



Hollister
Education™

Understanding Your Urostomy





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 booklet 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 MASTERS
TORONTO, CANADA

The information provided in this booklet is not medical advice and is not intended to substitute for the recommendations of your personal physician or other healthcare professional. This booklet should not be used to seek help in a medical emergency. If you experience a medical emergency, seek medical treatment in person immediately.

A photograph of a middle-aged couple walking outdoors. The woman, on the left, has short, curly grey hair and is smiling broadly. She is wearing a white ribbed polo shirt and a brown shoulder bag. She is holding a black camera. The man, on the right, has short blonde hair and is wearing sunglasses and a light blue button-down shirt. He is also smiling and looking towards the woman. The background is slightly blurred, showing green foliage and a building. The entire image is overlaid with a large, diagonal red graphic that covers the top-left and bottom-right portions of the frame.

If you are about to have — or have recently had — urostomy surgery, this booklet 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 booklet is provided to you by Holister Education. It complements information given to you by your healthcare professional, and your Wound, Ostomy, Continence (WOC) nurse, or Enterostomal Therapist (ET) nurse – a nurse who specializes in ostomy care.



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

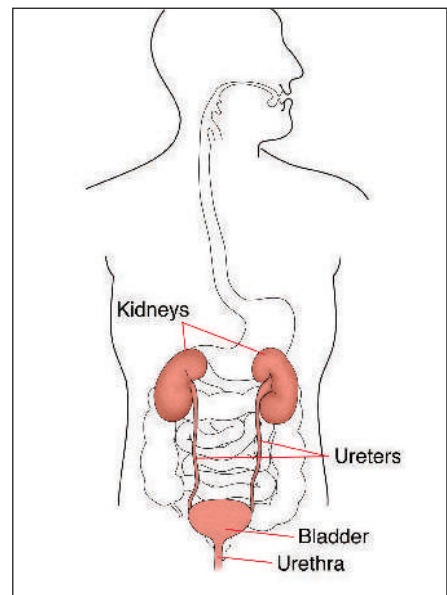
Before your surgery

Determining where the stoma will be placed on your abdomen is a very important part of preparing for surgery. Generally, an ileal conduit stoma (urostomy) is located on the abdomen in what is called the right lower quadrant. This area is located just below your waist, to the right of your navel – or belly button. The stoma for a colon conduit is usually located in the left lower quadrant.

Before your surgery, your WOC/ET nurse and your surgeon will determine the best location for your stoma. Ideally, the stoma should be placed on a smooth skin surface and should be located where you can see the stoma easily and take care of it yourself.

The urinary system

The human urinary system begins with the kidneys. The kidneys are two “bean shaped” organs located just above the waistline, toward the back. 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 (also known as an ileal conduit stoma) is a surgically created opening created to drain urine. A urostomy allows urine to flow out of the body after the bladder has been removed or bypassed. A urostomy may also be called a urinary diversion. When a person has a urostomy, urine is no longer eliminated through the urethra. Instead, it is eliminated through the urostomy.

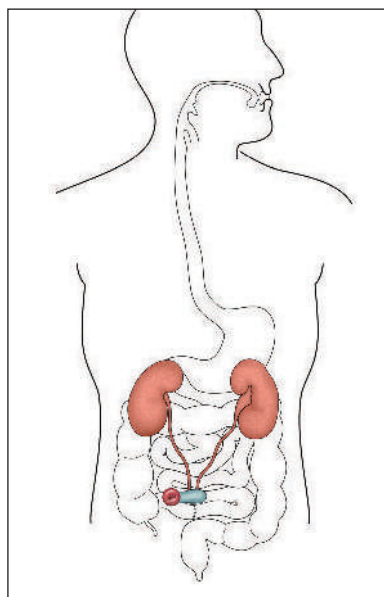
Because a urostomy does not have a sphincter muscle, you have no voluntary control over when to urinate. Instead, you wear a pouch to collect the urine.

Types of urostomies

Your surgeon may select one of several methods to create the urostomy, or urinary diversion. The most common method is called an ileal conduit.

To create an ileal conduit, the surgeon removes a short segment of the small intestine (ileum). This will be used as a pipeline – or conduit – for urine to flow out of your body. The few inches that the surgeon removes for the ileal conduit will not affect how the intestine works. The surgeon reconnects the intestine, and it continues to function just as it did before. Your surgeon 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 abdomen is called a stoma.

