

#### SOUTH AFRICAN SOCIETY OF OSTOMATES

# SURVIVAL GUIDE

This booklet was developed by Ostomates for Ostomates, their loved ones and care givers. The aim of this book is to provide information and practical guidance to help you transition to the NEW YOU.

Being told that you are getting a stoma can be an emotionally overwhelming moment in your life and the life of your loved one. This does not have to be the case. You are not alone and there is support available to assist you on YOUR journey.

In this book, we will discover what a stoma is, the types of stomas as well as the journey leading up to and after surgery. We will also explore some practical tips that Ostomates across the world have been using to become more accustomed to their new normal. We will also share with you YOUR RIGHTS as an Ostomate in the type of care and support you deserve.

It is also important to note that although these are tips and tricks that are used generally, in some instances some of what is mentioned in this guide may not work for you. The reason for this is because as much as you are an individual, so too is your stoma and you may find that some tweaking is required with applying and using your pouching system. It is important for you as the Ostomate to have a very good relationship with your Stoma Nurse. DO NOT ever feel that you cannot speak to them or feel too embarrassed to speak to them. You have the right to the support and care that will help you maintain a dignified life.

If you feel that you need additional support or would like to speak to fellow Ostomates, please do feel welcome to contact us on email at info@sasstomates.org.za or on WhatsApp 066 261 0654. We would also appreciate it if you can take a few moments to tell us about yourself by completing the survey on our website. This survey is a tool to help us better understand the needs of our Ostomy community and thereby empowering us to support you better.

https://sasstomates.org.za/sass-survey

We would also appreciate your feedback or recommendations for additions to this book.

We hope that this book is of good use to you and please do reach out if you need any additional support.

> Faizel Jacobs Chairperson - SASS

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The South African Society of Stomates (SASS) is a Non-profit organization formed by Ostomates across Southern Africa to facilitate a "holistic" approach to ostomy patient care by bridging the gap between the private and public sectors whilst advocating for the rights of fellow ostomates throughout the country.

SASS aims to advocate and align the standard of Stoma care and services across South Africa which will be applicable to both the private and public sectors. Thereby aligning to the global standards set out by The International Ostomy Association (IOA).

#### What we set out to achieve with YOUR help



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#### SO, I AM GETTING A STOMA - NOW WHAT?

Being told that you are getting a stoma can be an extremely overwhelming experience and can naturally lead to so many questions that you may need answered.



Depending upon your condition (the reason for stoma surgery), the surgery will involve removing the part of your bladder (urostomy), small intestine (ileostomy) or large intestine (colostomy) that is too damaged by your medical condition to recover on its own. In some instances, your stoma will be temporary, giving the damaged part of your intestine time to heal.

During the procedure, your surgeon will create a stoma which is an opening on the outside of your abdomen / belly for waste materials to leave your body.

Your stoma will, in most cases, improve your general health and get you back to living a full life.

#### WHAT IS A STOMA?



When you have stoma surgery, an opening called a stoma is created in the abdomen (belly).

Your stoma provides another way for the body's waste materials (poo or urine) to leave your body into a waste bag. The location of the stoma depends upon the type of surgery needed.

In the ideal situation, a Stoma Nurse or Therapist will have a consultation with you before your surgery. He or she will explain to you the types of bag options you have and will also "size you up" and mark out a position on your body where your stoma will be situated.



#### **DIFFERENT TYPES OF STOMAS**

The main types of stoma are: Colostomy, Ileostomy and Urostomy.

#### COLOSTOMY

In a colostomy operation, part of your colon is brought to the surface of your abdomen to form the stoma. A colostomy is usually created on the left-hand side of your abdomen. Stools in this part of the intestine are semi-formed to solid and, because a stoma has no muscle to control defecation, will need to be collected using a stoma pouching system.

#### THERE ARE TWO DIFFERENT TYPES OF COLOSTOMY SURGERY: END COLOSTOMY AND LOOP COLOSTOMY.

#### **END COLOSTOMY**

If parts of your large bowel (colon) or rectum have been removed, the remaining large bowel is brought to the surface of the abdomen to form a stoma. An end colostomy can be temporary or permanent. The temporary solution is relevant in situations where the diseased part of the bowel has been removed and the remaining part of the bowel needs to rest before the ends are joined together. The permanent solution is chosen in situations where it is too risky or not possible to re-join the two parts of the intestine.

#### LOOP COLOSTOMY

In a loop colostomy, your bowel is lifted above skin level and held in place with a stoma rod. A cut is made on the exposed bowel loop, and the ends are then rolled down and sewn onto the skin. In this case, a loop stoma actually consists of two stomas (double-barrelled stoma) that are joined together. The loop colostomy is typically a temporary measure performed in acute situations. It can also be carried out to protect a surgical join in the bowel.



#### ILEOSTOMY

In an ileostomy operation, a part of your small bowel called the ileum is brought to the surface of your abdomen to form the stoma. An ileostomy is typically made in cases where the end part of the small bowel is diseased, and is usually made on the right-hand side of your abdomen.

Stools in this part of the intestine are generally liquid and, because a stoma has no muscle to control defecation, will need to be collected in a pouching system.

# THERE ARE TWO DIFFERENT TYPES OF ILEOSTOMY SURGERY: END ILEOSTOMY

An end ileostomy is made when part of your small bowel (colon) is removed (or simply needs to rest) and the end of your small bowel is brought to the surface of the abdomen to form a stoma. An end ileostomy can be temporary or permanent.

The temporary solution is relevant in situations where the diseased part of the bowel has been removed and the remaining part needs to rest before the ends are joined together. The permanent solution is chosen in situations where it is too risky or not possible to re-join the two parts of the intestine.

#### LOOP ILEOSTOMY

In a loop ileostomy, a loop of the small bowel is lifted above skin level and held in place with a stoma rod. A cut is made on the exposed bowel loop, and the ends are then rolled down and sewn onto the skin. In this way, a loop ileostomy actually consists of two stomas that are joined together. Only one stoma will be functional and the second stoma can expell mucus.

The loop ileostomy is typically temporary and performed to protect a surgical join in the bowel. If temporary, it will be closed or reversed in a later operation.



#### UROSTOMY

If your bladder or urinary system is damaged or diseased and you are unable to pass urine normally, you will need a urinary diversion. This is called a urostomy, an ileal conduit or a Bricker bladder.

