

Understanding

Your Urostomy



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 healthcare professional. 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 Ostomy Surgery

“ As a person who lives with an ostomy, I understand the importance of support and encouragement in those days, weeks, and even months after ostomy 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 ostomy 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 ostomy, and back into your life.*

— BROCK M., LIVING WITH AN OSTOMY SINCE 2000





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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. 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. 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 specializes in ostomy care.

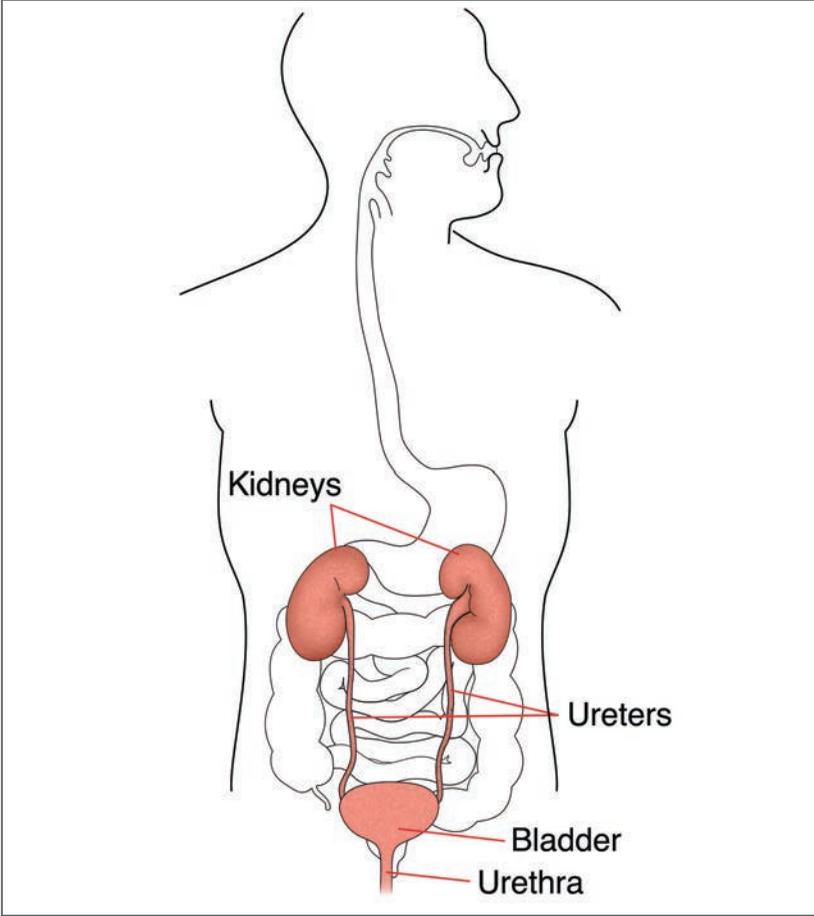
**A glossary is included at the back of this guide to help with some terms with which you may not be familiar.**



# Understanding Your Body

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

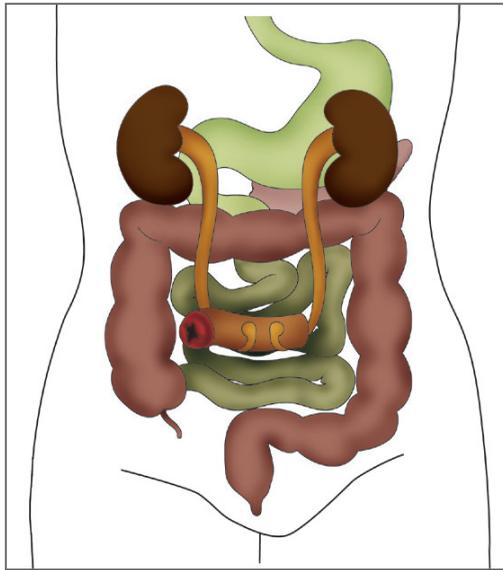
It begins with the kidneys. Urine or liquid waste flows from the kidneys through two narrow tubes called ureters and collects in the bladder.



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 – is a surgically created opening (ostomy) to drain urine out of the body after the bladder has been removed or bypassed.



With a urostomy, urine is eliminated through the ostomy instead of through the urethra. Because there is no sphincter muscle to voluntarily control when to urinate, urine collects into an ostomy pouching system with a drain tap at the bottom. ***Ostomy pouching 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 inches 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:



**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 ostomy pouching 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 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 ostomy 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 ostomy, 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.

