Urostomy Guide

Urostomy surgery is needed when the bladder isn’t working the way it should. There are 4 major bladder problems that may be treated with a urostomy:

- **Bladder cancer**
- Damage to the nerves that control the bladder (called neurogenic bladder disease)
- Birth defects
- Chronic inflammation of the bladder

For the thousands of people who have serious bladder diseases, a urostomy can be the start of a new and healthier life. If you have had a chronic (long-term) problem or a life-threatening disease like bladder cancer, you can look forward to feeling better after you recover from urostomy surgery. You can also look forward to returning to most, if not all of the activities you enjoyed in the past.

This guide will help you better understand urostomy – what it is, why it’s needed, how it affects the normal urinary system, and the changes it can bring to a person’s life.

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**What Is a Urostomy?**

Aurostomy is an opening in the belly (abdominal wall) that’s made during surgery. It redirects urine away from a bladder that’s diseased or not working as it should. The bladder is either bypassed or removed. (Surgery to remove the bladder is called a **cystectomy**.) After this surgery, urine is passed out of the body through an opening on the belly called a **stoma**. A Wound Ostomy Continence nurse (WOCN or WOC nurse) or the surgeon will figure out the best location for your stoma. (A WOC nurse is a specially trained registered nurse who takes care of and teaches ostomy patients. This person may also be called an ostomy nurse.)
The stoma will look pink to red and will be moist and shiny. The shape will be round to oval, and it will shrink over time after surgery. Some stomas may stick out a little, while others are flush with the skin.

You won’t be able to start or stop urine coming out through the stoma, so you might need a pouch to collect the urine as it comes out. The stoma has no nerve endings, so it’s not a source of pain or discomfort. It is just a change in the way urine comes out of your body.

A urostomy is not a disease, but a change in the way your body works. It surgically changes the way urine comes out of your body.

Why would you need a urostomy?

Urostomy surgery is done when certain diseases and conditions cause serious bladder problems.

If there’s cancer in the bladder, removing all or part of the bladder may be removed and detouring the urine through a urostomy might cure the cancer.

Some people find it easier to manage a urostomy than a defective bladder that may have been caused by something like a birth defect, surgery, or spinal injury. Bladder problems often mean that people can’t control the flow of urine – they are incontinent. This can be embarrassing and the constant wetting may cause skin problems. Some young people have even asked for urostomy surgery as a way to end this problem.

Some children are born with a defect in the urinary tract that causes urine to back up into the kidneys. This leads to chronic or repeat infections. For these children, a urostomy may be life-saving. Surgery can make a pathway through which the urine may travel easily, without any blockages (or obstructions) that cause it to back up. This allows the kidneys to work their best.

Getting ready for surgery

As you get ready for abdominal surgery, your doctor and/or ostomy nurse will explain the process and look at your abdomen to find the best location for the stoma. You may be asked to wear a sample pouch to make sure that the place chosen is on the flattest possible surface and that you are comfortable in all positions. If you have any hobbies or habits that might be affected by where the pouch is placed, talk to the doctor or the ostomy nurse.
Talking with someone who has gone through the same experience can help, too. Look for an ostomy visitor program in your area. This is a program that matches you with a volunteer from the United Ostomy Association of America who has a urostomy and has adapted well to the changes that it brings. He or she can answer many of your questions about day-to-day life. You may also find it helpful to take part in an ostomy support group. A support group allows you to share your feelings and ask questions as you recover and adjust to your urostomy. You can also share your story with others who may be helped by your experience.

**Types of Urostomies and Pouching Systems**

There are 2 basic options for urostomy surgery: the standard or conventional urostomy and the continent urinary reservoir.

Many factors must be considered when deciding which type is needed. The surgeon will talk with you about which is best for you.