An isolated part of the intestine is brought onto the surface of the right-hand side of your abdomen and the other end is sewn up. The ureters are detached from the bladder and reattached to the isolated section of the intestine.

Because this section of the intestine is too small to function as a reservoir, and there is no muscle or valve to control urination, you will need a urostomy pouching system to collect the urine.



There are many reasons why your physician may feel a stoma is a viable option to improve your quality of life based on your medical condition. The most common conditions / illnesses where a stoma is part of the treatment and or management include:



#### WHY WOULD I HAVE A STOMA?

Depending on the disease or wound, a stoma may be temporary (to allow for healing and a return to normal function) or permanent. Your doctor will tell you whether your stoma will be temporary or permanent. In some instances, patients feel that they prefer the quality of life living with a stoma and prefer not to have the reversal done.

#### Different types of Ostomy Bags



YOUR STOMA, YOUR OUTPUT AND YOUR POUCHING SYSTEM		
TYPE OF STOMA	TYPE OF OUTPUT	POUCHING SYSTEM
Colostomy	<ul> <li>Formed faeces / poo</li> <li>1 - 3 times per day</li> </ul>	Closed Bag 1 piece or 2-piece system
Ileostomy	<ul> <li>Semi – solid to liquid</li> <li>7 - 8 times per day</li> </ul>	Drainable Bag 1 piece or 2-piece system
Urostomy	<ul><li>Liquid (Urine)</li><li>Constantly</li></ul>	Urostomy Bag 1 piece or 2-piece system

#### **POUCHING SYSTEM ISSUES**

Coping with pouching system issues, ballooning and pancaking

Ballooning happens when there's a build-up of gas in the stoma pouching system, making it inflate like a balloon. Pouching systemes have charcoal filters that help deal with wind by deodorizing and releasing it from the pouching system. But if the filter capacity cannot handle the gas produced, or if it has become moist or blocked by solid output from the stoma, gas build-up can occur.

#### WHAT CAN YOU DO TO PREVENT BALLOONING?

One of the main ways to prevent ballooning is to minimise the amount of gas your digestive system produces. Chewing food thoroughly really helps, as can avoiding food and drinks that you know make you produce a lot of gas. These could be nuts, beans, fizzy drinks or sparkling wine.

If ballooning does occur, you can release the gas from the pouching system in the privacy of a toilet, if you use an open bag or use a two-piece system. Changing the pouching system when needed can also help prevent ballooning. Finally, it may be worth trying another type of stoma pouching system and filter type.

Pancaking happens when there is a vacuum in the stoma bag and the bag sticks together. This stops the output from dropping to the bottom of the bag and can block the filter. There is then a risk that the pouching system will be pushed off the abdomen.

#### WHAT CAN YOU DO TO PREVENT PANCAKING?

Blowing air into the pouching system before putting it on will help stop a vacuum from occurring. In addition, a drop of oil or lubricant in the pouching system will help the output to get to the bottom of the bag.



Your professional healthcare team is your best resource for answering all your questions and getting you back to the life you love. Below, discover their roles in your recovery, as well as some questions to consider asking when you meet with them.

#### YOUR SURGEON LEADS THE TEAM

When you see your surgeon before your operation, he or she will discuss which type of stoma is best for you. This will depend on the type of surgery you need. He or she will also discuss whether the stoma is going to be temporary or permanent. At that visit, your surgeon may also give you the name of a stoma care nurse.

"Should you be getting a temporary stoma, it is important to note that the time given for your reversal is a guide and may, for various reasons, be pushed further back. Discussing this with your surgeon upfront can aid in dealing with the potential disappointment of having to have your temporary stoma for longer than expected."

It is also a good idea for you to pay attention to the surgical procedure that your surgeon will be performing. Make sure to ask questions, especially questions around your recovery time, impact on lifestyle.

#### YOUR STOMA CARE NURSE IS YOUR BEST RESOURCE

A specialised stoma care nurse is a your professional, guide and teacher on throughout your stoma journey. As you adjust and go through life with a stoma, your nurse will be your go-to person.

If your surgery is not an emergency, ask your surgeon to refer you to a stoma nurse before your surgery. At this pre-surgery visit the stoma nurse will find out as much as possible about your lifestyle, needs and fears and will guide, teach and counsel you. From the information you provide and on examination your stoma nurse will recommend and mark the best position for your stoma on your belly so the surgeon can see where to form the stoma. If you would like to meet with someone who has or has had a stoma, your stoma nurse may be able to make arrangements.

If a specialised stoma care nurse is not available before your surgery, you can contact SASS on WHATSAPP on 066 261 0654 and we will try connect you with someone in your area.



#### CHOOSE AN APPROPRIATE STOMA SITE

The first step in preventive care starts with the selection of the best place for your stoma. A poorly placed stoma can cause the pouching systeming system to fail, in addition to causing skin and leakage problems.

Ideally your stoma nurse or surgeon will discuss some guidelines that help with this decision are with you the placement or "siting" of your stoma.

- The stoma site should be viewable and easily reached so that you can manage pouching systeming changes on your own.
- Ideally, the stoma should not be placed in or around skin folds, scars or bony prominences, as the pouching systeming system can adhere flat to the skin.
- Placement should be evaluated in sitting, standing and bending positions.
- Things like type of work that you do and lifestyle factors may also play a role in deciding where to place your stoma, so provide as much detail as possible.

#### OTHER QUESTIONS YOU MAY WANT TO ASK

Facing surgery can be difficult and stressful, and you might not remember all the questions you have during your pre-surgery appointments. Writing down a list of questions and bringing that list with you to these appointments can help you feel assured that all of your concerns are being addressed.

If possible, it's also smart to bring a trusted friend or family member with you to your appointments, to take notes and offer support.

#### HERE ARE SOME COMMON QUESTIONS FOR PEOPLE FACING STOMA SURGERY:

- Describe my stoma to me (height, position, size, appearance). What should I expect?
- Will my stoma be permanent or temporary?
- How does the stoma work?
- Will my stoma be visible under my clothes?
- What does a pouching system look like (size, types, colors, style)?
- How do I change the pouching system?
- Will the pouching system leak?
- Where do I get supplies?
- Will I have to change my diet?
- When can I go back to work?
- Will I be able to go out with family and friends?
- How will my stoma affect my sex life?
- Will I be able to travel?
- Where can I get extra help and support?
- Will I need any special care when I get home from the hospital?
- Will the stoma make me smell bad?
- Can I shower/bath with my stoma?
- Can I swim?