## Right after surgery...

- Your stoma will probably be swollen. It may take several weeks or months for your stoma to shrink to its permanent size.
- You may 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 2 weeks depending on the surgeon's preference. Do not cut or remove these stents on your own.
- Urine will begin flowing from your stoma immediately after surgery. At first, the urine may have a slight reddish color. After a few days, the urine should return to its normal color.
- You may see mucous in your urine as the urine collects in your pouch. The mucous 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 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.

If you discover red, broken, or moist skin around your stoma, seek the assistance of a healthcare professional. 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.***



Healthy peristomal skin should look like this.



Not like this.



# Ostomy Products Explained

There are many different types of ostomy pouching systems. The pouching system used by your healthcare team in the hospital will be best suited to help you recover from ostomy surgery.

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

## Ostomy Pouching Systems

Ostomy pouching systems consist of two main parts:

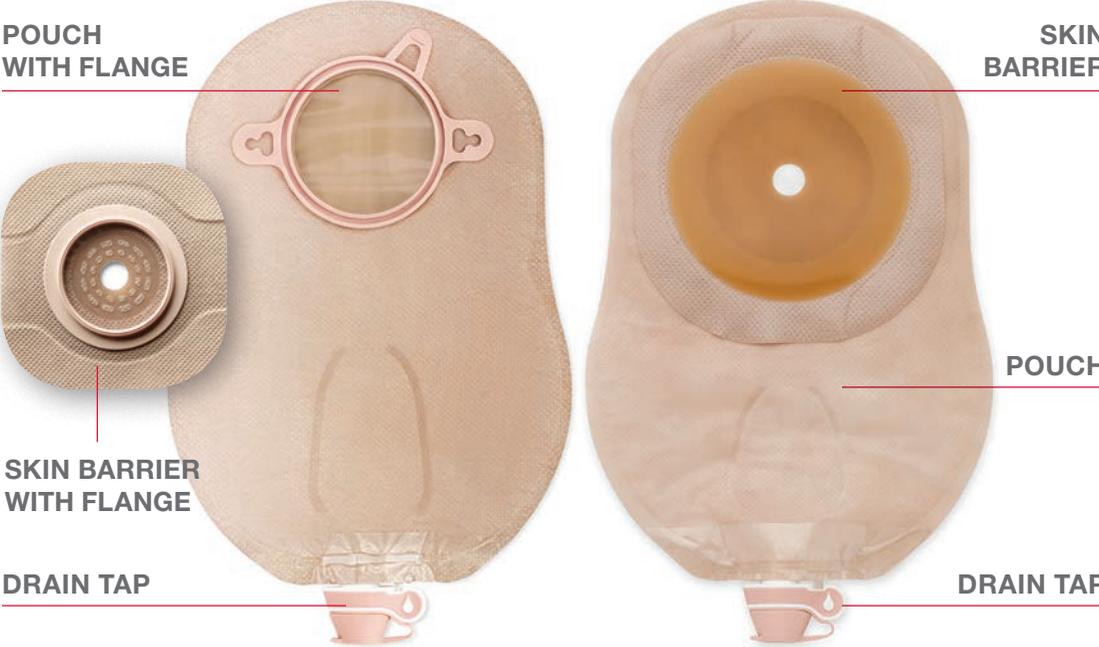
- The **skin barrier (or wafer)** should fit immediately around your stoma. It protects your skin and holds your pouching system in place.
- The **pouch** collects output from the stoma. Pouches come in a variety of options for different needs and ostomy types.

### 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 pouching system 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 pouching system and the *formulation* of the skin barrier go hand in hand. Your pouching system 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 pouching system 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 pouching systems offer some people an enhanced sense of security, while tapeless products 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 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

Ostomy pouches come in different sizes and with different features available to suit your needs. Here are some of the most common features for ostomy 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 valve that is twisted or a plug that is pulled out to allow emptying. Some valves, 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 ultra-clear, transparent 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.



