists of the kidneys, ureters, bladder and urethra. Urine is formed in the kidneys, and the ureters transport the urine from the kidneys to the bladder. The bladder then stores the urine until you feel the desire to urinate, when the muscle of the bladder will contract to force urine out of the body through a tube called the urethra.

The urinary system

Kidneys 1
Ureters 2
Bladder 3
Urethra 4



1. YOUR STOMA AND SURGERY

What is a stoma?

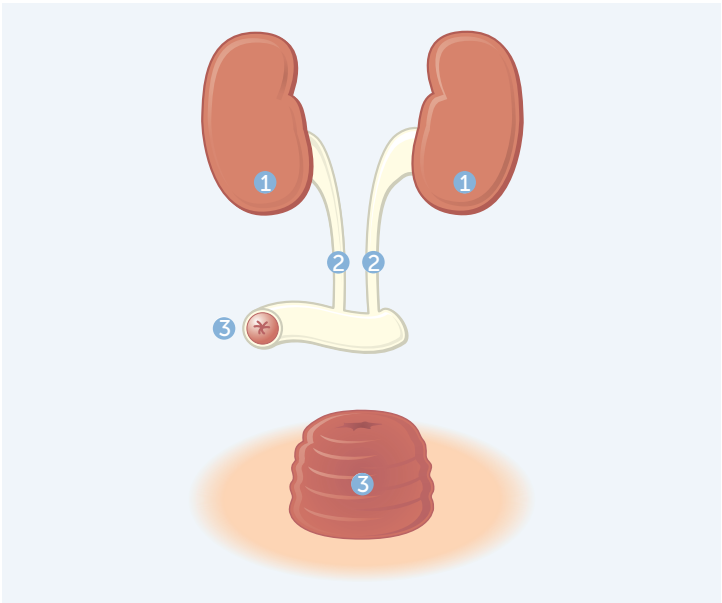
Stoma is a Greek word meaning 'opening' or 'mouth'. There are generally three types of stomas:

- **Colostomy:** from the large bowel
- **Ileostomy:** from the small bowel
- **Urostomy:** urinary stoma (you may hear this called an 'ileal conduit')

A urostomy is usually on the right-hand side of your abdomen, but in some circumstances it may be made on the left-hand side.

What is a urostomy?

A urostomy is a type of urinary diversion which involves disconnecting the ureters from the bladder and attaching them into a short length (15–25cms) of small bowel, which has been removed and re-formed, creating a reservoir through which the urine will flow. One end of the removed piece of bowel will be closed off, while the other will be brought to the surface of your abdomen, as a urinary stoma.
You may or may not have your bladder removed, depending on the reasons for your surgery. Your Stoma Care Nurse will be able to explain this in further detail.



Ileal conduit

1. Kidneys
2. Ureters
3. Stoma

1. YOUR STOMA AND SURGERY

Why am I having a urostomy?

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 a urostomy, such as:

- Cancer
- Trauma
- Bladder failure
- Congenital abnormalities

Before surgery

You will have the opportunity to meet with your Urology 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 urostomy 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.

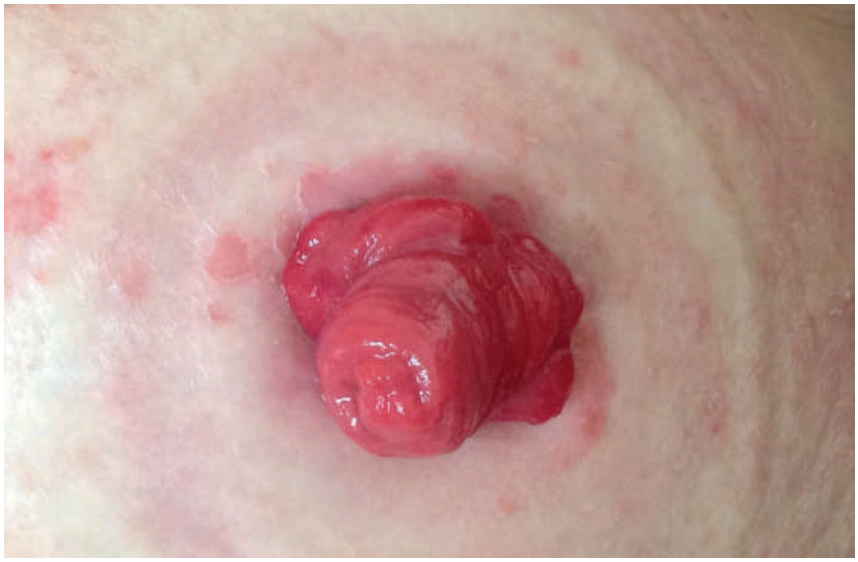
It is a good idea to take a member of your family or caregiver with you to your pre-operative appointments, as there is a lot of information to take in.

