

Understanding your urostomy





The information provided in this guide is not medical advice and is not intended to substitute for the recommendations of your GP or stoma care nurse. This guide should not be used to seek help in a medical emergency. If you experience a medical emergency, seek medical treatment in person immediately.

### Life After Stoma Surgery

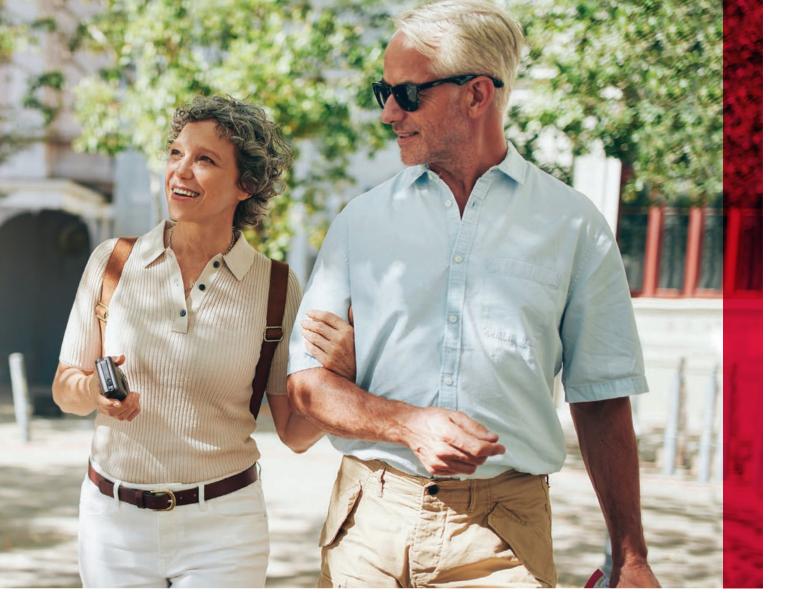
As a person who lives with a stoma, I understand the importance of support and encouragement in those days, weeks, and even months after stoma surgery. I also know the richness of life, and what it means to continue living my life as a happy and productive person. Can I shower? Can I swim? Can I still exercise? Will I still have a healthy love life?

These are the questions that crossed my mind as I laid in my bed recovering from stoma surgery. In the weeks following, I quickly discovered the answer to all of these questions for me was YES! I was the person who would empower myself to take the necessary steps and move forward past my stoma. Those who cared for and loved me would be there to support me through my progress and recovery.

Everyone will have a different journey. There will be highs, and there will be lows. Although our experiences will differ, I encourage you to embrace the opportunity for a new beginning and not fear it. Remember that resources and support are available to you — you are not alone. Our experiences shape our character and allow us to grow as people. Try and grow from this experience and embrace the world around you.

This guide has been carefully crafted for you — the individual, the spouse, the parent, the grandparent, the caregiver, the person with a stoma. Hopefully, it will help you obtain the knowledge and skills you need to move beyond your stoma, and back into your life.

- BROCK M., LIVING WITH AN STOMA SINCE 2000



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#### **40** GLOSSARY

It may be performed to repair an injury, or remove a tumour. No matter what the reason, having questions and concerns is a natural part of the process. This guide is intended to complement information given to you by your healthcare professional, such as a nurse who specialises in stoma care.

A glossary is included at the back of this guide to help with some terms with which you may not be familiar.

The more you know, the more you can ease some of the concerns you may have about living with a urostomy. It is important to remember that you are not alone. Every year, thousands of people have urostomy surgery. For some, it is a lifesaving event.

If you are about to have — or recently had — urostomy surgery,

this guide can help you understand what it is and how to manage it.

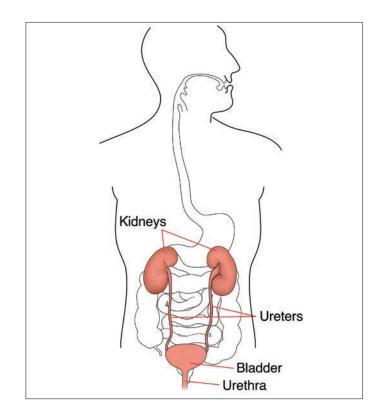
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## Understanding Your Body

In order to better understand your urostomy, it is helpful to first understand more about the human urinary system.

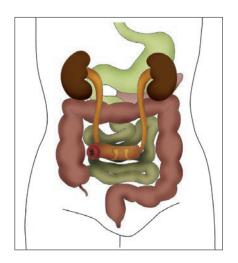
It begins with the kidneys. Urine or liquid waste flows from the kidneys through two narrow tubes called ureters and collects in the bladder.