Opaque Panel with Viewing Option

### **Multi-Chamber Design**

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

### **Anti-Reflux Valve**

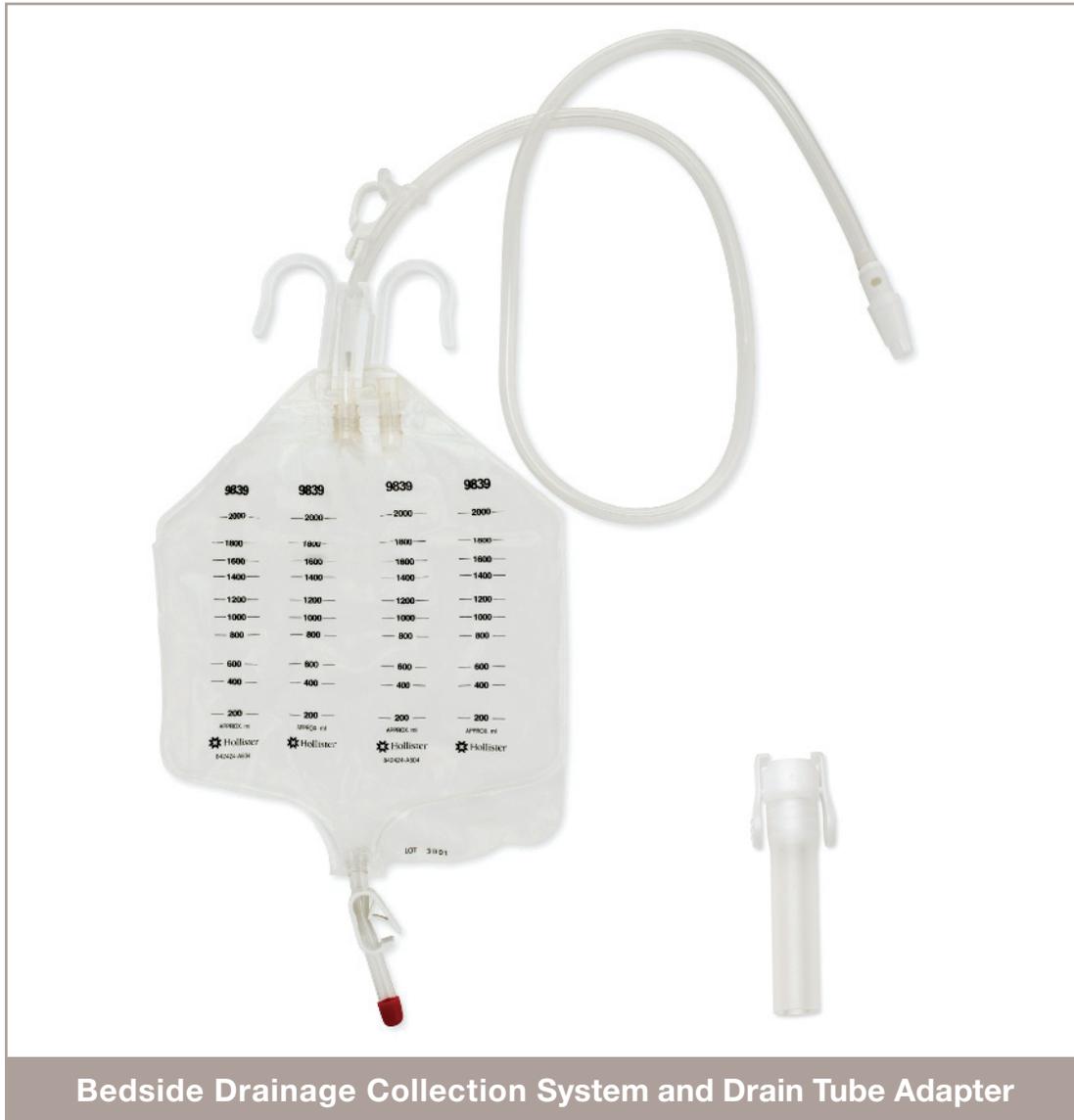
Part of the multi-chamber design, this appears as a curved line that runs across the center of the pouch. An anti-reflux valve in the pouch helps minimize the backflow of urine. This also keeps urine from refluxing to the top of the pouch and eroding the skin barrier, which is a critical component that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



Urostomy Pouch with Transparent Front Panel, Multi-Chamber Design, and Anti-Reflux Valve

## **Night Time Pouching 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 bedside drainage collector, which allows the urine to flow into a bedside collector while they sleep rather than taking trips to the bathroom to empty their pouch. You can connect your urostomy pouch to a bedside drainage collector by using a urostomy drain tube adapter.



Ostomy 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 an ostomy accessory:

Tips when using urostomy drain tube adapters:

- Leave a small amount of urine in the urostomy pouch before connecting to a bedside collector or leg bag to help minimize 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 ostomy pouch manufacturer's products.