#### PREPARING FOR SURGERY

Stoma surgery can be scary, but you're in good company. We can help you get ready—physically and mentally.

If you are facing stoma surgery, you have a medical condition or injury that is stopping your bowel or bladder from working properly. But you're not alone. There are thousands of people today, of all ages and backgrounds, living active productive lives with a stoma.

Stoma surgery is life changing in many ways. Like any major surgery, it can also be nerve-wrecking—for you and your loved ones. The process of feeling comfortable living with your stoma starts with understanding the procedure and what questions you should ask your healthcare team before surgery. We're here to help you—now and every step of the way on your stoma journey.

#### **IN HOSPITAL**

If your surgeon does not discuss stoma placement with you, we encourage you to ask about it before surgery.

Correct stoma placement is important for your future comfort and ability to take care of your stoma. To manage pouching system changes as easily and

independently as possible, you will want to make sure the stoma is put on a smooth skin surface and that you can easily see and reach the stoma.

Questions you might want to ask

### Here are common questions you may choose to ask your healthcare professional while you are in the hospital:

- How soon will I be able to eat and drink?
- How long will I be in the hospital?
- What do I do if I am in pain?
- Does everyone with a stoma need to use a pouching system?
- Who will show me how to use my equipment?
- Where do I get supplies?

After your surgery, your stoma care nurse will talk to you about the operation, help you understand what has happened to your body, and teach you how to manage your new stoma as you recover in the hospital and transition to home care. Depending on your needs, you may also get referrals to other specialists or clinics for more help.

It is important to remember that everyone is different, and we all adapt to change in different ways. The support you can expect to receive from your nurse will always be geared toward your individual needs. There are many people like you who have had the same operation, and your doctors and nurses are there to listen and help.

#### WEEKS FOLLOWING SURGERY

When you are in the hospital, you will be taught how to care for your stoma.

Your nurse will help you find the right products and pouching systeming system for your individual needs. It is important to note there is a variety of product suppliers and bag types available to assist you. There is "NO ROLLS ROYCE". Finding the right system to assist you will take discussion and in some instances trial and error to get the fit that suits you. Make sure you contact your nurse if you or your caregiver is having trouble with the equipment.

You should also know that your stoma will shrink during the months following surgery. Your stoma care nurse can help you adapt your pouching systeming system appropriately. Additionally, any changes to your

belly size (from pregnancy, weight loss/gain, exercise, etc.) may require re-sizing of your pouching systeming system.

#### Questions you may want to ask

After your surgery, you may have questions about many things: diet, clothing, returning to work, intimate relations, etc. Below is a starter list of questions you may want to ask your healthcare professional before you leave the hospital, or at your post-surgery appointments:

- My stoma looks large. Will it always be this size?
- Who should I tell about my surgery?
- How active can I be after surgery?
- Should I bathe or shower with my pouching system on?
- Do I need to use special soap?
- Will my pouching system cause odour? How can I control this?
- How many times a day will I need to empty the pouching system?
- What is the correct way to empty a drainable pouching system?
- How long can I wear one appliance between changes?
- Where can I order supplies?
- How often should I cosult with my stoma nurse?
- Will medical aid pay for pouching systemes?
- Will the public hospital supply puches?

#### THERE ARE MORE THAN JUST BAGS AVAILABLE



Talk to your stoma nurse about the supporting products to fit your lifestyle and needs.

#### **GOING HOME FROM THE HOSPITAL**

Leaving the hospital is an important milestone, but it can cause anxiety for anyone with a new stoma. It's normal to feel nervous about living with a stoma , but it's also important to remember that you are never alone.

You may find that you have many questions in the days and weeks following your surgery. During this time, you may also find that you are feeling depressed, down or angry. You may experience some frustration until you get comfortable with your pouching system. All of these feelings are perfectly normal.

Reach out to your stoma care nurse for help and encouragement.

You can also reach out to SASS via WhatsApp on 066 261 0654 if you needing any additional means of support.



#### HOW TO APPLY YOUR BAG



Before you begin, make sure all of your supplies are within easy reach.

#### Supplies generally include:

- A new pouching system.
- A clean towel
- Adhesive removers to prevent skin damage
- Skin wipes or cleaning supplies
- Scissors
- A measuring card
- A skin barrier such as stoma powder (optional)
- Any additional products your stoma nurse has advised for you individually eg. skin barrier, rings, paste, powder etc

#### STEP 1



Keep your skin clean and dry. Make sure your skin is clean and completely dry before you apply the barrier to your skin. If your stoma produces a little moisture, you can take a soft tissue to absorb the extra moisture before applying the barrier.

#### STEP 2



Measure and check often – it's quite normal to have changes in both the shape of your body and your stoma, so it is really important to regularly check if your cutting template is the right size and shape for your stoma, especially if you have a hernia.



Cut carefully. The hole in the barrier should fit your ostomy exactly. We recommend 1mm bigger than your actual stoma to prevent direct stoma damage which can cause bleeding

#### STEP 4



Make it stick! Use your hand to apply a little pressure to the baseplate/ flange/ skin barrier and smooth it out until you're certain there's full contact between the adhesive and your skin.

#### STEP 5



Change when in doubt. Change your pouching systeming system as soon as you feel a sense of leaking discomfort or itching.

#### IT IS A GOOD IDEA



Check the back when you remove your pouching system from your skin, check not only your skin, but also the back side of the baseplate/ flange/ skin barrier: Do you see signs of ostomy output? This tells you there was leakage - and means you should try to get a better fit.

#### YOUR STOMA AND CHANGES TO YOUR BODY

In the months and years following your operation, you may notice certain changes to your body. These changes can include:

- Weightloss or Weight Gain
- Folds or scarring of the skin around the stoma and in particular under your "wafer"
- A hernia occurence connected to your stoma

As these changes occur, it is important to ensure your pouching system continues to provide the right fit; this may mean adding additional supplies such as pastes, rings, powders, seals or changing the system completely.