The flow of urine is fairly constant. A sphincter muscle allows the bladder to store urine until it is convenient to empty the bladder, or urinate. When a person urinates, the sphincter muscle relaxes, allowing urine to flow out of the body through a narrow tube called the urethra.

### What Is a Urostomy?

A urostomy – sometimes called a urinary diversion or ileal conduit – is a surgically created opening (stoma) to drain urine out of the body after the bladder has been removed or bypassed.



With a urostomy, urine is eliminated through the stoma instead of through the urethra. Because there is no sphincter muscle to voluntarily control when to urinate, urine collects into a stoma pouch with a drain tap at the bottom. Stoma pouch systems are

explained further on page 11.

### How a Urostomy Is Created

Your surgeon may select one of several methods to create the urostomy. The surgeon removes a short segment of intestine to use as a pipeline – or conduit – for urine to flow out of your body. The few centimetres that the surgeon removes for the conduit will not affect how the intestine works. The surgeon will reconnect the intestine, and it will continue to function just as it did before. The surgeon then closes one end of the conduit, inserts the ureters into the conduit, and brings the open end of the conduit through the abdominal wall. This new opening in your abdominal wall is called a stoma (or ostomy).

### **FACT**

The clinical name for your type of urostomy is based on which portion of your intestine is used to create the diversion. For an ileal conduit, the most common type, the surgeon uses a short segment of the small intestine (ileum).

### The Stoma

While stomas come in a variety of sizes and shapes, a healthy stoma:



- Is not painful
- Bleeds easily when rubbed or bumped (for example, when washing), but should resolve quickly

• Is pink or red in colour and is slightly moist

**End Stoma** 

Whether your stoma is large or small, protrudes above the level of the skin, or is flush with the skin, drainage should empty into your pouch without leaking under the skin barrier. See more about stoma pouch systems on page 11.

Determining where the stoma will be placed on your abdomen is an important part of preparing for surgery. Generally, the stoma is placed in an area just below your waist between your navel and hip. An ileal conduit stoma is often located on right side (also called the right lower quadrant).

Before your surgery, your stoma care nurse and your surgeon may evaluate where your stoma may be placed. To do so, your stoma care nurse may look at your abdomen in multiple positions such as lying down, sitting, bending, and standing. Other considerations for placement may be the type of stoma, the surface of the skin, your ability to see the area, and your lifestyle. This placement is a recommendation; the final placement will be determined by your surgeon during surgery.

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### Right after surgery...

- Your stoma will probably be swollen. It may take several weeks for your stoma to shrink to its permanent size.
- You will have small tubes called stents inserted during surgery that extend out of your stoma and ensure the flow of urine into your pouch. The stents are typically left in place anywhere from 5 days to 4 weeks depending on the surgeon's preference. Do not cut or remove these stents on your own.
- Urine will begin flowing from the stents coming out of your stoma immediately after surgery. The stents will be removed by your healthcare provider at a time determined by your Consultant Urologist. At first, the urine may have a slight reddish colour. After a few days, the urine should return to its normal colour.
- You may see mucus in your urine as the urine collects in your pouch. The mucus comes from the segment of intestine that was used to form your conduit.



**End Stoma with Stents** 

### The Skin Around Your Stoma

The skin around your stoma (also called peristomal skin) should be intact without irritation, rashes, or redness. It should look similar to healthy skin anywhere else on your body. Itching with otherwise healthy-looking skin can also indicate a problem.

Problems with the skin around your stoma can create difficulty with keeping a stoma pouch in place, which may lead to higher product usage and higher costs. It could also mean less time spent doing things you enjoy with the people who are important to you.



Healthy peristomal skin should look like this.



Not like this.

If you discover red, broken, or moist skin around your stoma, seek the assistance of a stoma care nurse. Check the skin around your stoma on a regular basis to ensure your skin is healthy and to help address any issues in a timely manner. You should never accept leakage and unhealthy skin as a normal part of living with a stoma.

For more information about maintaining healthy skin around your stoma, see page 24.



## Stoma Products Explained

There are many different types of stoma pouch systems.

The stoma pouches used by your healthcare team in the hospital will be best suited to help you recover from stoma surgery.

After you are home from your surgery, you may want to try some different stoma pouches that are right for you as your stoma changes, or as you start different activities. There are also different stoma products that may be used together with a pouching system to help extend wear time, maintain peristomal skin health, or make stoma care easier.

### Stoma Pouching Systems

Stoma pouches consist of two main parts:

- The skin barrier (or baseplate) should fit immediately around your stoma. It protects your skin and holds your pouch in place.
- The **pouch** collects output from the stoma. Pouches come in a variety of options for different needs and stoma types.