- 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 restroom

This chart explains a few common ostomy accessories.

If	Then Use	Example	Comments for Use**
You want to help ensure a good seal around the stoma and skin barrier opening	Paste as caulk.		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 customized 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.		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 bedside drainage collector 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 minimize the suction effect and allow urine to drain better into the collection system.
You want added sense of security	An ostomy belt to help secure an ostomy pouch. A healthcare professional 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.
An additional layer of security for your skin barrier that moves as you move	Barrier extenders to create a custom frame around your skin barrier.		Thin, flexible strips help conform to uneven body contours. May help increase wear time by reducing barrier edge lifting.

To learn more about these and other ostomy accessories you may visit the website or catalog of your ostomy product manufacturer or supplier.

\*Consult your healthcare professional if experiencing peristomal skin problems

\*\*See product specific instructions for use

## Ordering Ostomy Product Supplies

When you are in the hospital or when you are receiving care from a home health service, your healthcare professionals will typically supply your ostomy products. Once you are discharged from their care, a supplier can provide you with an ongoing supply of ostomy products.

Ostomy products are specialized supplies that are not available through all pharmacies. You may choose to use mail order supply companies or purchase through a local retailer. Many ostomy supplies are covered by private insurance plans, military benefits, Medicare, and Medicaid. Check with your carrier to find out your level of coverage and if you must use a specific supplier.

There are several considerations when choosing a supplier:

- Do you want to work with a national or regional durable medical equipment (DME) supplier who can mail your supplies, or do you prefer to pick up supplies at a local pharmacy or DME supplier?
- Can the supplier bill your insurance in-network to minimize your out-of-pocket expense?
- Do you already have a DME supplier that serves your other medical device needs?

If you do not have insurance, or are looking to get products that are outside of your insurance coverage, it is still possible to purchase ostomy products from some suppliers.

***Hollister Secure Start services offer free dedicated ostomy support, and can help you to find a supplier who works with your insurance. Learn more on pages 36-37.***

## How Much and When to Order

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

Your monthly quantity of ostomy supplies is determined primarily by the type of ostomy, its location on the body, and the condition of the skin surface surrounding the stoma. It really depends on your specific situation. Medicare has established monthly “usual maximum quantities” that provide guidance on the maximum amount of various products to accommodate most individuals. Private insurers are not required to follow the Medicare usual maximum quantities but many of them do—or at least use Medicare’s quantities as a guide to establishing their own.

### TIP

Maintaining healthy skin around your stoma can help to minimize your ostomy product costs. Problems with the skin around the stoma can create difficulty with keeping a pouching system 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 ostomy 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 specializes in ostomy 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 pouching system 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 ostomy accessories if needed.

## Bathing or Showering

With a urostomy, you can shower or bathe just as you did before. Soap and water will not flow into your stoma or hurt it in any way. You may shower or bathe with your pouching system 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 moisturizers, oils, and residue.

If you use a two-piece pouching system, 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 or bathing, it's suggested to also remove the skin barrier to prevent exposing it to too much moisture.

## 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, check with your healthcare professional, ostomy care nurse, or a dietitian.

### General Diet Guidelines

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

## Managing Odor

Today's urostomy pouches are made with odor-barrier film, so odor from the urine is contained inside the pouch. You should notice it only when you are emptying or changing your pouch. If you notice odor 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 odor.

## 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 healthcare professional or your ostomy 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

Your healthcare professional may take a urine sample to help identify a possible urinary tract infection. Urine samples for laboratory testing should be obtained from a fresh pouch or a catheterized sample; never from an existing pouch or bedside bag.

## Dealing with Emotions

People who have ostomy 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 healthcare professional or a support group. Ostomy support groups can be in person or online. Your ostomy 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
- Change your skin barrier 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 or bathe with your skin barrier and pouch in place, or you can remove them before bathing — 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 healthcare professional or ostomy care nurse



Living

Daily Life

When your healthcare professional 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 Traveling

As with any surgery, you will need some time to recover. Be sure to check with your healthcare professional 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 healthcare professional will guide and direct you accordingly.