A tight seal between the pouching system and your skin is essential for good stoma care. If, for example, the area around your stoma changes from being regular to being more inwards, it may be time to switch to a convex pouching systeming system. You may also need to use additional supporting products

products.

It's a good idea to consult with your stoma care nurse about pouching system fit and additional supporting products.

#### MANAGING SMELLS & GAS

- Every Ostomate's greatest fear is SMELL and very often you find that you will smell something that those around you don't. This is normal and remember, your waste no longer leaves your body from the rear end, its now almost below your nose.
- Bag technology has significantly improved and provided you maintain the correct fit, smells and leaks should not be too much of a problem accessories are available to assist too.

#### HOW TO MANAGE SMELLS

Pouching systemes are typically lined with a odour barrier film which helps to keep the smells inside your bag. You should only notice smells when you are emptying or changing your bag. If there are smells at any other time, check your pouching system for any leaks.

Here are a few more ways to keep odour at bay:

- Empty your pouching system when it is a third to half full.
- The best time to change your pouching systeming system is in the morning

before you have had anything to eat or drink

- Emptying or changing your pouching system regularly can help reduce the risk of leakage. It can also help to avoid a bulge if your pouching system is too full.
- Your diet can also affect the odour of your output. So, make sure you develop healthy eating habits.

#### MANAGING GAS BUILD UP

If you have a colostomy or an ileostomy, you may notice some bulging of your bag. This can happen bowels begin functioning after surgery. This gas build up is the result of "farting" which now happens into your bag. The downside to having a colostomy or an ileostomy, is that you will be able to "squeeze / hold" that fart as you use to.

Gas build-up is mostly caused by the foods we eat or what we drink.

If you are concerned about gas, you can use a pouching system with a filter.

- The filter lets the gas out of the pouching system, but not the odour
- It also minimizes gas from building up, so the pouching system does not inflate like a balloon
- Filters work best with a more formed discharge, but can be used with other stoma output consistencies.
- Speak to your stoma nurse about your concerns.

A Note about medication and supplements

Some side effects of medication and even nutritional supplements may make it challenging to maintain good hygiene. Colour, odour and consistency of your output may change as a result of these. Even non-prescriptive medications may have an impact and could cause constipation, diarrhea or excessive farting.

A risk that is associated with constipation is a blockage developing and this can result in a painful experience. It is therefore strongly recommended that you speak with your healthcare professional or pharmacist before taking any medication and or supplements.

#### **SLEEPING WITH A STOMA**

Once you receive your stoma, you may need to adjust your sleeping habits and patterns to accommodate the change to your body. This may seem intimidating because you have had your sleeping habits since the day you were born, but with a little guidance and tweaks, you will find yourself having a good night's sleep again in no time.



- Sleeping on your tummy may cause your output to "blow-out / leaks" from the sides, and it is therefore advised you try sleeping on your back. This may take some time to get use to but will become easier in no time.
- Try putting pillows around you to prevent you from rolling onto your pouching system.
- Wearing a shirt that's a size or 2 too small may help keeping the bag snug to you body while you sleep
- Before bed, it is a good idea to have a quick inspection of your bag and wafer looking for signs of "wear" and change your pouching system if necessary.
- If you have a urostomy, speak to your stoma nurse about a night time drainage system. These typically collect urine throughout the night without the need for you to drain your pouching system.
- For those with a high output ileostomy, speak to your stoma nurse about high output bags. These may assist with you getting an uninterrupted sleep.
- It is always a good idea to have your supplies handy should you need to change in the middle of the night.
- During the early stages of your transition to your new normal, it may be helpful to line your bed with linen savers to protect soiling your bed linen from any mishap.

It is not uncommon for Ostomates to experience "Blow-Outs" in the early stages of their new life with a Stoma. This is when your output pushes out from your pouching systeming system ( as it can be both skin barrier or bag) and causes a mess. This can be extremely frustrating and humiliating, but the important thing to remember is that it gets easier as you adjust to this new normal. Being prepared, knowing your pouching systeming system and monitoring your output levels can and will help you minimise the impact of these potential mishaps - may sound kinder and not so scary. If you feel that you are not coping, do speak to your Stoma nurse who will be able to provide you with alternative support measures if needed.

#### SKIN CARE MANAGING YOUR PERISTOMAL SKIN

Managing your peristomal skin or the skin around your stoma (the skin around your stoma that is covered by the barrier) is PROBABLY the most important part of your stoma care routine.

Peristomal skin health impacts how well your ostomy supplies work and how often you need to change your barrier plate.

## Why peristomal skin health is important

The simple truth is that barriers / flange / baseplate work best on healthy, unbroken skin. Ostomy barriers need healthy skin to create a good seal and to provide the best protection.

If your skin becomes irritated, weepy, denuded (the skin layers are rubbed away), or macerated (the skin is breaking down), you may have trouble getting the barrier to adhere/ stick to the skin. That may lead to more frequent barrier changes or leakage, which can cause the skin to break down further and increase risk factors for stoma complications.

#### What is good peristomal skin?

The skin around your stoma should look like the rest of your skin on your abdomen, there shouldn't be any breaks or rashes.





Examples of good peristomal skin

#### FACTORS THAT AFFECT SKIN AND STOMA HEALTH

For ostomates, your activity level, your stoma location, body shape, and how much you sweat impact wear time between barrier changes and can result in skin problems.

#### COMMON CAUSES FOR PERISTOMAL SKIN AND STOMA COMPLICATIONS

In a perfect world, your stoma would be located in a spot with no problems. Surgical procedures sometimes dictate a change in plans and our stoma placement ends up being tricky to work with.

#### Your stoma might:

- Be located in a skin fold
- Retracts into the skin
- Have a parastomal hernia
- Be next to scar tissue or bellybutton, you might experience additional challenges.

The number one thing you can do to prevent and treat skin issues is to ensure your barrier fits correctly.

#### **PREVENTING SKIN ISSUES**

Probably the best way to prevent skin related complications is to ensure that your barrier fits correctly.

Here are a few reasons why this could happen:

#### Pouching system has been cut too big

One of the biggest reasons is that your pouching system has been cut too big and the effluent is actually going onto your skin and not directly into your bag. That can cause your skin to not break down quite quickly in the area of your stoma. How to prevent this from happening: Make sure the size of your pouching system is cut out to exactly the shape and size of your stoma. If you have difficulty doing that, go back to your stoma care nurse and ask to have your stoma measured and sized. There are certain pharmacies or certain deliveries services that will cut your pouching system out to the exact shape and size. Many of the manufacturer companies have pre-cut pouching systemes that might suit you.

