

# Understanding your ileostomy



Ostomy Care Healthy skin. Positive outcomes.



The information provided in this guide is not medical advice and is not intended to substitute for the recommendations of your personal physician or other 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

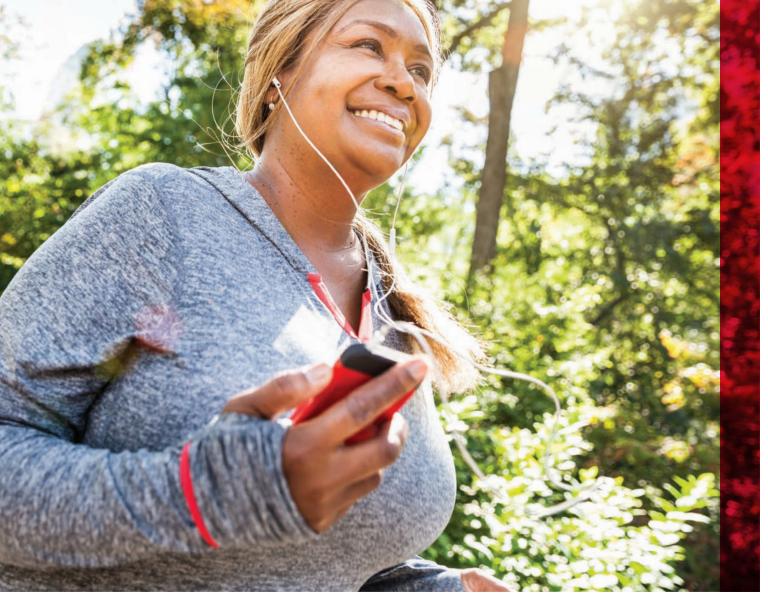


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If you are about to have — or recently had — ileostomy surgery, this guide can help you understand what it is and how to manage it. The more you know, the more you can ease some of the concerns you may have about living with an ileostomy. It is important to remember that you are not alone. Every year, thousands of people have ileostomy surgery. For some, it is a lifesaving event.

It may be performed to repair an injury, or remove a tumor. 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.



## Understanding Your Body

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

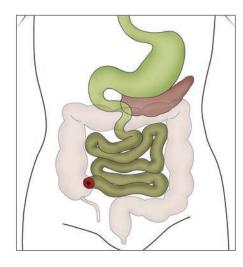
When you chew your food and swallow it, the food goes down your esophagus into your stomach. Stomach acids and chemicals called enzymes break down the food until it becomes a liquid mixture.

Liver Stomach Gallbladder Large Intestine Small Intestine Anus From your stomach, the liquid food mixture goes into your small

intestine, where most digestion takes place. Vitamins, minerals, proteins, fats, and carbohydrates are all absorbed into your body through your small intestine. Any food that is not absorbed in the small intestine goes into the large intestine (colon) as liquid waste or stool. Your large intestine absorbs water from your stool so it becomes more formed as it moves through. It also stores your stool until you have a bowel movement. When you have a bowel movement, stool and gas go from your colon into your rectum, and then out of your body through your anus. A muscle in your anus, called the anal sphincter, allows you to control when to have a bowel movement.

### What Is an Ileostomy?

An ileostomy is a surgically created opening (stoma) to eliminate waste out of the body after a section of the small intestine, or the entire large intestine (colon), has been removed or bypassed.



With an ileostomy, waste is eliminated through the stoma instead of through the anus. Because there is no sphincter muscle to voluntarily control when to eliminate waste, it collects into a drainable stoma pouch system. Stoma pouch systems are explained further on page 11.

### How an lleostomy Is Created

To construct an ileostomy, your surgeon brings part of the small intestine (ileum) through the abdominal wall. This new opening in your abdominal wall is called a stoma (or ostomy).

An ileostomy may be temporary or permanent, depending on the medical reason for the surgery. In some cases where the anal sphincter is intact but a portion of the bowel needs to rest and heal, a temporary stoma is created. In a procedure often referred to as creating a j-pouch (ileal pouch anal anastomosis or ileal reservoir), the colon is removed and the small intestine is used to create a reservoir pouch that is placed in the pelvis and connected to the anus.

### The Stoma

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



**End Stoma** 

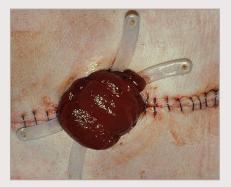
- Is pink or red in color and is slightly moist
- Is not painful
- Bleeds easily when rubbed or bumped (for example, when washing), but should resolve quickly

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 can be an important part of preparing for surgery. Generally, the stoma for an ileostomy is placed in an area just below your waist between your navel and hip on the right side of your body (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 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.