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

- When flying, pack ostomy supplies in your carry-on bag
- Check with your airline about restrictions on traveling with liquids, gels, scissors, and aerosols
- Explore carrying a travel card that has information about your ostomy — this can be helpful when communicating with airport security personnel
- Fasten the seat belt above or below your stoma
- Store your ostomy products in a cool, dry place
- Know where to contact a local ostomy care nurse when traveling
- 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 healthcare professional 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, 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. Also, you may want to add additional tape or barrier extenders to the edges of your skin barrier before swimming.

- Empty your pouch before swimming
- You may add tape or 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 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 healthcare professional or ostomy 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 urostomy surgery. If you have questions about getting pregnant with a urostomy, be sure to ask your healthcare professional or your ostomy care nurse.



## Relationships and Finding Support

Today's ostomy pouching systems 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 ostomy.

- If you are speaking to children or grandchildren about your ostomy or your ostomy surgery, there are age appropriate books and dolls available from ostomy 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 Ostomy Care Nurse

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

- Any sign of urinary tract infection (*see page 27*)
- Skin irritation
- Urine crystals on or around your stoma
- Recurrent leaks under your pouching system or skin barrier
- Warty, discolored 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

## Hollister Secure Start Services

You may have questions about your ostomy, how to care for your stoma, and how to keep living the life you want to live, but you don't have to figure it out on your own. Hollister Secure Start services offer FREE dedicated ostomy support for as long as you need it, regardless of the brand of products you use.

When you choose to join Hollister Secure Start services, you'll be matched with a Consumer Service Advisor who is ready to help you find solutions to the challenges you may face living with an ostomy. We're here to help with:

- **Finding the right products:** Whether you recently had ostomy surgery or are just looking for more options, we can help.
- **Sorting out insurance coverage for products:** Based on your insurance plan, we can explain your options and help you determine whether an ostomy product, regardless of brand, is covered, as well as the allowable quantities.
- **Identifying supplier options:** We'll provide you with information about suppliers who accept your insurance and who can provide you with your requested product. We'll support you with the supplier selection of your choice.
- **Resources and education:** If you request a Hollister Secure Start introductory kit, the kit may include educational materials, product samples, and guides for use. We can also help you navigate the latest lifestyle, product, and clinical information available online at [www.hollister.com](http://www.hollister.com).
- **Accessing a nurse for clinical product guidance:** While your healthcare professional is your source of medical information, we have nurses available to answer questions over the phone related to ostomy products.
- **Community resources:** Hollister Secure Start services has longstanding relationships with a variety of organizations to connect you with people, knowledge, and tools to help support the life you want to live.

***To learn more about how Hollister Secure Start services can support you, please call us at 1.888.808.7456 or visit [www.securestartservices.com](http://www.securestartservices.com).***

## Resources and Organizations

Your healthcare professional and your ostomy 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:

### Ostomy Learning Center

[www.hollister.com/ostomylearningcenter](http://www.hollister.com/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 ostomy. This section of the website includes articles and videos on a wide range of topics, including:

- Understanding an ostomy
- Living with an ostomy
- Maintaining healthy skin
- Using ostomy products

### Hollister Incorporated YouTube Channel

[www.youtube.com/hollisterincorporated](http://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](http://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 an ostomy identify common skin problems, provide next steps for care or management, and prompt when it is appropriate to seek support from a wound, ostomy and continence (WOC) nurse.



Ostomy support groups are available to people who have had ostomy 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.

### Hollister Secure Start Services

1.888.808.7456 | [www.securestartservices.com](http://www.securestartservices.com)

### United Ostomy Associations of America, Inc. (UOAA)

1.800.826.0826 | [info@uoaa.org](mailto:info@uoaa.org) | [www.ostomy.org](http://www.ostomy.org)

### Crohn's & Colitis Foundation of America, Inc. (CCFA)

1.800.932.2423 | [www.ccfa.org](http://www.ccfa.org)

### Colon Cancer Coalition (CCC)

1.952.378.1237 | [www.coloncancercoalition.org](http://www.coloncancercoalition.org)

### Friends of Ostomates Worldwide-USA (FOW-USA)

1.502.909.6669 | [www.fowusa.org](http://www.fowusa.org)

### Youth Rally

[www.youthrally.org](http://www.youthrally.org)

### Lifestyle Series and Care Tips

Available from your clinician or for PDF download at:

[www.hollister.com/ostomyresourcesforyourpatients](http://www.hollister.com/ostomyresourcesforyourpatients)

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

# 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 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.

## **Urostomy**

An ostomy created to drain 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.

## **WOC (wound ostomy continence) nurse**

A nurse with additional education who specializes in ostomy care.

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