# CHANGE THE TYPE OF POUCHING SYSTEM YOU ARE USING

If it's an ongoing problem and perhaps the stoma is retracting in and coming back out again, maybe that's what's causing irritation on the skin. You might need to think about an alternative pouching system.

How to prevent this from happening: If you're using a flat bag, you might need to talk to your stoma care nurse about trying a convex pouching system. If you need a little bit of extra protection, a seal or a ring used around the stoma can prevent this problem from happening.

Sometimes people who have developed a parastomal hernia or shape and size of the stoma is changing can lead to the pouching system not adhering well next to the stoma. You may need to speak to your stoma nures about supporting product to assist you with an optimal seal.

Some other people like using a skin preparation this is very important as it protects the skin by forming a barrier.

Some products advise you do not use these as it may interfere with the adherence of the pouching systeming system.

#### AREA BEYOND OF THE FLANGE

A common complaint is when the area beyond your pouching systeming system breaks down - known as skin stripping.

How to prevent this from happening: A remedy to prevent that from happening is to use an adhesive remover spray or wipe, which allows you to remove your pouching systeming system without any trauma. There are some countries that don't allow having an adhesive remover spray/wipe in your prescription or you have to buy it and perhaps that's not possible for you. If that's the case, use warm water and hold your pouching system away from the skin and very gently wash the pouching system off the skin so you're not just pulling the adhesive off your delicate peristomal skin. Page 23

#### WIDER AREA OF SORE SKIN

You can take an allergic reaction, sensitivity issues or for some men, if you have a lot of hair on your abdomen and you are having to shave the skin around your stoma, you can develop a larger area of peristomal problems.

If your stoma nurse is not able to help resolve persistant skin problems, you may need a referal to a dermatologist who is better equiped to deal with skin related issues.

#### HOW DO I CLEAN AROUND MY STOMA AND SKIN?

The stoma itself does not need to be cleaned, although it can be helpful to wipe away output during a barrier change.

Here's a step-by-step guide to cleaning around your stoma:

- Gather and set up all equipment and materials you will need in a clean environment.
- Wash your hands before and after caring for your stoma.
- The best way to clean the skin around your stoma is to use warm water and a washcloth, or soft paper towels. You do not need to use gauze or gloves. It is not necessary to use soap to clean around your stoma. If you prefer to use soap, use a mild soap and rinse well.
- Avoid using soaps and cleansers with oils, perfumes, or deodorants. These products may cause skin problems or keep your pouching system from sticking.
- Do not use pre-moistened wipes, baby wipes, or towelettes not made for cleaning the skin around a stoma. While wipes can be used in an emergency, many of these products contain ingredients that can interfere with the pouching systeming system adhesives. They also may irritate your skin.

- If paste is part of your pouching systeming system, don't be concerned if a little bit of paste is left on your skin after cleaning. It will not harm your skin or keep the new pouching system from sticking.
- Unless recommended by Stoma nusrse or health care provider, do not apply powders or creams (except for special ostomy powders) to the skin around your stoma as they can keep your pouching system from sticking.
- Always dry your skin well before you put on a new pouching system.

#### SHAVING PERISTOMAL SKIN

Shaving is not recommended. shaving increases risk of skin infection

- Use an electric razor
- Dry shave with a safety razor and an ostomy skin barrier powder
- Wet shave with mild soap and water.
- If you use shaving foam, avoid foam that has moisturizers or perfumes that may irritate the skin or interfere with the barrier's adhesive.
- Always rinse the skin well with water after shaving.
- Assess for any injury to the stoma or bleeding as you may necessarily feel it if there is an accidental injury.

#### WHEN CLEANING, KEEP IN MIND THAT:

- Sometimes you may see a small amount of blood when you are cleaning around the stoma.
- The stoma has small blood vessels that may bleed for a short time when cleansed. Any bleeding that does not stop should be reported to your health care provider.
- Be gentle when cleaning around the stoma.
- The stoma does not have nerve endings, so you usually are not able to feel if you are rubbing too hard.

#### MY STOMA AND MY DIET

Having a Stoma should not impact your eating habits. There are things to consider though:

#### **EATING:**

- Slow and steady wins the race
- Chew, Chew and Chew your food. Proper chewing will help in significantly in reducing the risk of forming a blockage
- If you are going to try new food, have a small portion to see how YOUR body reacts.
- Keep a food journal, especially for the first few months as you are adjusting to the new you. Record the foods that work and those that don't. Record your output frequency. This will also help you to manage the gaseous build up in your bag

#### HYDRATION - DONT WAIT TO HYDRATE

- Drink water regularly, between 8 to 10 glasses minimum.
- Be very aware of dehydration. If you experience symptoms like dizziness, a dry mouth or discoloured urine, drink water immediately

#### MEALS

- Eating smaller meals more often have been reported to be a good option for most Ostomates. Instead of the 3 meals, having 6 well balanced smaller meals. By eating your largest meal midday, you decrease the amount of stool output at night.
- Certain foods are notorious for causing gas and odour and this is no different for Ostomates.

#### Some examples are :

- 1. Beans and lentils
- 2. Asparagus, broccoli, brussels sprouts, cabbage, and other vegetables
- 3. Fructose, a natural sugar found in artichokes, onions, pears, wheat, and some soft drinks
- 4. Lactose, the natural sugar found in milk
- 5. Fruits, oat bran, peas, and other foods high in soluble fiber, which gets digested in your large intestine
- 6. Corn, pasta, potatoes, and other foods rich in starch
- 7. Sorbitol, the artificial sweetener
- 8. Whole grains, such as brown rice, oatmeal, and whole wheat
- 9. Chewing gum. You swallow air when chewing gum, which goes into your digestive tract and can cause gas.
- 10. Drinking with a straw. You also swallow air when you drink through a straw.
- 11. Soy milk. Sure, it's healthy, but it can also be gassy.



# CAN I EXERCISE NOW THAT I HAVE A STOMA?

No matter what level of physical activity you want to pursue, ostomy surgery shouldn't hold you back. Whether you've had colostomy, ileostomy or urostomy surgery, your abdominal muscles need time to heal and strengthen, and it might seem difficult to be active again. Your muscles may be weaker than usual, due to the time spent in the hospital but these things can be overcome with gradual training and exercises.