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

Where possible, your Stoma Care Nurse will involve you in marking the ideal site for your urostomy 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 nurse has marked.

What will my urostomy look and feel like?

Your urostomy should protrude slightly, however it can be flat to your abdomen. 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 urostomy 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.



Urostomy

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, it is normal for you to be cared for in the intensive care unit for a short period of time. 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, with very little discomfort. You will be wearing a urostomy 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. A night drainage bag will be attached to collect your urine at first.

After surgery, you will have some thin tubes called stents coming out from your urostomy. The purpose of the stents is to protect the newly formed join where the ureters meet the piece of small bowel. The stents may fall out by themselves, but if they don't your Stoma Care Nurse will gently remove them, once the initial post-operative swelling has started to reduce. Looking after your urostomy can be a bit fiddly until this time, but management will feel easier once they are removed.

You will feel tired and 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.

After your operation, you may experience some constipation. It is normal for there to be some disruption to your bowel movements following this procedure as a result of using part of your small bowel to create your urostomy, and also because your usual pattern of eating and drinking has been disrupted. Once your bowels start to work again, you may experience diarrhea for a short while, but this will pass and gradually things should settle.

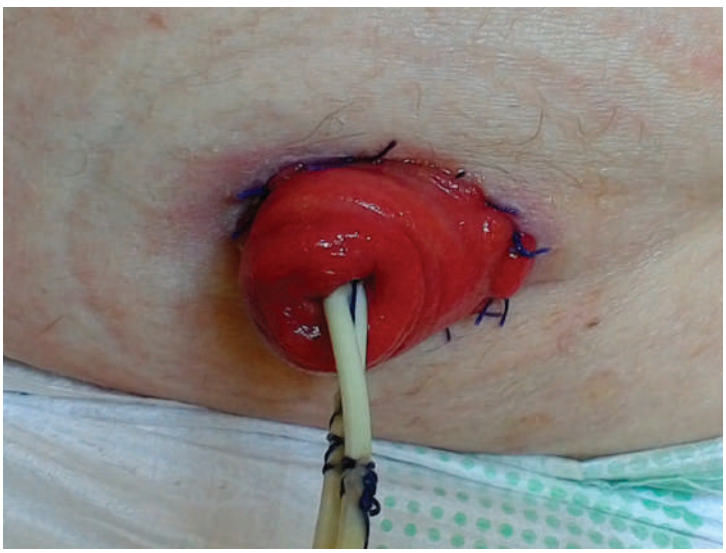
2. AFTER YOUR SURGERY

When will my urostomy start to work?

You will notice that your urostomy will work as soon as it is formed and also that you have no control or sensation over when you pass urine. Initially, your urine may have a slight red colour to it – this is nothing to worry about and it will quickly return to normal. You may also notice some mucus in your urine or around your stoma.

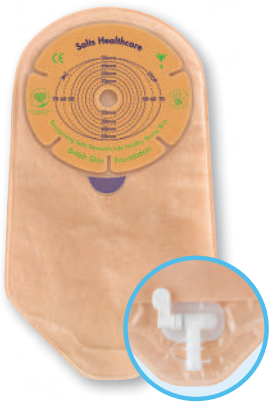
All of this is normal and is to be expected.

Your urostomy will produce a small amount of urine every few seconds, but this can vary. 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 urostomy bag every 3-5 days, but it is up to you.



Urostomy with stents

2. AFTER YOUR SURGERY



Urostomy bag – front and back

Wearing a stoma bag

There are a variety of different bags for you to choose from, and you can try a one- 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. A urostomy bag has a non-return valve discreetly placed inside the bag which prevents the urine from flowing back and pooling around the stoma, reducing the chance of urinary infections. All bags will also have a tap or bung to allow you to drain the urine out of the bag and into the toilet. Some people with reduced movement in their fingers may prefer to use a tap, as this perhaps requires less dexterity, but is usually made of a harder plastic material than the softer bung.

