Understanding Your Urostomy

Hollister Ostomy. Details Matter.
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. December 18th 2000, I discovered what it meant to rediscover life after ostomy surgery.

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. 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 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 advice of your personal physician or other healthcare provider. 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.
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Look for this symbol for Lifestyle Tips throughout the booklet.
Your Urostomy

If you are about to have — or have recently had — urostomy surgery, this booklet can help you understand your urostomy and how to manage it. It is intended to help answer some of your questions, and to help ease some of your concerns about living with a urostomy.

Remembering that you are not alone is important. 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. Whatever the medical reason for your surgery, it is natural to have questions and concerns.

This booklet is provided to you by your healthcare team. It complements information given to you by your doctor, and your Wound, Ostomy, Continence (WOC) Nurse, or ET Nurse — a nurse who specializes in ostomy care. When you have questions, write them down on page(s) 26-27. You should discuss these questions with your doctor, or WOC Nurse.

For a list of terms used in this booklet that you may not be familiar with, we have provided a glossary on page 24-25. Terms that are featured in the glossary are in bold face type throughout the booklet.

About Your Urostomy

Before your surgery

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

Before your surgery, your WOC 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 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 an Urostomy?

A urostomy is a surgically created opening usually on the abdomen. 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 short segment of intestine 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.

Each stoma is unique. Chances are, your stoma will look different from someone else’s. Your stoma will probably be swollen after surgery; it may take several weeks for the stoma to shrink to its permanent size.

The Stoma

- Not painful
- Always red and moist
- May bleed easily

The stoma is always red and moist – somewhat like the inside of your mouth. It should not be painful. The stoma may also bleed easily, especially if it is hit or rubbed. This type of minor, temporary bleeding is normal. If the bleeding continues, or if the urine from the stoma is bloody, you should contact your WOC Nurse.

Urine from a urostomy

Urine will begin flowing from your stoma immediately after surgery. At first, the urine may have a slight reddish color. However, after a few days, the urine will 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.
The pouching system selected for use in the hospital is often basic, and designed to work for a variety of different stomas. After you are home, you may want to try some different pouching systems to find the one that works best for you.

The following general information about pouching systems can help you in finding the product that best meets your needs.

**One-piece and two-piece pouching systems**

There are two types of pouching systems: **One-piece pouching systems** and **two-piece pouching systems**. Each has different advantages, and individuals tend to choose their pouching system based on what best meets their needs.

Both pouching system types include a **skin barrier**. The skin barrier is the adhesive portion of your pouching system. It helps protect your skin, and adheres your pouching system to your skin.

In a one-piece pouching system, the skin barrier is attached to the pouch — so that it is in “one-piece”. When changing a one-piece pouching system, the pouch and skin barrier are removed together since they are connected.

In a two-piece pouching system, the skin barrier is separate from the pouch — so they are in “two-pieces”. The two-piece pouching system allows you to change your pouch while the skin barrier stays in place on your body.
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 the pouch about as often as they would normally go to the restroom.

Bedside collector

At night, a length of flexible tubing can be attached to the drain valve on your pouch. 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.

Skin care

It is very important for the skin around the stoma to remain healthy and free of irritation. The peristomal skin should look just like the skin elsewhere on your abdomen. To prevent skin irritation or other skin problems, you should have a skin barrier and pouch that fit properly.

Each time you remove your skin barrier and pouch, look carefully at your peristomal skin. If you notice any swelling, redness, or rash, you could have irritated skin. Sometimes – but not always – irritated skin is painful. If the problem persists or gets worse, be sure to contact your WOC Nurse.

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.

If you wear a two-piece system and decide to shower with only the pouch removed, water may possibly interfere with the skin barrier adhesion. Be sure to check afterwards.
Diet and fluids

For most people, a urostomy has very little effect on diet. Chances are, you will have to increase the amount of fluids you drink. To keep your kidneys functioning properly – and to help prevent urinary tract infections – you should drink plenty of water each day.

Of course, each person’s needs are unique. If you have any questions about diet or fluids, check with your doctor, WOC Nurse, or a dietitian.

Lifestyle Tips

- Drinking plenty of water each day is the best way to prevent urinary tract infections
- Eat a balanced diet
- Eating beets will turn your urine a reddish color — this is temporary, and is no cause for alarm
- Asparagus and seafood may cause odor

Odor

Odor is a concern for people who have ostomy 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 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. 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

If you notice any of these symptoms, contact your doctor or your WOC Nurse.
When your doctor says it is appropriate, you can resume your normal activities. You will get used to your pouching system from Hollister and develop a schedule that fits your lifestyle. Here are a few guidelines for successful care of your urostomy.