- Your stoma will probably be swollen. It may take several weeks or months for the swelling in your stoma to resolve.
- The stool from an ileostomy can vary. It typically starts out as a watery liquid in consistency, and then may become thicker as you resume a regular diet.
- The digestive enzymes make the output from your stoma very corrosive, so protecting the skin around your stoma is extremely important.
- If you have a temporary stoma, it may be a loop or double barrel stoma. A loop ileostomy may have a supporting device (called a rod, or bridge) that is normally removed a few days after surgery — sometimes sooner. Be sure to remind your stoma care nurse about this if it has not been removed after this time.



Loop Stoma with Bridge



Double Barrel Stoma

### 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 pouching system 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 22.



### 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

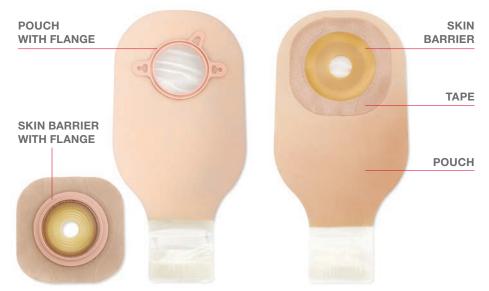
Stoma pouching systems consist of two main parts:

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

#### **Two-Piece Pouch**

**One-Piece Pouch** 

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



The type of pouch most commonly used with an ileostomy is a drainable pouch like the ones shown here. They either have a clamp or an integrated closure (shown), and should be emptied when they are about 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. Both tape and tapeless options are available. Tape-bordered pouches offer some people an enhanced sense of security, while tapeless products remain an option for people with sensitive skin or allergies to adhesive products.

> 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?

TIP

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 newer 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.

#### **Closure Systems**

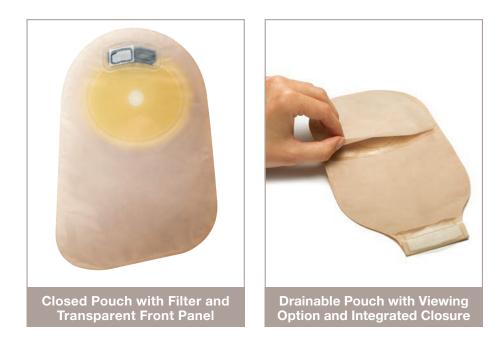
The type of pouch most commonly used with an ileostomy is a drainable pouch. When using a drainable pouch, you have two options for containing stomal output. Typically the pouch will have an integrated closure system (a closure mechanism that is built into the pouch). In some scenarios you may use a bung or an integrated closure.



**Drainable Pouch with Integrated Closure** 

#### **Filters**

Some pouches include filters that help to minimise gas from building up, so the pouch does not inflate like a balloon. The filter slowly lets the gas out, but not the odour.



#### **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.
- Viewing option (available on one-piece system) offers the discretion of an opaque panel and the confidence of a clear pouch all-in-one. When the opaque flap is lifted, the stoma and output can be observed clearly and privately.



### 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 eliminating odour

This chart explains a few common stoma accessories.

lf	Then Use	Example	Comments for Use**
You want to help ensure a good seal around the stoma and skin barrier opening	Paste as caulk.	Adapt	This accessory is not an adhesive or glue. Too much paste can interfere with a good skin barrier seal. Apply the paste to the inner edge of the skin barrier, next to the opening where the stoma will be.
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.	996 Mara Para Mara Para Para Mara Para Para Mara Para Para Mara Para Para Mara Para Para Para Para Para Para Para	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 reduce odour when you empty or change your pouch, or you want to more easily empty the contents of your pouch	Lubricating deodorant to help reduce odour and make emptying easier.	Adapt Oraciant	Add approximately one teaspoon or one packet to your new pouch, then rub to coat the inside of the pouch. Avoid filter. Add after every time you empty your pouch.
You want added sense of security	A stoma belt may help to 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 catalog of your stoma product manufacturer or supplier.

\*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 stoma care nurse will typically supply your stoma products. Once you are discharged from their care, a supplier can provide you with an ongoing supply of stoma products.

Stoma products are specialised supplies that are available through 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.

There are several considerations when choosing a supplier:

- Do you want to work with a national or regional medical equipment supplier who can deliver your supplies, or do you prefer to pick up supplies at a local pharmacy?
- Do you already have a supplier that serves your other medical device needs?

### How Much and When to Order

Most people with an 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 usages. 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, 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 an ileostomy, 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.

If you use a two-piece pouch, you may find it convenient to switch to a different pouch for the shower so that the pouch you wear stays dry. If you choose to remove the pouch while showering, it's suggested to also remove the skin barrier to prevent exposing it to too much moisture.

### Maintaining Diet and Fluids

Immediately after surgery, you may be on a restricted diet. To promote optimal healing and help you regain weight you may have lost either before or after your operation, it is vital to re-establish a healthy diet. After you recover from surgery, you should be able to go back to your usual diet unless you are otherwise instructed. However, it is important to know that certain foods may impact the odour or consistency of your output. *Learn more on page 25.* 

### **General Diet Guidelines**

- Eat a balanced diet
- Eat slowly and chew your food well
- Drink plenty of water each day
- Add different foods to your diet gradually, to see how those foods agree with your system

### Be aware of food blockage

Swelling may occur in the bowel, which may narrow it. This usually happens in the first four to six weeks after surgery, and can make some foods difficult to digest. Cramping and abdominal pain along with watery diarrhoea or no stool output may indicate a food blockage or obstruction. If you suspect you might have an obstruction or blockage, contact your healthcare provider immediately.