### **Two-Piece Pouching System**

The skin barrier and the pouch are two separate pieces connected by a plastic ring called a flange. The pouch can be removed and changed without removing the skin barrier from your body.

### **One-Piece Pouching System**

The skin barrier and the pouch are a single unit and must be removed together when changed.



All urostomy pouches have a drain tap at the bottom of the pouch, so it can be emptied as needed. The pouch should be emptied when it's 1/3 to 1/2 full.

### The Role of the Skin Barrier

The skin barrier is the most important piece of your stoma pouch because of the role it plays in helping to maintain healthy skin around your stoma. It is important to understand that the *fit* of the pouch and the *formulation* of the skin barrier go hand in hand. Your pouch will not maintain a good seal without proper *fit*. Without the correct *formulation*, the skin around your stoma can be at risk for complications.

### What Is Fit?

The *fit* of the pouch will help to provide the most secure seal around the stoma to help prevent leakage under the skin barrier and maintain skin health.



#### Flat skin barrier

A skin barrier that has a level or even surface area that comes in contact with the skin. This type of barrier might be used if your stoma sticks out above the level of your skin, and the area around your stoma is flat in all positions.



### **Convex skin barrier**

A skin barrier that curves outward toward the peristomal skin to increase the depth of the skin barrier. This outward curving is designed to come in contact with the skin directly around the stoma, which may help promote a good seal between the pouching system and the skin. This type of skin barrier might be used if the stoma is flush with or retracted from the skin. Convexity can be firm or soft. Your stoma care nurse will determine if this is suitable for you.

Skin barriers with and without adhesive borders are available. Pouches with a skin barrier and adhesive border offer some people an enhanced sense of security, while products without an adhesive border remain an option for people with sensitive skin or allergies to adhesive products.

TIP

A good fit is when the skin barrier opening is snug around the stoma where the skin and stoma meet, and you have filled in any gaps, creases, or folds. Measure your stoma size before every barrier application during the first 6-8 weeks after surgery to be sure of your stoma size as swelling reduces. After that, measure periodically to ensure the stoma size has not changed due to other factors like weight gain or loss.

#### What Is Formulation?

The *formulation* of the skin barrier is the combination of ingredients with different adhesive and fluid handling properties that have been blended together to give the skin barrier its performance expectations. The ingredients inside the skin barrier work together to provide three main things:

- **1. Adhesion** to adhere (or stick) the barrier to the skin.
- **2. Absorption** to absorb moisture from the stoma or perspiration on the skin.
- 3. **Erosion Resistance** to hold the skin barrier together in the presence of fluid and provide the right wear time.

#### **Standard Wear**

A skin barrier that provides gentle adherence to the skin but may be less durable than an extended wear barrier. Sometimes called regular wear.

#### **Extended Wear**

A skin barrier that contains special additives that may achieve stronger adhesive attachment to the skin and may be more resistant to breakdown.

#### **Infused Barrier**

A skin barrier option that is infused with an additional ingredient, such as ceramide. Ceramide is a natural component of human skin that helps protect against damage and dryness. In addition to helping keep the skin healthy, these infused skin barriers also provide adhesion, absorption, and erosion resistance.

TIP

Ceramides are found in cosmetics, lotions, and creams. As you may know, it is not recommended to use any lotions or creams on your peristomal skin, because it may interfere with the barrier's ability to adhere to the skin. A ceramide-infused skin barrier is different – the ceramide is part of the barrier formulation, so it does not interfere with the ability of the skin barrier to adhere to your skin.

### Pouch Options and Features

Stoma pouches come in different sizes and with different features available to suit your needs. Here are some of the most common features for stoma pouches.

### **Drainage System**

• The type of pouch most commonly used with a urostomy is called a urinary drainage or urostomy pouch. Urostomy pouches have a drain tap that is twisted or a plug that is pulled out to allow emptying. Some drain taps, on the bottom of the urostomy pouch, include a cap that can be removed, the pouch drained, and the cap replaced.



### **Visibility Options**

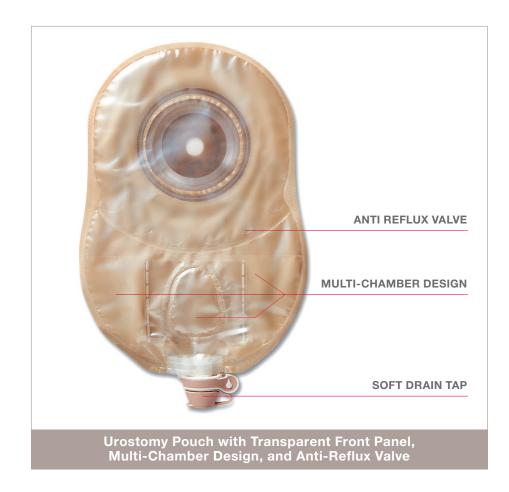
**Pouch panel (or film)** options are available in Clear and Opaque. You can also select pouches that have a soft cover, to help increase your comfort and provide added discretion.