#### **GETTING STARTED**

Before you start working out and becoming active again, it is always a good idea to chat with your physician and or stoma nurse about your plans. Take some time to test your physical state and check for any limitations you may have. A good rule of thumb: "If it hurts, STOP!" Starting off gradually and constantly building your strength and confidence and adjust your goals as you progress every day.

- Learn how your bag reacts to the exercise and increased movements. It may be necessary to chat with your stoma nurse about additional support devices such as tapes and or stoma belts.
- The more you move about, the easier it will become
- Having a stoma should not limit you from doing the things you love such as running, swimming, climbing or skiing.

**Check out this link** https://www.colostomyuk.org/active-ostomates/ team-colostomy-rugby-league/



Learn to place and secure your ostomy pouching system. Try using an ostomy belt to help keep your pouching system secure and supported against your body, which may help increase wear time.

Walk around and get a feel for how your ostomy reacts to different movements.

Move more and more each day, building up towards your wanted level of exercise.

Do anything you feel comfortable doing.

Running, jogging, swimming, climbing, skiing; when it comes to working out with an ostomy, you shouldn't be prevented from staying fit the way you want to.

Trust the process to progress. Patience is key and while your muscles may need more time to heal and strengthen, you are making progress with each movement you make.

#### THE DO'S AND DON'TS OF EXERCISE

Exercising after ostomy surgery is about patience and doing what feels right. It's important to take your time and know your limits. When you begin working out again, you may run into some challenges or limitations. Be patient and don't give up. Before long, nothing will stand in your way.

#### **OPTIMAL OSTOMY EXERCISES**

After ostomy surgery, many people may find these activities to be easier than others. But before starting any new exercise, talk to you doctor to make sure you're ready.

#### CORE MUSCLE CONDITIONING

Disclaimer: Please note that the below exercises mentioned are recommendations. You should always consult with your physician before starting any exercise program. You are also advised to seek the guidance of a physiotherapist, biokenticist or personal trainer to support your training program.

People who have an ostomy are at greater risk for having weakened core due to years of digestive or bladder issues, coupled with surgery.

Building back core stability and flexibility is important, as it makes exercises and routine activities easier. Here are a few basic exercises to get started:

- Hip Extensions
- Upper Body Extensions
- Arm/Leg Extensions
- Pelvic Tilt
- Bridging

#### SWIMMING

Swimming is great exercise. It works your whole body without putting strain or pressure on your stoma. Most ostomy pouching systems are water resistant, even for swimming. First, ensure that your pouching system is securely in place. Then, cover the vent on your deodorizing filter with a filter cover to prevent water from entering the pouching system.

#### WALKING

Get your steps in. Walking is a simple and energizing way to exercise. When walking, you can build up fitness at your own pace. Walking can also reduce stress and constipation.

#### **REMINDER!**

Choose an activity you enjoy. Running, jogging, swimming, climbing, skiing; when it comes to working out with an ostomy, you shouldn't be prevented from staying fit the way you want to.

#### TRAVELLING

Extra security precautions are being taken at airports and other transit hubs worldwide. A little pre-planning and understanding of both security rules and your right to privacy can help you avoid problems in transit and enjoy your travels.

In particular, remember that all airport screenings must be conducted with courtesy, dignity and respect. You may request screening in a private area.



- Carry a statement from your healthcare professional stating your need for ostomy supplies. It may also be a good idea to have this notification printed into the language of the country you are travelling to.
- You can be screened without having to empty or expose your ostomy; however, you may need to conduct a self pat-down of the ostomy, followed by a test of your hands for any trace of explosives.
- If you are traveling to a foreign country, bring this information written in the appropriate language. Google Translate may be helpful with translations. If you find you need additional supplies while traveling, a local pharmacy is a great starting point. The local pharmacist should be able to provide you with the necessary supplies and/or refer you to a local clinic/hospital for support.
- Pre-cut all cut-to-fit barriers at home. Keeping your ostomy scissors in your checked luggage may avoid delay and extra screening.
- Consider purchasing travel insurance that guarantees getting you to a hospital, if necessary.

Bring disposable cleansing wipes and disposal bags. Sometimes a pouching system change may require a little clean up. Scent free baby wipes is a great alternative to soap and water.

(Cleansers with moisturizers are not recommended for use around the stoma.)

Drink up. Be sure to pack your refillable water bottle so you can stay hydrated. Nothing slows down a vacation more than dehydration. Read more about tips on hydration.

Traveling to a foreign country? It is a good idea to have key questions, such as "where is the bathroom?", written down in the local language. Google Translate is helpful in almost any language.Carry a statement from your healthcare professional stating your need for ostomy supplies.

Don't forget to leave your anxiety at home. Travel with confidence. If you have other questions about traveling with your ostomy, speak with your Stoma nurse or feel free to contact SASS.

#### WHAT TO CARRY IN YOUR BAG WHEN LEAVING YOUR HOME

When leaving the home, it is a good idea to take supplies with should you need an emergency bag change; EVERY OSTOMATE SHOULD HAVE A "GO" BAG.

#### Some ideas for your "GO" BAG

- A new pouching system.
- A clean towel
- Adhesive removers to prevent skin damage
- Skin wipes or cleaning supplies
- Scissors
- A measuring card
- A skin barrier such as stoma powder (optional)
- Any additional products your stoma nurse has advised for you individually eg. skin barrier, rings, paste, powder etc
- Disposable nappy bag or zip-lock bag to hygienically dispose of your bag.
- Clean shirt / blouse & change of underwear incase of an emergency.



#### SEX AFTER SURGERY

Sex After Ostomy Surgery: Do's and Don'ts

Are you worried about your ostomy's impact on your sex life? The good news is that it may not have any impact at all. Explore some simple do's and don'ts here.

Yes, it is possible to continue to have a healthy sex life – or even improve upon it – after ostomy surgery. Here are a few intimacy do's and don'ts to consider after your operation.

DO start slowly. You'll need to take it easy and gently to start. Keep in mind that tenderness and romance make sex pleasurable as well. Remember that loving, kissing, and touching are an important part of sexuality.