### Be aware of diarrhoea

With a ileostomy, you can still get diarrhoea for a variety of reasons. If your output changes to mostly fluid output and you experience a marked increase in the volume of drainage, you may have diarrhoea. During this time, avoid foods and beverages that cause loose stools. If you have diarrhoea, you may need to drink more fluids to prevent dehydration. Signs of dehydration include dry mouth, dark urine, reduced urine, weakness, muscle cramps, and feeling faint. If the diarrhoea persists, call your stoma care nurse.

### Foods that may thicken your stool include:

- bananas
- cheese
- marshmallows
- noodles (cooked)
- pretzels

- smooth peanut butter (not chunky)
- white pasta
- white rice
- white toast
- yogurt

### Managing Odour and Gas

Today's ileostomy pouches are made with odour-barrier film, designed to contain odour from output 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.

Emptying your pouch regularly can help reduce the risk of leakage, and therefore odour. Empty your pouch when it is 1/3 to 1/2 full of discharge or gas (typically, four to six times per day). The best time to change your pouching system is in the morning before you have had anything to eat or drink.

As your bowel begins to function after surgery, you may notice gas in your pouch. The amount of gas varies. If you had excessive gas before your surgery, you will likely have similar experiences after your surgery.

It is normal to have gas, but drinking and eating some foods can certainly produce more gas. It can also be the result of swallowing air. Drinking carbonated beverages, smoking, chewing gum, and chewing with your mouth open can all increase the amount of air you swallow.

### Foods and beverages that may increase odour and gas:

- asparagus
- beans
- beer
- cabbage family
- carbonated beverages

fish

- eggs (hard boiled)
  - spiced foods

milk products

melon

onions

TIP 🖌

Most pouches in the UK have a integrated filter. The filter slowly lets the gas out of the pouch, but not the odour. It also prevents gas from building up, so the pouch does not inflate like a balloon. Filters work best with a more formed discharge, but can be used with other output consistencies.

### **Taking Medication**

Some medications or nutritional supplements may change the colour, odour, or consistency of your stool. Even non-prescription medications like antacids, can cause changes such as constipation or diarrhoea. Some medications may not be completely absorbed when you have had your colon removed. These types include:

- Enteric-coated
- Timed-release
- Extended or sustained release

Before taking any medication, it's a good idea to ask your stoma care nurse or pharmacist.

### **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 stoma care nurse 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 stool or gas
- 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 water will not harm or flow into your stoma
- 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 ileostomy 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, some 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 ileostomy 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 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



### Activity, Exercise, and Sports

When your stoma care nurse says it is appropriate, you may resume your normal activities. An ileostomy 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 ileostomies are able to swim, water ski or snow ski, play golf, tennis, volleyball, softball, 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. For an extra sense of security you may consider adding barrier extenders to the edges of your skin barrier before swimming.

- Empty your pouch before swimming
- You may add barrier extenders to the edges of your skin barrier 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 ileostomy 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 ileostomy. Supportive personal relationships can be major sources of healing after any type of surgery.

Ileostomy 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 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

### 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 ileostomy surgery. If you have questions about getting pregnant with an ileostomy, be sure to ask your stoma care nurse.



## 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 and dolls 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:

- Skin irritation
- Recurrent leaks under your pouching system or skin barrier
- Excessive bleeding of your stoma
- Blood in your stool
- A bulge in the skin around your stoma
- Persistent diarrhoea
- Diarrhoea with pain and/or vomiting
- A stoma that appears to be getting longer

### **Resources and Organisations**

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

#### **Stoma Learning Center**

*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 an 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 ostomies.

### 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

#### **Ileostomy Association**

Ileostomy and Internal Pouch Association, known as IA, is a registered charity supporting people living with an ileostomy or internal pouch, their families, friends and carers.

Freephone: 0800 018 4724 Email: info@iasupport.org Web: www.iasupport.org



Ileostomy & Internal Pouch Association

### Glossary

### **Closed pouch**

A pouch without a spout or clamp. It must be removed to be emptied.

### **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.

### **Drainable pouch**

A pouch with an opening at the bottom. An integrated closure or clamp is used to keep the pouch closed until it is time to empty it.

### 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.

#### Filter

Releases gas but not odour from a pouch.

### 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.

#### lleostomy

A surgically created opening in the small intestine.

### Infused skin barrier

A newer 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 pouching system that fits immediately around the stoma. It protects the skin around the stoma and holds the pouching system 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.

### 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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#### www.hollister.co.uk



To find out more about how to maintain healthy skin,

visit www.hollister.co.uk

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