### **Multi-Chamber Design**

Multiple chambers inside the urostomy pouch are designed to more evenly distribute urine within the pouch, which helps keeps the pouch from unsightly bulging between draining.

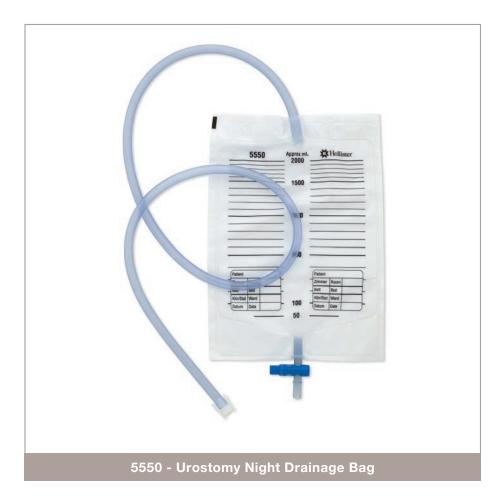
#### **Anti-Reflux Valve**

Part of the multi-chamber design, this appears as a curved line that runs across the center of the pouch. An anti-reflux valve in pouch helps minimise the backflow of urine. This also keeps urine from refluxing to the top of the pouch and eroding the skin barrier, which is a critical component that connects your pouch to the skin around your stoma.



## Night Time with a Urostomy

Because urine flow is fairly constant, it can be surprising how a urostomy pouch may fill through the night – sometimes multiple times. Many people choose to use a night drainage bag which allows the urine to drain into the urostomy night bag while they sleep, rather than taking trips to the bathroom to empty their pouch. You can connect your urostomy pouch to a urostomy night bag by using a urostomy drain tube adapter.



Tips when using urostomy drain tube adapters:

- Leave a small amount of urine in the urostomy pouch before connecting to a urostomy night bag or leg bag to help minimise the suction effect and allow urine to drain better into the collection system.
- If the bottom of the pouch starts to twist, turn the adapter clockwise or counter clockwise until the pouch lays flat.
- Adapters are not interchangeable between different stoma pouch manufacturer's products.



### Common Stoma Accessories

Stoma accessories are sometimes used together with your pouching system. Each serves a specific function and is used only when indicated. You may use one or more of these products.

Here are a few reasons why you might use a stoma accessory:

- It may help enhance the performance of your pouching system.
   For example, an accessory might help increase wear time or protect your skin.
- It may help solve a problem such as leakage or skin irritation.
- It may help improve your quality of life by avoiding night time trips to the bathroom.

This chart explains a few common stoma accessories.

If	Then Use	Example	Comments for Use**
You want to fill an uneven skin surface or there is a gap between the stoma and the skin barrier opening.	Barrier rings to help protect the skin, fill in uneven skin areas, or as an alternative to paste.		Flat ring can be stretched and shaped, or used in pieces to fill in gaps, creases or folds. Round or oval convex ring helps provide uniform pressure around stoma for customised fit. Apply to clean dry skin or adhesive side of skin barrier on pouching system.
Your skin is slightly irritated* and moist.	Stoma powder to help absorb moisture on the skin.	Askapt  Section Askapt  Sectio	Dust on. Brush off excess powder. Stop using when your skin is no longer weeping. Do not use stoma powder for the prevention of skin irritation or on skin that is red but not moist.
You want to connect to a night drainage bag or leg bag.	Drain tube adapter.		Leave a small amount of urine in urostomy pouch before connecting to a bedside collector or leg bag to help minimise the suction effect and allow urine to drain better into the collection system.
You want added sense of security.	A stoma belt to help secure a stoma pouch. A stoma care nurse may recommend a belt to enhance convexity.		Should be worn around the body in line with the stoma. Can only be used with a pouching system that has belt tabs.

To learn more about these and other stoma accessories you may visit the website or catalogue of your stoma product manufacturer or stoma care nurse.

<sup>\*</sup>Consult your stoma care nurse if experiencing peristomal skin problems \*\*See product specific instructions for use

### Ordering Stoma Product Supplies

When you are in the hospital your healthcare professionals will typically supply your stoma products. Once you are discharged from the hospital, a supplier can provide you with an ongoing supply of stoma products. Stoma products are specialised supplies that are not available through all pharmacies. You may choose to use a DAC (Dispensing Appliance Contractor) or Chemist.