**Standard or conventional urostomy**

- **Reasons surgery may be needed:**
  - Bladder cancer
  - Neurologic dysfunction
  - Birth defects
  - Chronic inflammation of bladder

- **Output:**
  - Urine and some mucus; will be continuous (non-stop) drainage

- **Management:**
  - Skin protection is needed; will need a drainable, valve-end pouch that’s adaptable to night drainage

For this type of urostomy, an ileal conduit is made. An ileal conduit is a small pouch that holds urine. It’s surgically created from a small piece of bowel (intestine).

To make an ileal conduit, a 6- to 8- inch piece of the lower part of the small intestine (called the ileum) is cut out near where it attaches to the large intestine (colon). The rest of the ileum is then re-connected to the large intestine. The ureters are detached from the bladder and attached to the piece of ileum that was removed. The bladder may or may not be removed. The far end of the piece of ileum is brought through the front of the abdomen wall to form the stoma. The other end is sewed closed to make a pocket that holds the urine inside the body. This surgery is a life-long change. The urine output
cannot be controlled and a collection pouch will have to be worn at all times.

The small intestine produces mucus naturally. The segment of intestine that was used to form the ileal conduit or urine pocket will keep making mucus, too. The mucus will collect in the pouch along with the urine. This is normal.

**Continent urostomies**

For a continent urostomy, the surgeon also makes an internal pouch. In this case, the pouch has valves to keep the urine from backing up the ureters into the kidneys. There’s also a valve to keep the urine in the pouch until it’s removed. The pouch must be drained 4 or 5 times a day with a thin, flexible tube called a catheter. The doctor or ostomy nurse will teach you how to drain the pouch and help you make a schedule to do it.

**Different types of continent urostomies:**
Types of pouching systems

Pouches come in many styles and sizes, but they all include an adhesive part that sticks to your skin (called a flange, skin barrier, or wafer) and a collection pouch. There are 2 main types of systems available.

- One-piece pouches are attached to the skin barrier
- Two-piece systems are made up of a skin barrier and a pouch that can be taken off and put back on the barrier

While you are in the hospital after your surgery, an ostomy nurse will talk to you about your personal needs and help you pick a pouching system. For some, this pouch is the type worn for a lifetime. Others will need to change to a new or different type of pouching system later on if they gain weight, grow (in the case of a child), or for other reasons. Do not keep using a recommended pouch if it’s not working the way you need
it to. Try different types until you find one that feels good, works well, and is easy to use.

**Fitting the skin barrier**

The constant flow of urine from the stoma can irritate the nearby skin. The pouching system’s skin barrier is designed to protect the skin from urine and be as gentle to the skin as possible. Depending on the design, you may need to cut a hole out for your stoma, or it may be sized and pre-cut.

Right after surgery the stoma is swollen, but it will shrink over the next 6 to 8 weeks. During this time the stoma should be measured about once a week. A measuring card may be included in boxes of pouches or skin barriers, or you can make your own template that matches your stoma shape. The opening on the skin barrier should be no more than 1/8-inch larger than the stoma size to keep urine off the skin.

**Using an ostomy belt or tape**

Wearing an ostomy belt to help hold the pouch in place is a personal choice. The belt attaches to the pouching system and wraps around your waist. Some people with urostomies wear a belt because it makes them feel more secure and it supports the pouching system, which can get heavy as it fills with urine. Others find a belt awkward and use tape instead. Tape can be put around the outside edge of the skin barrier like a frame, to help hold it in place.

If you choose to wear an ostomy belt, adjust it so that you can get 2 fingers between the belt and your waist. This helps keep you from getting a deep groove or cut in the skin around the stoma, which can cause serious damage to the stoma and sores (pressure ulcers) on the nearby skin.
If you use an ostomy belt, it shouldn’t ride above or below the level of the belt tabs on the pouching system. People who are in wheelchairs may need special ostomy belts. Supply companies often carry special belts, or an ostomy nurse can talk to you about making one yourself.

Choosing a pouching system for standard urostomy

You will need a pouching system to collect urine that comes out of the stoma. It must have a barrier that protects the skin around it.