DON'T change anything (unless you want to). How do people with stomas have sex? The same way as people without stomas. Conventional sexual positions are almost always possible. Of course, sex is about your comfort level and individual preferences.

DO empty your pouching system. Take a few minutes before you get intimate to empty your pouching system. It will give you a little more confidence and ease your mind.

DON'T let the pouching system get in the way. If your pouching system doesn't have a comfort panel, consider using a fabric pouching system cover made from cotton during sex. This will prevent the pouching system from rubbing on you and your partner's skin. It will also hide contents if you use a transparent pouching system. Another option is to wear an ostomy wrap with an inner pocket. The wrap will conceal your pouching system and hold it close to your torso. There are also various clothing accessories such as belly bands, cummerbunds, and crotchless underwear that help conceal the pouching system during intimacy.

DO wear what makes you comfortable. Some women choose to wear a silky or cotton vest-like top that covers the pouching system and torso. There are also smaller pouching systemes that can be worn discreetly for certain stomas.

DON'T use the stoma for intercourse under any circumstances. You or your partner should never use the stoma for a sexual activity (penetration).

#### 5 COMMON INTIMACY CONCERNS AND WHAT TO DO ABOUT THEM

It's natural to feel stressed about possible relationship issues related to your ostomy. Explore common concerns about new and existing relationships, and how to put your mind at ease.

Get help with intimacy concerns after ostomy surgery.

What if my partner looks at me differently, or maybe even rejects me in some way? How will the pouching system affect my sex life? How do I approach new relationships?

These and many other questions reflect the worries many people have about intimacy after ostomy surgery. The good news is that you can have a healthy dating life or, if you're already in a relationship, a lifestyle that you and your partner enjoy. You just have to be proactive and communicate.

# HERE ARE SOME COMMON CONCERNS, AND SUGGESTIONS THAT MIGHT HELP.

#### I'M WORRIED ABOUT WHEN I SHOULD TELL SOMEONE I'M DATING ABOUT MY STOMA.

When you are fully clothed, no one needs to know that you have had ileostomy, colostomy, or urostomy surgery. You can decide if you want to share that information. However, if you are planning to be intimate and remove your clothes, the pouching system can't be ignored.

# OKAY, SO HOW DO I DEAL WITH NEW INTIMATE RELATIONSHIPS?

Once you anticipate that things will get serious, be sure to have a discussion before getting physical. Start by rehearsing a short explanation to yourself or a friend. Go over your illness or accident. Explain the surgery and why you need to wear a pouching system. Once you practice how to talk about your situation, it will go easier with a new partner.

#### MY PARTNER AND I ARE WORRIED ABOUT THE IMPACT ON OUR SEX LIVES.

If you are in a committed relationship, involve your partner as soon as you learn that you need ostomy surgery. Once you do, the topic of sex will likely come up. That's why it's important for both of you to talk to your surgeon or stoma nurse specialist about how your particular surgery will or won't impact your sex life. Many couples say that sharing this experience actually brings them closer.

#### I'M WORRIED THAT POUCHING SYSTEM CHANGES WILL SCARE MY PARTNER.

Part of involving your partner early on is having them see the pouching system changed in the hospital. The simple act of seeing the stoma helps minimize concerns. Doing pouching system changes while a healthcare professional is there to answer questions can help put both of you at ease. For many people, the reality of a stoma is much less of a shock than the anticipation of it.

#### I'M WORRIED I WON'T BE ABLE TO HAVE SEX FOR A WHILE.

Recovery from a major operation takes time. Many people who have stoma surgery had a debilitating condition first, which slows the recovery process. Do not expect to resume your sex life as soon as you get home.

Talk to your healthcare professional about when you can resume sexual activity. There is no set timetable and each couple will have a different comfort level.



#### **RETURNING TO WORK**

From industrial jobs to the classroom, from long shifts at the hospital to dancers – and all workplaces in between – people living with an ostomy are successfully returning to work following ostomy surgery. Below are some tips to help you return to work with more confidence and less anxiety.

- Be prepared. Pack a "GO" bag with the items you need for a full change of pouching systeming system and a change of clothes. You may not need your "emergency kit" at all, but it can offer peace of mind knowing that it is at the ready.
- Pack your water bottle and stay hydrated. Drinking water is one of the simplest ways to improve your health and well-being. Learn more about hydration with an ostomy.
- Initially, you may be self-conscious about emptying your pouching system in public due to odor or sound. Create a buffer with a layer of toilet paper in the toilet bowl to avoid splashing when emptying you pouching system.Some people also include toilet deodorizing products in their ostomy supply kits.
- Dress comfortably. Do not worry that others will notice the pouching systeming system through your clothes. Having an ostomy may seem very noticeable to you, but in reality it is rarely noticed by others.
- Consider starting back to work on a Thursday, allowing you to ease back in with a short work week. You will be able to rest over the weekend before taking on a full week of work.
- Think about what facilities are available in your work restroom and plan accordingly. If no paper towels are available, have premoistened paper towels in zip lock plastic bags or moisturizer-free wipes. Try to think of how to accomplish a pouching system change in that setting if needed.
- Take breaks. It is easy to get wrapped up in the task at hand, but allow yourself time to empty your pouching system.
- Don't try out new products or foods right before going back to work. Save testing new products or diet changes for the comfort of home.

- Most likely, your co-workers will not realize you have an ostomy unless you tell them. It is a personal choice whether or not to tell your employer about your ostomy. Although it may help to tell your manager or trusted co-worker(s) if you require frequent breaks or accommodations.
- The law provides cover for physical disability and medical conditions which can cause unfair discrimination in the workplace against certain people. The Employment Equity Act requires employers to provide reasonable accommodation for individuals with disabilities, unless such accommodation would cause undue hardship.

Consult your physician or healthcare professional before returning to work.



#### **KNOW YOUR RIGHTS!**

#### CHARTER OF OSTOMATES RIGHTS

This Charter of Ostomates Rights presents the special needs of this particular group and the care they require. They have to receive the information and care which will enable them to live a self-determined and independent life and to participate in all decision making processes.

It is the declared objective of the International Ostomy Association that this CHARTER shall be realised in all Countries of the World.