Most stoma supplies are covered by the NHS, though if you are required to pay you will be advised on how to obtain a pre payment certificate. Please note that if your stoma is permanent you will not need to pay prescription costs, speak to your GP regarding an exemption certificate.

There are several considerations when choosing a supplier:

- Would you like to collect your supplies?
- Do you want your products delivered to you straight to your door?
- Or do you need your skin barrier to be cut to size?

### How Much and When to Order

Most people with a stoma place an order and receive their supplies once every month or three months.

Your monthly quantity of stoma supplies is determined primarily by the type of stoma, its location on the body, and the condition of the skin surface surrounding the stoma. It really depends on your specific situation. Your stoma care nurse will advise you on the typical usage and help you with the understanding.

TIP

Maintaining healthy skin around your stoma can help with your stoma product usage. Problems with the skin around the stoma can create difficulty with keeping a pouch in place and can lead to higher product usage and higher costs.





## Practicing Self Care

It is important to care for your body and mind after stoma surgery.

### Maintaining Skin Health

It is important to establish healthy skin cleaning habits to help maintain healthy skin around your stoma. Skin barriers adhere best to clean, dry skin. Get into the habit of cleaning and assessing your peristomal skin each time you change your barrier. Less product is better when caring for the skin around your stoma: for most people, warm water is sufficient for cleaning the skin. Soaps and cleansers are generally not recommended, as they may leave a residue on the skin that can interfere with the adherence of the skin barrier.

It is also important to keep an eye on the condition of your skin. Assess it regularly during pouching changes, looking for signs of rashes, redness, or irritation. Remember, skin irritation is not normal. If you discover red, broken or moist skin around your stoma, seek the assistance of a nurse who specialises in stoma care.

Leakage is one of the main causes of skin irritation, and one way to help prevent this is to ensure the skin barrier of your pouch fits securely around your stoma. Measure your stoma with a stoma measuring guide to ensure the opening in the skin barrier is the size and shape of the stoma. Be sure to fill in any gaps, creases, or folds with stoma accessories if needed.

### Showering

With a urostomy, you can shower just as you did before. Soap and water will not flow into your stoma or hurt it in any way. You may shower with your pouch on or off – the choice is yours. Soap residue can sometimes interfere with how well the skin barrier or adhesive sticks to your skin. So choose a soap or cleanser that is free from all moisturisers, oils, and residue.

## Maintaining Diet and Fluids

For most people, a urostomy has very little effect on diet. To keep your kidneys functioning properly and to help prevent urinary tract infections, you should drink plenty of water each day. If you have any questions about diet or fluids, contact your GP or stoma care nurse.

#### **General Diet Guidelines**

- Drink plenty of water each day to help prevent urinary tract infections
- Eat a balanced diet
- Be aware that eating beetroot will turn your urine a reddish colour — this is temporary, and is no cause for alarm.
   Certain medications can also affect the colour of urine
- Be prepared that asparagus, seafood, nutritional supplements, and some medications may affect the odour of your urine

## Managing Odour

Today's urostomy pouches are made with odour-barrier film, so odour from the urine is contained inside the pouch. You should notice it only when you are emptying or changing your pouch. If you notice odour at any other time, check the pouch seal for leakage.

Some foods such as asparagus and seafood, nutritional supplements, and some medications can cause your urine to have a strong odour. A urinary tract infection can also cause odour. If you notice a change in the odour contact your stoma care nurse.

### Identifying Urinary Tract Infections

People with urinary diversions can develop urinary tract infections. This can lead to kidney problems. If you notice any of these symptoms, contact your GP or stoma care nurse.

### Some warning signs of a urinary tract infection include:

- Dark, cloudy urine
- Strong-smelling urine
- Back pain (where your kidneys are located)
- Fever
- · Loss of appetite
- Nausea
- Vomiting

Do not have your urine dipsticked as this will give false readings.

A specimen of urine may be taken via a catheter by the stoma care nurse or alternatively a clean catch may be used to obtain a urine specimen

### Dealing with Emotions

People who have stoma surgery react with different emotions and responses. Some people express their feelings by talking with friends, family or others who have had similar experiences. Some find reading and learning about their situation works best for them.