There are a range of different sizes which are designed to be worn under your normal clothes. 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 functions.

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

Using a night drainage bag

Your stoma will work throughout the day and night, so it is advisable to use a night drainage bag at night. This will allow the drainage of your urostomy bag during the night to prevent you having to get up to drain your bag. You will be advised by your Stoma Care Nurse regarding the type and use of night drainage bags.

Using a leg bag

Some people with a urostomy may choose to use a leg bag, which is attached to their urostomy bag to provide additional capacity and prevent the need to drain as often. This option might be something you choose for long car or train journeys, if you are unwell or not very mobile.

Changing your stoma bag

Ensure you have everything on 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 bag.

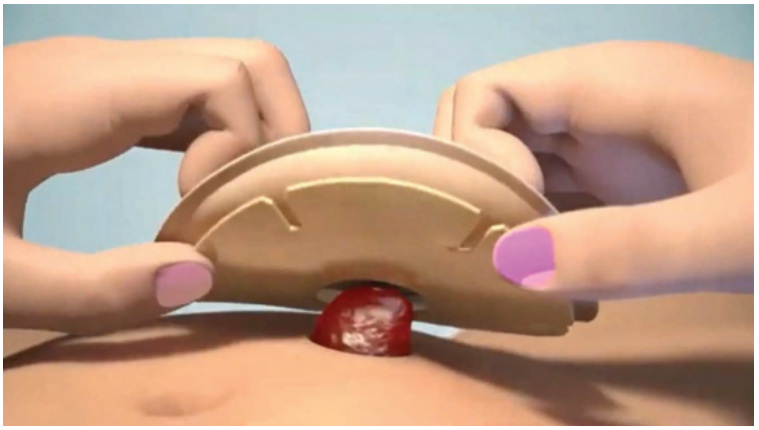
To change your bag

- Draw the template of your stoma onto the adhesive of the bag, then cut it out.
- Ensure the tap or bung is closed on your new bag.
- Drain your bag.

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



Bag removal

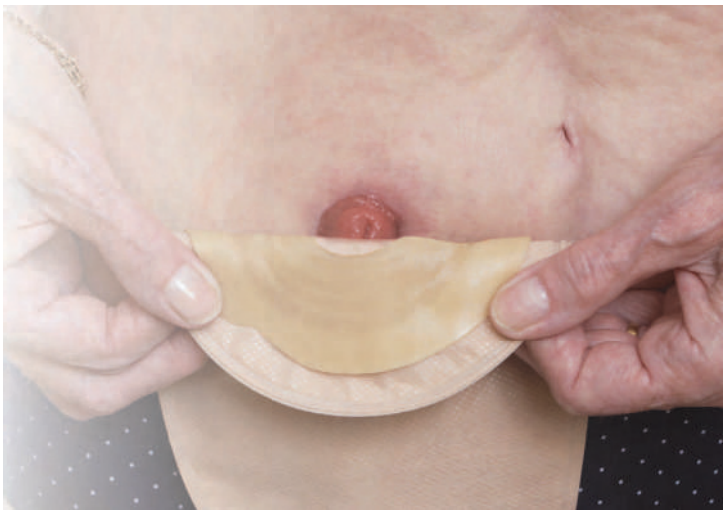
- To remove the bag carefully release the adhesive, working from the top down whilst supporting the skin (if you choose to use an adhesive remover, spray a small amount as you peel away the adhesive to help with removal).
- Once removed, fold the adhesive section of the used bag in half so it seals.
- 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 disposal sack (do not put them in the toilet as they may block it!)
- Ensure the skin around the stoma is dry.