- Empty your pouch when it is one-third to one-half full.
- Change your pouch on a routine basis, before it leaks — you will get more comfortable with this once you learn what works best for you.
- Seven days is generally recommended as the maximum length of time you should wear a single skin barrier.
- 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.
- Rinse your skin with water, and dry it completely before you apply the new pouch.
- After you apply your skin barrier, hold it against your body for 30-60 seconds — the pressure and warmth will help activate the adhesive.
- If you wear a two-piece system, try putting your skin barrier on at an angle, making 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 — be sure to check afterwards.
- If your skin becomes red and sore, or your pouch is not staying in place, be sure to see your doctor or WOC Nurse.
- Use a night drainage system (or get up regularly during the night to empty your pouch).
Clothing

After usrostomy 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, whichever is more comfortable for you. Women can wear panty hose or girdles. Also, choosing a patterned swimsuit, instead of one in a solid color, will help to visually conceal your pouch.

Returning to work and traveling

As with any surgery, you will need some time to recover. Be sure to check with your doctor before returning to work or starting 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. When you travel, take your urostomy supplies with you. Take 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.

Lifestyle Tips

- When flying, pack your ostomy products in your carry-on bag
- Carrying scissors on board an aircraft is now prohibited, so be sure to pre-cut your products
- Check with your airline about restrictions on traveling with liquids, gels, 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 Nurse when traveling
Activity, exercise, and sports

When your doctor 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.

Lifestyle 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 about them with your doctor or WOC Nurse.

If you are concerned about 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 you doctor or your WOC Nurse.

Lifestyle Tips

- Empty your pouch before having sexual relations
- Sexual activity will not hurt you or your stoma
- You may wear a small pouch or stoma cap 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
Discharge information

Your WOC Nurse can help you keep a record of your surgery and recommend the right products to maintain the health of your urostomy.

Type of ostomy: __________

Date of surgery: __________

Stoma size and shape: __________

Recommended pouching system: __________

Your WOC Nurse: __________

Phone: __________

Other recommended products: __________

Other suggestions: __________

New start programs

Manufacturers often offer “new start” programs. These programs vary, but typically they include sending initial product samples directly to the home after you are released from the hospital.

One example is the Secure Start Program offered by Hollister. The Secure Start Program is unique in that it offers support beyond product samples throughout the continuum of care. When you are released from the hospital, Hollister sends a customized kit, based on your nurse’s recommendation. It arrives at your home within 48 hours. You are then assigned a dedicated Secure Start Coordinator who can answer questions and provide assistance with finding a network of providers for supplies. Your Secure Start Coordinator will remain in contact with you throughout the recovery period to offer support, education, and product assistance. Ask your WOC Nurse for more information.

Supplies

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. If you need assistance in finding a supplier for Hollister products, contact us at 1.800.323.4060.

When to call your WOC Nurse

Call your WOC 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
Your doctor and your WOC 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 such as:

- The “What’s Right For Me - Colostomy” Booklet — provides information related to products available for people with Urostomies

- The “Lifestyle” 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

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.

Knowing that you are not alone in your situation is also helpful. These support groups often share information through their newsletters, magazines, and websites.

Additionally, you can visit the following websites for information and support — some of them also offer support groups that you can join:

- C3Life.com: www.c3life.com

- National Family Caregivers Association: www.nfcacares.org

- United Ostomy Associations of America, Inc. (UOAA): www.uoaa.org

- International Ostomy Association (IOA): www.ostomyinternational.org

- American Cancer Society (ACS): www.cancer.org

- Crohn’s & Colitis Foundation of America (CCFA): www.ccfa.org

- Hollister Incorporated: www.hollister.com

- Brenda Elsagher’s Website: www.livingandlaughing.com

For more information on the Hollister Secure Start Program, call 1.888.808.7456.
Glossary

**Bladder**  The bladder is 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 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**  Pouching system that has the skin barrier attached to the pouch

**Peristomal skin**  The skin area around the stoma.

**Pouch**  The bag that collects the discharge from the ostomy.

**Skin barrier**  An important part of the pouching system. It protects the skin and helps to hold the pouching system to the body.

**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**  Another term for ostomy, a surgically created opening.

**Two-piece pouching system**  Pouching system that has the skin barrier separate from the pouch. Both pieces are needed to make a complete pouching system.

**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. Also called a urinary diversion.