Strong and intense emotions should not be kept to yourself. Getting them out into the open, talking about them, and discussing them with your loved ones may help you work through your feelings. If you feel your emotions are affecting your quality of life, consider talking with your GP or a support group. Stoma support groups can be in person or online. Your stoma care nurse may be able to help provide you information about finding support. *You can also learn more about support resources on pages 36-39.* 

### General Care Guidelines

- Empty your pouch when it is 1/3 to 1/2 full of urine.
- Use a urostomy night drainage bag at night (or get up regularly during the night to empty your pouch).
- Change your pouch on a routine basis. You will get more comfortable with this after you learn what works best for you.
- Wear time is based on personal preference, stoma characteristics, and skin barrier formulation.
- If you use soap, make sure it does not contain creams, lotions, or oils that may leave a residue. This can interfere with your skin barrier adhesion.
- Make sure the peristomal skin is clean and dry before applying your skin barrier.
- Verify that no skin is showing between the skin barrier opening and the stoma to help prevent leakage and skin irritation.
- If you wear a two-piece pouching system, try placing the skin barrier on your body in a diamond shape for a smoother fit.
- After you apply your skin barrier, apply gentle pressure for about a minute for best adhesion.
- You can shower with your skin barrier and pouch in place, or you can remove them before showering. Do not have baths without your pouch being applied.
- Removing a pouch from a two-piece system before showering may affect the skin barrier adhesion — it's best to leave the pouch on or remove both the pouch and skin barrier.
- Be sure to assess your peristomal skin on a regular basis to ensure your skin is healthy and to help address any issues in a timely manner.
- If you discover red, broken or moist skin around the stoma, or your pouching system is not staying in place, be sure to see your stoma care nurse.



## Living Daily Life

When your stoma care nurse says it is appropriate, you can resume your normal activities. You will get used to your pouching system and develop a schedule that fits your lifestyle.

## Clothing

After urostomy surgery, many people worry that the pouch will be visible under their clothing. Some people think they will not be able to wear "normal" clothes, or that they will have to wear clothes that are too big for them. You should be able to wear the same type of clothes you wore before your surgery.

In fact, today's pouches are low profile and fit so close to the body, chances are no one will know you are wearing a pouch unless you tell them. Emptying your pouch regularly can also help to avoid a bulge from a pouch that is too full.

The pouch can be worn inside or outside of your underwear. Select the option that is most comfortable for you.

### Returning to Work and Travelling

As with any surgery, you will need some time to recover. Be sure to check with your stoma care nurse before returning to work or starting any strenuous activity. Once you have recovered from the surgery, your urostomy should not limit you. You should be able to return to work or travel just about anywhere. Your stoma care nurse will guide and direct you accordingly.

When you travel, take your stoma supplies with you. It's a good idea to pack more than you think you will need. If you need to buy supplies while travelling, you will find that stoma products are available from select medical or surgical retailers throughout the world.

- When flying, pack stoma supplies in your carry-on bag.
- Check with your airline about restrictions on travelling with liquids, gels, scissors, and aerosols.
- Explore carrying a travel card that has information about your stoma — the Urostomy Association (see page 39) can provide travel cards specifically for a urostomy, in lots of different languages, this can be helpful when communicating with airport security personnel.
- Fasten the seat belt above or below your stoma.
- Store your stoma products in a cool, dry place.

- Know where to contact a local stoma care nurse when travelling.
- Consider using a leg bag if you will be unable to empty your pouch when it is 1/3 to 1/2 full.

## Activity, Exercise, and Sports

When your stoma care nurse says it is appropriate, you may resume your normal activities. A urostomy should not prevent you from exercising or being physically active. Other than extremely rough contact sports or very heavy lifting, you should be able to enjoy the same type of physical activities you enjoyed before your surgery.

People with urostomies are able to swim, water ski or snow ski, play golf, tennis, football, volleyball, hike, sail, or jog just as they did before their surgery. Please be aware that heat and moisture can reduce the wear time of the pouching system. During warm months, and after activity, you should watch how your skin barrier performs.

- Make sure you wear a pouch when swimming and ensure it is emptied before. Empty your pouch before swimming.
- You may need to change your pouch more often if you wear it in a hot tub or sauna.

## Sex and Intimacy

Because urostomy surgery is a body-altering procedure, many people worry about how this procedure will affect their physical and emotional relationship with their partner or spouse. For people who are dating, a big concern is how and when to tell someone about their urostomy. Supportive personal relationships can be major sources of healing after any type of surgery.

Urostomy surgery affects both partners in a relationship and it is something to which both partners must adjust in their own way. Let your partner know that sexual activity will not hurt you or your stoma, though you never want to use the stoma for intercourse. If you have concerns about your emotional adjustment after surgery, be sure to talk with your GP or stoma care nurse.

- Empty your pouch before having sexual relations
- · Sexual activity will not hurt you or your stoma
- An opaque pouch or pouch cover can help hide the pouch contents
- Intimate apparel can hide the pouch and keep it close to your body

### **Impotence**

For some, impotence following surgery can be an issue. This is the inability to get or sustain an erection long enough to ejaculate or climax.