Peel

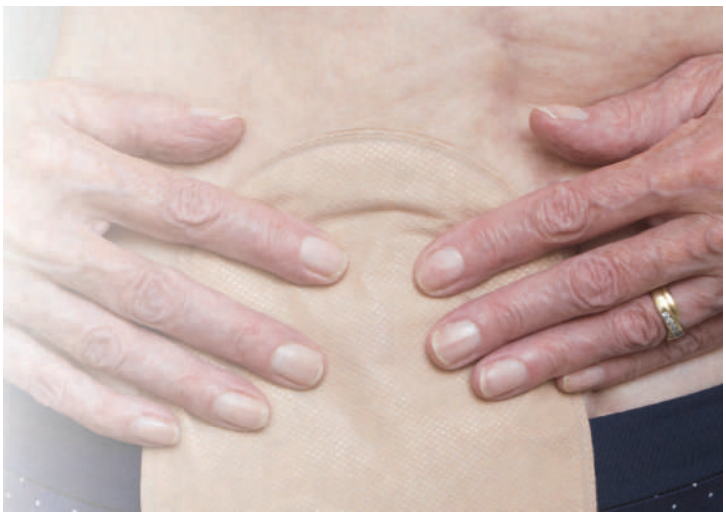
TIP: To clean your stoma and skin, water is considered adequate and acceptable. However if you prefer to use soap, a simple non-perfumed, non-moisturized soap should be used. Ensure that it is rinsed away before drying your skin to prevent irritation.

2. AFTER YOUR SURGERY

- Remove the backing film from the adhesive of the new bag.
- 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

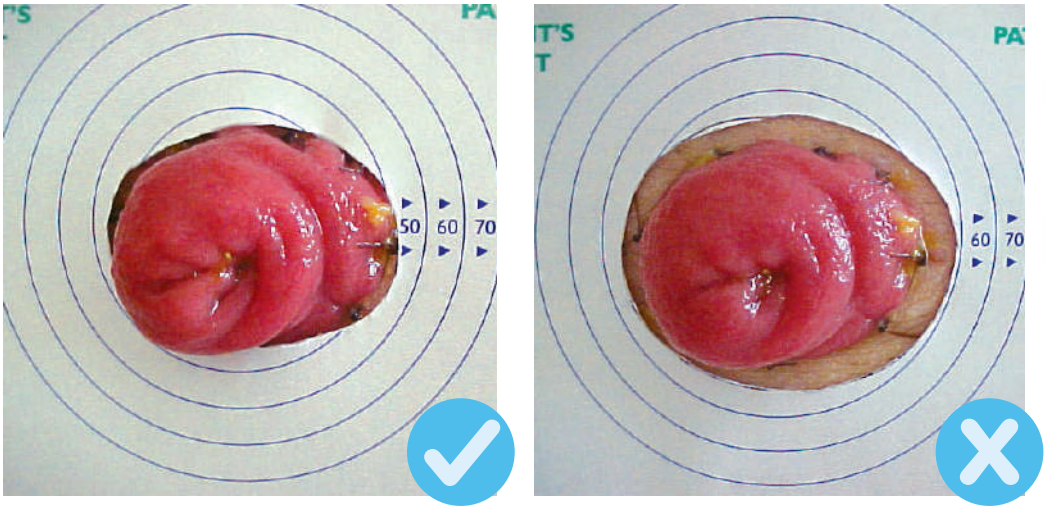
2. AFTER YOUR SURGERY

Caring for your skin

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

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 urostomy 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 foods 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 moisturized 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 44.

SECTION 3

LIVING WITH A STOMA

Adjusting to life
with your urostomy

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 45.

Early days at home

When you are first discharged from hospital you will feel tired and find everyday tasks, such as having a shower is 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 effect 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

Infection

Urinary tract infections (UTIs) are common. In people with urostomies, it effects the upper part of the urinary system: the ureters and kidneys.

Signs and symptoms of a UTI

- Flu-like symptoms
- High temperature
- Pain in back and sides
- Shivering
- Chills
- Cloudy and/or smelly urine

Treatment of a UTI

It is important that you contact your GP or Stoma Care Nurse if you experience any of the above symptoms. They will need a sample of your urine and will advise you when to take a sample, as the urine should be as fresh as possible.

WARNING: It is not recommended to take a sample from your used urostomy bag or night drainage bag.

Ideally your Stoma Care Nurse will take a urine sample using a catheter which is inserted into your stoma. However, it is also acceptable to obtain a urine sample from a clean stoma without a bag on. You can do this by obtaining a urine sample container from your Stoma Care Nurse or GP and holding it directly underneath your stoma, allowing the urine to collect in the container. It is important to ensure the container does not touch your stoma or skin, and your fingers should not come into contact with the inside of the container.