Another type of urinary diversion is called a colon conduit. A colon conduit is formed in much the same way as an ileal conduit with one major difference. To construct a colon conduit, the surgeon uses a short segment of the large intestine (colon) and brings the open end of the conduit through the abdominal wall. Again, creating an opening in your abdomen called a stoma.



Ileal Conduit

The stoma

Your stoma will probably be swollen after surgery. It may take several weeks or months for the stoma to shrink to its permanent size. While stomas come in a variety of sizes and shapes, a healthy 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. If the bleeding continues, contact your WOC/ET nurse or healthcare professional

Whether your stoma is large or small, protrudes well, or is flush with the skin, drainage should empty into your pouch without leaking under the skin barrier. If the urine from the stoma is bloody, you should contact your WOC/ET nurse or healthcare professional.

You may have small tubes called stents inserted during surgery. These will be removed several weeks after surgery. Stents extend out of your stoma and ensure the flow of urine into your pouch. They will be removed by your WOC/ET nurse or healthcare professional.



Urine from a urostomy

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.

If you have either an ileal or a colon conduit, you will 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.



Pouching Systems Explained

The urostomy pouching system selected for use in the hospital is often basic, and designed to work for a variety of different stomas. Once you are home, you may want to try some different pouching systems to find the one that works best for you.

The pouching system consists of two main parts — the skin barrier and the pouch.

The skin barrier is the adhesive portion of your pouching system that fits immediately around your stoma. It protects your skin and holds your pouching system in place, and is sometimes called a wafer.

There are two types of pouching systems (both include a skin barrier):

One-piece pouching system

For this type of system, the skin barrier and the pouch are a single unit.

Two-piece pouching system

For this type of system, the skin barrier and the pouch are two separate pieces. The plastic ring in a two-piece system that is used to connect the two parts together is the flange.

Drain valve

All urostomy pouches have a drain valve at the bottom of the pouch, so it can be emptied as needed. During the day, most people find it necessary to empty their pouch when it's 1/3 to 1/2 full.

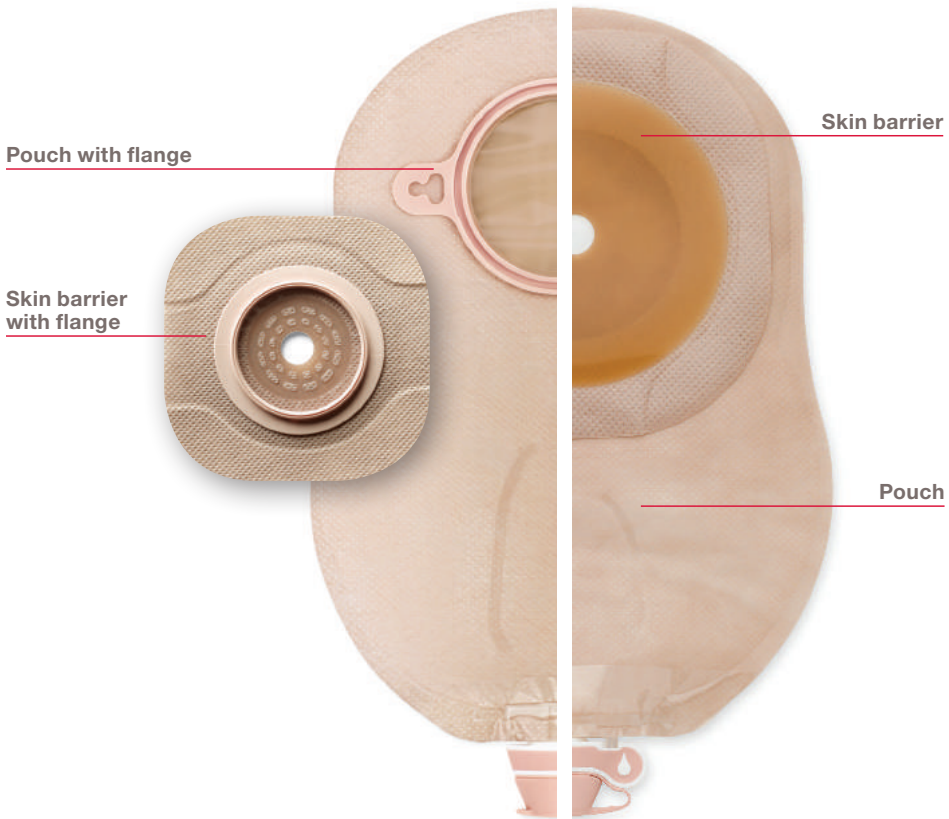


Bedside drainage collection system

This allows the urine to flow into a bedside collector while you sleep. Many people find a bedside collector preferable to getting up during the night and emptying the pouch.