Temporary impotence is not unusual following stoma surgery, so don't think that all hope is lost if, within a couple of months after surgery, you have not begun to have sexual relations. The healing process sometimes takes a long time. It can take up to two years before it is clear whether a person is permanently impotent or whether sexual function will come back. If you are undergoing further

treatment, such as chemotherapy or radiation therapy, this also can affect your sexual desires and ability to have sexual intercourse.

There is a risk that the nerves governing erection and ejaculation can be damaged in surgery. Erection happens when stimuli travel along the nerve pathways. These fibres run close to the rectum. If these fibres are damaged in surgery, the ability to have an erection can be wholly or partially lost. Ejaculation is also dependent on the nervous system. These pathways are vulnerable in surgery too. Surgery for bladder cancer is extensive and therefore, can be more damaging. Impotence is a highly complex phenomenon. It can occur in people of any age and for many reasons, which are not a direct result of

In the case of permanent impotence, there are possibilities for help. Over the past few years, medical science has developed surgical techniques that may help some people, including people with stomas. This type of surgery is highly specialised. If you are interested, the first step is to talk to your stoma care nurse, surgeon or GP.

### Vaginal dryness

surgery.

Another common issue is vaginal dryness, making intercourse difficult and uncomfortable. Penetration may be uncomfortable because of tissue scarring following removal of the bladder.

Not every person has the same type of surgery, and many of these problems are related to specific types and extent of surgery.

There are solutions. For dryness, a lubricating jelly can be used. If your partner wears a lubricated condom, this may help.

It is important to remember that dryness may be a side effect of a medication you are taking, and your stoma care nurse will be able to provide recommendations.

If penetration is painful, consider trying alternate sexual positions.

TIP

Referral to a physiotherapist may also be a helpful option. A physiotherapist can teach exercises that strengthen the pelvic floor, which is important for satisfying intercourse.

### Parenthood

If you are considering having children, you will be happy to know that after a satisfactory recovery it is usually still possible for a person who has a stoma to have children. Many people have become parents after having urostomy surgery. If you have questions about getting pregnant with a urostomy, be sure to consult with your urology consultant or your stoma care nurse.

It is very important that a woman with a urostomy considering getting pregnant consults with her Consultant Urologist first, as they will need to be carefully monitored throughout and possibly during labour.

Also note that urine testing for pregnancy will give false positives, contact your GP or stoma care nurse who will be able to arrange a blood test.



# Relationships and Finding Support

Today's stoma pouches are designed to be discreet. No one ever needs to know that you are wearing one.

It is up to you to decide who you will tell and how you will go about it. Be open and honest with those people you think need to know, and say nothing to others unless you think it is important. Remember that those around you will take cues from you. If you are comfortable, confident and straightforward about your health, people are generally accepting and unaffected.

### Talking with Others

Your stoma is part of your life. It is also part of your family's and your partner's life. Some people find it useful if their partner or a family member knows how to change and empty your pouch in an emergency. Bringing those close to you into the details of your stoma care can be great for your relationship and your peace of mind.

Your friends, relatives, and co-workers may also be concerned about you, especially if you have been ill over a period of time. When they see you looking better, they will not only be pleased, but they may want to know what type of treatment you had. It is, of course, for you to determine what details you reveal to others.

Here are some tips that might help if you are thinking about speaking with others about your stoma.

- If you are speaking to children or grandchildren about your stoma
  or your stoma surgery, there are age appropriate books available
  from stoma manufacturers to help with these questions.
  Honest and simple explanations are important, and they help form
  the basis of good relationships with younger family members. How
  much or little you decide to tell them, and whether you decide to
  show your stoma to them, depends on the nature of your family as
  well as their age.
- If you are speaking to people who are not as close to you, one way to satisfy their curiosity is to explain you had a serious illness that became a threat to your life. Because of that, you had major surgery and now wear a pouch. With an explanation like that, there are very few other questions that can be asked unless you want to offer more information.

• If you are in a new romantic relationship, it is worth discussing your situation before the relationship gets physical. Plan ahead by rehearsing a short explanation to yourself. Start with the fact that you had a serious illness, which had to be treated surgically. The result is that you wear a pouch. Once you practice how to talk about your situation, it will be easier to find a comfortable time to explain it to a potential new partner.

### When to Call Your Stoma Care Nurse

Call your stoma care nurse if you notice any of the following problems listed below:

- Any sign or symptoms of a urinary tract infection (see page 27)
   You can also contact your GP.
- Skin irritation.
- Urine crystals on or around your stoma.
- Recurrent leaks under your pouching system or skin barrier.
- · Warty, discoloured skin around your stoma.
- Excessive bleeding of your stoma.
- Blood in your urine.
- A bulge in the skin around your stoma.
- A stoma that appears to be getting longer.