Be aware this may take some time and you will need to fill at least a quarter of the urine sample container.

3. LIVING WITH A STOMA

A UTI that is causing symptoms is usually treated by a short course of antibiotics, following collection of a urine sample.

Tips to avoid a UTI

- Drink plenty of fluids
- Ensure the tube of your night drainage bag is kept clean
- Drink cranberry juice or take cranberry tablets

If you experience recurring UTIs speak to your Stoma Care Nurse as you may need to change your urostomy bag and night drainage bag more frequently.

TIP: Cranberry juice and tablets are not currently considered a treatment for urine infections, but can be of benefit in the reduction of mucus, and for some people they can help prevent urine infections. However, please be aware that if you are taking warfarin, you should avoid any products containing cranberries.

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

Diet and hydration

After your surgery you may find your appetite is reduced, but it is still important to eat little amounts 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.

Some foods may affect the colour and smell of your urine:

- Beetroot
- Food dyes
- Red drinks
- Asparagus

General advice

You should aim to drink around two litres of fluid a day. This should be increased in hot weather or if you sweat a lot e.g. when exercising, or if you have a raised temperature. If your urine appears dark, this may be a sign that it is more concentrated, so you need to drink more to ensure that the urine is diluted and lighter in colour. If your urine remains dark, odorous or cloudy, this may be a sign of infection. Please seek advice from your Stoma Care Nurse.

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

Training and exercise

Continue with the abdominal exercises you were shown in hospital.

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 advised to reduce the chance of a chest infection. You may be taken for a stair assessment prior to discharge.

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 when 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.

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

Travel

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.

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

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

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 few weeks before departure. When booking or checking in try to choose an aisle 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.

Some airports are now offering a distinctive lanyard to passengers with a hidden disability or medical condition. This allows travellers to discreetly identify themselved 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

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!

3. LIVING WITH A STOMA

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

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

Coping with the emotional challenges of having a stoma

Your stoma may have been formed for a variety of reasons including cancer, trauma or incontinence. 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 times 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

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

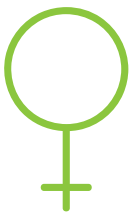
Initially you will be recovering from your surgery and getting used to the practicalities of living with a stoma so may not feel ready to be intimate. This is fine – give yourself time to recover from surgery first. Speak openly with your partner regarding your feelings and experiences as they may be 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.

This surgery will impact on your sexual function and is due to physical changes to this area of your body. Nerves, blood supply and surrounding areas will be affected. There should be time to discuss this before and after surgery with your Stoma Care Nurse and Urology Surgeon.

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

In some cases this type of surgery involves the removal of the womb and part of the vaginal wall. You may experience loss of sensation, pain or dryness. 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.