Two-Piece System | One-Piece System



Taking Care Of You

Skin care

The skin around the stoma is called the peristomal skin. Get into the habit of cleaning the peristomal skin each time you change your barrier. Less is better when caring for the skin around the stoma. For most people, water is sufficient for cleaning the skin.

The peristomal skin should be intact without irritation, rash, or redness. It should look similar to the skin anywhere else on your body. A properly fitting skin barrier and the right skin barrier formulation helps protect the skin from being irritated by the stoma drainage.

If you discover red, broken, or moist skin around the stoma, seek the assistance of a WOC/ET nurse or healthcare professional. 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.

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 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 residue-free and free of all moisturizers and oils.

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.

Diet and fluids

For most people, a urostomy has very little effect on diet. Add foods gradually to see how they agree with your system. 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, WOC/ET nurse, or a dietitian.

TIPS

- **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**



Odor

Odor is a concern for people who have urostomy surgery. 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, and nutritional supplements can cause your urine to have a strong odor and some medications can affect the odor of urine.

Preventing urinary tract infections

People with urinary diversions can develop urinary tract infections, and this can lead to kidney problems. If you notice any of these symptoms, contact your healthcare professional or your WOC/ET 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

Caring for Your Urostomy

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. Here are a few guidelines for successful urostomy care.

- 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 and stoma characteristics, but three to four days is considered normal
- If you use soap, make sure it does not contain creams or lotions that may leave a residue, which can interfere with your skin barrier adhesive
- Make sure the peristomal skin is clean and dry before applying your skin barrier
- After you apply your skin barrier, apply gentle pressure for about a minute for best adhesion
- Verify that no skin is showing between the skin barrier 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
- 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
- If you discover red, broken or moist skin around the stoma, or your pouch is not staying in place, be sure to see your healthcare professional or WOC/ET nurse
- Be sure to assess your peristomal skin on a regular basis to ensure your skin is healthy and help to address any issues in a timely manner
- Use a bedside drainage collection system at night (or get up regularly during the night to empty your pouch)

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.

The pouch can be worn inside or outside of your underwear. Select the option that is more 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. As directed by your healthcare professional, you should be able to return to work or travel just about anywhere. When you travel, take your urostomy 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 urostomy products are available from select medical or surgical retailers throughout the world.

TIPS

- **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 in 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 WOC/ET 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 from 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 to the edges of your skin barrier before swimming.

TIPS

- Empty your pouch before swimming
- You may add tape 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 personal relationships

Because urostomy surgery is a body-altering procedure, many people worry about sex and intimacy, and about acceptance by their spouse or loved one. 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. The key, of course, is understanding and communication.

Urostomy surgery affects both partners in a relationship and it is something to which both partners must adjust; each in his or her own way. Let your partner know that sexual activity will not hurt you or your stoma, although 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 WOC/ET nurse.

If you are considering having children, you will be happy to know that after a satisfactory recovery it is usually still possible for a woman who has a stoma to have children. Many men have become fathers after having urostomy surgery. If you have questions about pregnancy, be sure to ask your healthcare professional or your WOC/ET nurse.

TIPS

- **Empty your pouch before having sexual relations**
- **Sexual activity will not hurt you or your stoma**
- **You may wear a small closed pouch during sex**
- **A beige pouch or pouch cover can help hide the pouch contents**
- **Intimate apparel can hide the pouch and keep it close to your body**

Follow-Up Care

Discharge checklist

Now that you are leaving the hospital, there are a few things you will need to know.

Below you can find a checklist of some basic ostomy skills for you to review with your WOC/ET nurse that will assist you with the transition from hospital to home.

LEARN HOW TO:

- Empty your pouch
- Remove your pouching system
- Assess and care for your stoma and the skin around your stoma
- Apply your pouching system
- Assess the signs of potential complications and when to contact a healthcare professional
- Follow dietary and fluid guidelines
- Follow instructions for home healthcare (if applicable)
- Enroll in Secure Start services – your WOC/ET nurse can facilitate your enrollment



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. Secure Start services offers FREE dedicated ostomy support for as long as you need it, regardless of the brand of products you use.