## Resources and Organisations

Your stoma care nurse will be a very important resource for you in the days ahead. You also have ongoing access to online information or printed educational materials such as:

### **Stoma Learning Centre**

www.hollister.co.uk/en-gb/ostomycare/ostomylearningcenter

Whether you are about to have surgery, have had your stoma for years, or want to learn how to keep your skin healthy, we are here to help with information and education so you can live your best life with a stoma. This section of the website includes articles and videos on a wide range of topics, including:

- Understanding a stoma
- Living with a stoma
- Maintaining healthy skin
- Using stoma products

# Hollister Incorporated YouTube Channel www.youtube.com/hollisterincorporated

View a variety of how to and lifestyle videos. Also includes interviews and tips from people living with stomas.

# Peristomal Skin Assessment Guide for Consumers psag-consumer.wocn.org

Take your skin health into your own hands with the Peristomal Skin Assessment Guide for Consumers. It is a free, easy-to-use, digital tool designed to help teens and adults living with a stoma identify common skin problems, provide next steps for care or management, and prompt when it is appropriate to seek support from a stoma care nurse.



Stoma support groups are available to people who have had stoma surgery. Here, you can interact with others who are facing many of the same challenges. The ability to discuss issues with someone who understands what you are experiencing can be very beneficial.

### **Lifestyle Series and Care Tips**

Available from your clinician or for PDF download at: www.hollister.co.uk/en-gb/ostomycare/educationaltools

- The "Living with a Stoma" Series provides information on lifestyle related topics such as diet, travel, sports, and fitness
- "Caring for Your Loved One with a Stoma" Guide —
   provides information and support for your loved one(s), in helping
   you live life to the fullest after stoma surgery
- "Routine Care of Your Stoma" Care Tip provides information on how to care for a stoma



### **Urostomy Association**

The Urostomy Association is a UK registered national charity representing the interests of people with a urinary diversion.

Urostomy Association offers support, reassurance and practical information to anyone who may be about to undergo, or who has already had surgery resulting in a urostomy, continent urinary pouch or a neo-bladder. Appropriate support and information is also offered to families and carers both before and after surgery.

Tel: 01386 430140

Email: info@urostomyassociation.org.uk Web: www.urostomyassociation.org.uk

### Glossary

#### **Convex skin barrier**

A skin barrier that is not flat but curves outward toward the peristomal skin to increase the depth of the skin barrier.

#### **Cut-to-fit skin barrier**

A skin barrier that can be cut to the right size and shape for the stoma.

#### **Extended wear skin barrier**

A skin barrier that contains special additives that may achieve a stronger adherence to the skin and may be more resistant to breakdown.

### **Flange**

The plastic ring that is used to connect the two pieces of a two-piece pouching system together.

#### Flat skin barrier

A skin barrier that has a level or even surface area that adheres to the skin.

#### Infused skin barrier

A skin barrier option that is infused with an additional ingredient, such as ceramide. Also provides adhesion, absorption, and erosion resistance.

### One-piece pouching system

A skin barrier and pouch that are a single unit.

### **Ostomy**

A surgically created opening in the gastrointestinal or urinary tract. Also known as a stoma.

### Peristomal skin

The area around the stoma starting where the skin/stoma meet and extending outward to the area covered by the skin barrier.

#### **Pouch**

The bag that collects output from the stoma.

### **Pouching system**

Includes the skin barrier and the pouch. Options are a one-piece or two-piece pouching system.

#### Pre-sized skin barrier

A barrier opening that is already cut to the proper size of the stoma.

#### Skin barrier

The portion of the pouch that fits immediately on the peristomal skin. It protects the skin around the stoma and holds the pouch in place. Sometimes called a wafer

#### Standard wear skin barrier

A skin barrier that provides a gentle adhesion to the skin but may be less durable than an extended wear barrier. Sometimes called regular wear.

#### **Stoma**

A surgically created opening in the gastrointestinal or urinary tract. Also known as an ostomy.

### Two-piece pouching system

A skin barrier and pouch that are two separate pieces.

### **Urostomy**

A stoma created to divert urine.

### **Urostomy pouch**

Pouch with a drain tap at the bottom so urine can be emptied.

#### Wear time

The length of time a pouching system can be worn before it fails. Wear times can vary but should be fairly consistent for each person.

For more information or for FREE samples, contact us on:

**UK:** 0800 521 377

email: samples.uk@hollister.com

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To find out more about how to maintain healthy skin, visit **www.hollister.co.uk** 



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