Men

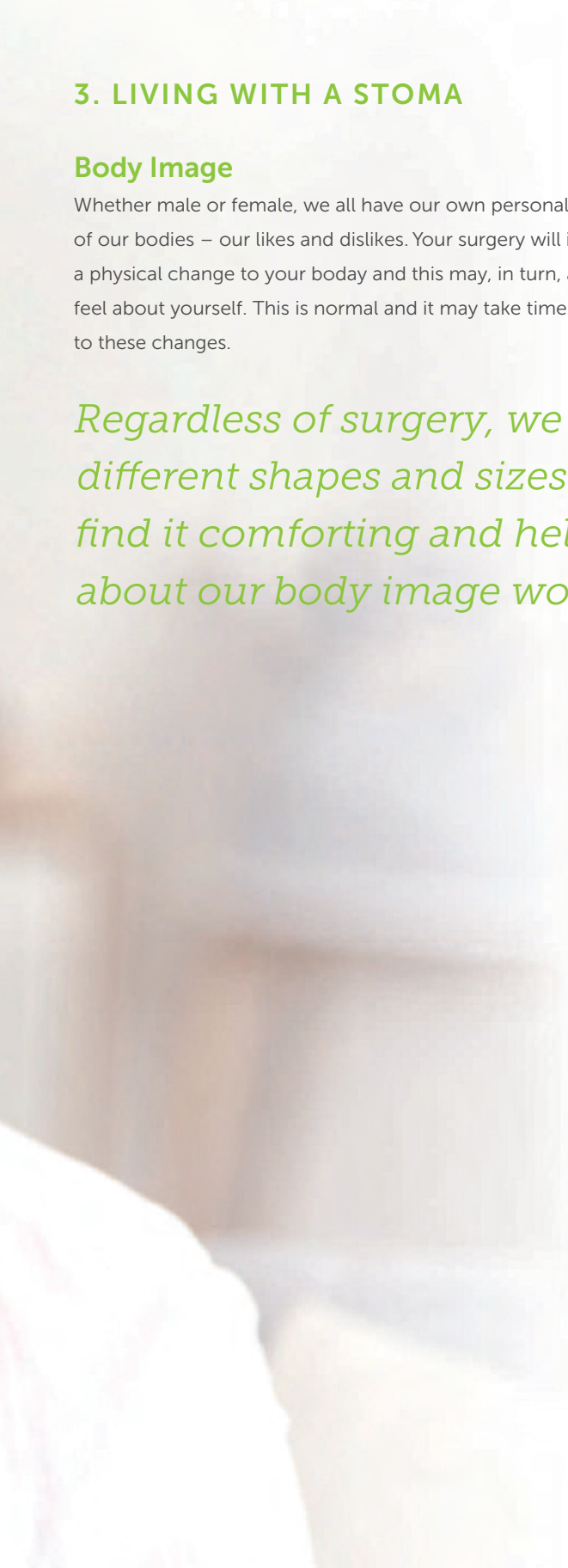
Men may experience difficulties in getting and maintaining an erection and ejaculation. This is because the nerves and blood supply involved with this may become bruised, damaged or cut during surgery. It is advisable to speak to your Stoma Care Nurse, as drugs and treatments such as Viagra, penile injections,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

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 boday 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

3. 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.

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 ostomates:

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."

3. LIVING WITH A STOMA

Medication

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

- Antibiotics can alter the colour of your urine
- Some anti-depressants can make urine blue/green coloured
- Warfarin can make urine orange coloured

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

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 urine:

  Any change in your urine could contribute to sore skin. Highly acidic or alkaline urine may affect the adhesion of your bag. This could be a sign of infection and you should consult your Stoma Care Nurse.

- Trauma to stoma or skin:

  Your stoma and the surrounding skin is at risk of damage and so it 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.

3. LIVING WITH A STOMA

Infection

Please refer to the 'Early days at home' section, page 24.

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.

Parastomal hernia

A hernia is a weakness in the muscle wall. A parastomal hernia can occur around the stoma and is more common depending on the following risk factors:

- Age
- Weight
- Strenuous or heavy lifting

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.

For 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 affect 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.

3. LIVING WITH A STOMA

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
- Smoking
- Multiple abdominal and/or emergency surgery

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 urine 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 bowel can extend in length, similar to a telescope effect, and this is called a prolapsed stoma. Despite the prolapse, your urostomy 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.

Phosphate deposits

This occurs when your urine is too alkaline and forms grey crusty deposits on your skin, and can result in sore skin and leakage. These deposits must be covered by your stoma bag and it is important not to cut the hole bigger. Treatment may include white vinegar soaks: either by dabbing the surrounding area with a cloth soaked in equal parts white vinegar and water, or spraying or covering the area with this same solution. Your Stoma Care Nurse will show you how to do this. You should also increase your fluid intake.

3. LIVING WITH A STOMA

Stenosis

Stenosis results in the stoma becoming very small and tight. The output from the stoma may appear delayed and then suddenly spurt out. This is due to having such a small opening to the stoma, causing a build up of urine. 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. You may need surgery to refashion your stoma.

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.

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.

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".

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

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.

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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.

Diarrhea:
Loose, watery stool.

Hydrocolloid:
The sticky part of your bag or base plate.

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.

Ileal Conduit:
Another word for a urostomy.

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.

4. OTHER HELPFUL ADVICE

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.

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

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

Urostomy:
A urinary stoma.


COFFEE

4. OTHER HELPFUL ADVICE

Notes

4. OTHER HELPFUL ADVICE

Notes

WESTECH
HEALTH CARE LTD.

Contact us for free samples and details of the complete range of ostomy products available from Salts:

Westech Health Care Ltd.

Toll free 1 844.323.0022

info@westechhealth.com

www.westechhealth.com

@SaltsHealthcare

SaltsHealthcare

SaltsHealthcare

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