Enrolling is simple and provides lifetime access to Secure Start services. Ask your clinician for help enrolling, or you can speak to a member of our team by calling 1.888.808.7456.

Here's how it works:

After you enroll, you will receive an introductory kit that includes a travel bag, stoma measuring guide, mirror, scissors, and educational booklets. You will be matched with a dedicated Consumer Service Advisor who can walk you through the introductory kit and work with you to ensure you get the care you need, including help with:

- Finding the right products
- Helping you sort out insurance coverage
- Identifying product supplier options
- Accessing an ostomy nurse over the phone to find answers to clinical product questions
- Providing product information and condition-specific education
- Finding local resources

Your Consumer Service Advisor will check in periodically to see how you are doing and to answer any questions. You should expect your first phone call within 48 hours of enrolling.

To learn more about taking care of your ostomy or how Secure Start services can support you, please call us at 1.888.808.7456 or visit www.securestartservices.com.

Ostomy product supplies

Once you have established a product fit that is right for you, it is time to find a supplier that can provide you with an ongoing supply of ostomy products. 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?

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.

How much to order

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.

When to call your WOC/ET nurse

Call your WOC/ET nurse if you notice any of the following problems listed below:

- Any sign of urinary tract infection:
 - dark, cloudy, or strong-smelling urine
 - back pain (where your kidneys are located)
 - nausea or vomiting
 - fever
 - loss of appetite
- Skin irritation
- Urine crystals on or around your stoma
- Recurrent leaks of your pouch 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

Resources

Your healthcare professional and your WOC/ET nurse will be very important resources for you in the days ahead. You also have ongoing access to online information, or printed educational materials, at www.hollister.com/ostomycareresources such as:

- **The “Living with an Ostomy” Booklet Series** — provides information on lifestyle-related topics such as diet, travel, sports, and fitness
- **“Caring for Your Loved One with an Ostomy” Booklet** — 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
- **“Ostomy Educational Theatre” Video Modules** — provide an overview of ostomy products, helping you to choose the products that are right for you and learn how to use them
- **“Living with a Stoma” Video Modules** — provides insights from other people who have been through stoma surgery on how to lead full and productive lives

Ostomy support groups are also available to individuals who have had ostomy surgery. Here, you are able to interact with people who are facing many of the same challenges that you are. The ability to discuss issues with someone who understands what you are experiencing can be very beneficial.

Secure Start Services

1.888.808.7456

www.securestartservices.com

United Ostomy Associations of America, Inc. (UOAA)

1.800.826.0826

info@uoaa.org

www.ostomy.org

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

1.800.932.2423

www.ccfa.org

Inspire.com

Inspire.com is an online community offering members a safe place to discuss condition-specific health questions and concerns.

www.inspire.com

Glossary

Bladder: A hollow organ where urine is stored prior to voiding (urination). It is removed or bypassed in urostomy surgery.

Colon: Another term for the large intestine or last portion of the gastrointestinal tract.

Colon Conduit: A procedure where the ureters are implanted into a section of the colon to direct urine into a stoma made from the colon.

Ileal Conduit: This is the most common type of urostomy. The ureters are connected to a small section of the ileum used to create a stoma.

Mucous: A sticky, thick fluid that looks like cloudy material in the urine. This is normal to see in the urine from an ileal or colon conduit.

One-piece pouching system: The skin barrier and pouch are a single unit.

Peristomal skin: The area around the stoma starting at the skin/stoma junction and extending outward to the area covered by the pouching system.

Pouch: The bag that collects output from the stoma.

Skin barrier: The portion of your pouching system that fits immediately around your stoma. It protects your skin and holds the pouching system in place. Sometimes called a wafer.

Sphincter: A muscle that surrounds and closes an opening. An ostomy does not have a sphincter.

Stents: Small tubes that may be inserted during surgery. They come out of your stoma and drain into your pouch. They are temporary and will be removed by your doctor or nurse.

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

Two-piece pouching system: The skin barrier and pouch are two separate pieces.

Ureters: Narrow tubes that drain urine from your kidneys to your bladder.

Urethra: The narrow tube from the bladder through which urine drains from your body.

Urinary diversion: General term for a surgical procedure to reroute the urinary system. Also called a urostomy.

Urostomy: An ostomy (surgical opening) created to drain urine.

Urostomy pouch: Pouch with a drain tap at the bottom so urine can be emptied quickly and easily.

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.

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