The ostomate shall:

- Receive preoperative counseling to ensure that they are fully aware of the benefits of the operation and the essential facts about living with a stoma.
- Have a well-constructed stoma placed at an appropriate site, and with full and proper consideration to the comfort of the patient.
- Receive experienced and professional medical support and stoma nursing care in the preoperative and postoperative period both in hospital and in their community.
- Receive support and information for the benefit of the family, personal carers and friends to increase their understanding of the conditions and adjustments which are necessary for achieving a satisfactory standard of life with a stoma.
- Receive full and impartial information about all relevant supplies and products available in their Country.
- Have unrestricted access to a variety of affordable ostomy products.
- Be given information about their National Ostomy Association and the services and support which can be provided.
- Be protected against all forms of discrimination.
- Receive assurance that personal information regarding their ostomy surgery
  will be treated with discretion and confidentiality to maintain privacy; and that
  no information about their medical condition will be disclosed by anyone
  possessing this information, to an entity that engages in the manufacture,
  sales or distribution of ostomy or related products; nor shall it be disclosed to
  any person that will benefit, directly or indirectly, because of their relation to
  the commercial ostomy market without the expressed consent of the
  ostomate.

Issued by the IOA Coordination Committee

June 1993: Revised June 1997 Revised by World Council 2004, 2007

Source: European Ostomy Association

https://ostomyeurope.org/ostomates-rights/



#### I HAVE A COLOSTOMY BUT I HAVE FLUID OOZING OUT OF MY ANUS, IS THIS NORMAL?

If you've had a colostomy but your anus is intact, you may have a mucus discharge from your anus. Mucus is produced by the lining of the bowel to help with passing faeces (stools, poo). The lining of the bowel continues producing mucus, even though it no longer serves any purpose. It can either leak out of your anus or build up into a ball, which can become uncomfortable.

Some people have a rectal discharge every few weeks, while others have several episodes a day. Contact your stoma Nurse or surgeon if there's blood or pus in the discharge.

# WHY DOES MY STOMA BLEED IF I RUB/WASH IT TOO HARD?

Your stoma has many blood vessels, so it may bleed easily with touch or irrigation. It's common to have a small amount of blood on the tissue when cleaning your stoma. The bleeding should stop on its own within a few minutes. If you're on a blood thinner or aspirin, you may bleed more easily and for a longer period. If you bleed a lot or if the bleeding doesn't stop after seek medical advice.

#### HOW OFTEN DO I HAVE TO CHANGE MY BAG?

Wear time, or the number of days between changes (removing the pouching systeming system and applying a new one), is a hot topic. A maximum of 2 - 3 days between changes is recommended. The average number of days between changes is three. This means some people change daily, some people change once a week, and lots of people are anywhere in between. Your wear time may also be impacted by lifestyle and climate. If you are an active person or have a physically demanding job, sweat can cause your wafer to break down sooner than anticipated. The timeframe for wear time is a guide but should not be a rule of law. Ostomates with an ileostomy are recommended to change more frequently

#### FOR MORE INFO

Most of the information in this booklet derives from these websites listed below. For more extensive information you may want to visit them.

- https://www.coloplast.co.za/stoma/people-with-a-stoma/before-stoma-surgery/
- https://www.hollister.com/en/ostomycare/ostomylearningcenter
- https://meplus.convatec.com/sections/answers/
- https://joinbetter.com/community/blog/ostomy/stoma-peristomal-skin-healthy/
- https://abiggerlife.com/
- http://ostomyinternational.org/
- https://ostomyeurope.org/

#### CONTACT US WE ARE HERE TO HELP YOU.

#### INFO@SASSTOMATES.ORG.ZA 066 261 0654



# **Coloplast Direct**

#### **Our values**

Closeness...to better understand Passion... to make a difference Respect and responsibility...to guide us

As part of Coloplast Direct you get access to:



*Free* nursing consultation: Get trained on your new ostomy product by our dedicated team of nurses



**Free case management:** We liaise with your medical aid to simplify the claims process





**Products:** Get access to our innovative range of ostomy products



**BodyFit** 

**Technology** 

Ensures that all Mio

baseplates follow

individual body

movement

**Free home delivery:** Convenient, discrete delivery straight to your door

#### Where do I order appliances and accessories?

Please contact your local stoma nurse or Coloplast to find out more about assistance available in South Africa.

Find out more:



Less Ballooning

Pre-Filter reduces ballooning by up to 61%<sup>1</sup>

<sup>1</sup>For ileostomies, 52% for colostomies, Coloplast, Clinical Study, 2010



Goes unnoticed

The discreet grey bag stays unnoticed under clothing



#### dtcsa@coloplast.com



Flexible comfort Integrated flexlines bends around the

stoma



SenSura®Mio







ConvaTec is a global medical products and technologies company focused on therapies for the management of chronic conditions, with leading market positions in advanced wound care, ostomy care, continence and critical care, and infusion devices.

ConvaTec has 9,400 employees and does business in more than 100 countries.



The me+<sup>™</sup> program offers you the right support so you feel stronger, more confident and ready for what's ahead. The ostomy products and support you need, tips and advice for stoma care, and a community you can grow with.

# If you are interested in learning more about ConvaTec or the products and services we offer, please contact:

T: 010 880 3833 I www.convatec.com/za



#### About Hollister:

Hollister Incorporated is an independent, employee-owned company that develops, manufactures and markets healthcare products and services worldwide.

We offer advanced medical products for Ostomy Care, Continence Care and Critical Care. We also provide healthcare programs and services, as well as educational materials for patients and healthcare professionals.

Hollister has been serving healthcare professionals and patients for more than 100 years - making a difference in the lives of people throughout the global community.

#### Hollister Online Learning Centre:

Whether you are about to have surgery, have had your stoma for years, or want to learn how to keep your lskin healthy, we are here to help. Our always available Online Learning Centre will provide you with information and education so you can live your best life with an ostomy.

Link to learning Portal: https://www.hollister.com/en/ostomycare/ostomylearningcenter

#### Hollister Products:

In South Africa we have a variety of Ostomy and Incontinence products available to meet the individuals needs - proudly distributed by HARTMANN.

#### Got Questions:

Links to social pages Facebook: https://www.facebook.com/HollisterIncorporated/ Twitter: https://www.twitter.com/HollisterInc Instagram: https://www.instagram.com/hollister\_incorporated Linkedin: https://www.linkedin.com/company/hollister-incorporated



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