It’s best to talk with an ostomy nurse or someone who has experience in this area when you’re trying out your first pouching system. There should be someone in the hospital who can get you started with equipment and instructions after surgery.

As you’re getting ready to leave the hospital, be sure you get referrals to an ostomy nurse, an ostomy clinic, an ostomy manufacturer, or a chapter of the United Ostomy Associations of America. Even if you must go out of town to get such help, it’s worthwhile, as you want to get a good start and avoid mistakes. Even with help, you may have to try different types or brands of pouching systems to find the one that best suits you.

The size of the stoma, abdominal firmness and shape, the location of the stoma, scars and folds near the stoma, and your height and weight all must be considered. Special changes may have to be made for stomas near the hipbone, waistline, groin, or scars. Some companies have custom-made products to fit unusual situations.

A good pouching system should be:

- Secure with a good leak-proof seal that lasts for 3 to 7 days
- Odor-resistant
Protective of the skin around the stoma
Nearly invisible under clothing
Easy to put on and take off

**Emptying the pouch**

The urostomy pouch has a drain valve at the bottom, so it can be emptied as needed. Since bacteria grow quickly in urine, it’s important to empty the pouch often, at regular times. A lot of urine in the bag also could damage the pouch seal. It’s a good idea to empty your pouch when it’s about 1/3 to 1/2 full.

During the day most people need to empty the pouch about as often as they used the bathroom before they had urostomy surgery or other bladder problems – for many people, this might mean every 2 to 4 hours, or more often if you drink a lot of fluids. Children may have to empty more often because their pouches are smaller. Follow these steps:

- Sit as far back on the toilet as you can.
- Place a small strip of toilet paper in the toilet to decrease splashing.
- Hold the bottom of the pouch up and open the valve.
- Gently empty the contents right into the toilet.
- Close the valve.
- Dry the end of the valve with toilet paper.

At night a piece of flexible tubing can be attached to the drain valve on your pouch. This allows the urine to flow into a bigger bedside bag or drainage bottle while you sleep. Many people find a bedside drainage unit better than getting up during the night to empty the pouch. (This is discussed further in Using a night drainage system.)

**Factors that can affect the pouching system seal**

The pouching system must stick to your skin. It’s important to change it before it loosens or leaks. The length of time the pouch stays sealed to the skin depends on many things, such as proper fitting, the weather, skin condition, scars, weight changes, diet, activity, and the shape of your body near the stoma. Here are some other things that may affect how long a pouch sticks:

- Sweating will shorten the number of days you can wear a pouch. Body heat, added to outside temperature, will cause skin barriers to loosen more quickly than usual.
• Moist, oily skin may reduce wearing time.
• Weight changes will affect how long you can wear a pouch. Weight gained or lost after urostomy surgery can change the shape of your abdomen. You may need an entirely different system.
• Physical activities may affect wearing time. Swimming, very strenuous sports, or anything that makes you sweat may shorten wearing time.

Using a night drainage system

At night the bottom of the pouch can be connected to a night drainage system which carries urine away from the stoma while you sleep. This lets you sleep undisturbed. Gravity drains the urine to a bedside container. This keeps your pouch from getting so full and heavy that it pulls away from your body. It also protects your stoma and skin against the build-up of strong urine.

When connecting the pouch to the bedside drainage bag, leave a small amount of urine in the pouch before attaching the tubing. This keeps you from setting up a vacuum in the system. The bedside container should be vented and the tubing should be secured at the top of the bag or bottle with no more than one inch of it going down into the bag.
or bottle. If the urine backs up into the tubing it will stop draining. The drainage container can be hung on the side of the bed, or put in another container on the floor. A small wastebasket may be used for this purpose. Clean the tubing and beside drainage collector every morning. Pour about 2 ounces of a vinegar-and-water solution into the emptied pouch that’s attached to the night drainage system. (Use 1 part of white vinegar to 3 parts of water.) Let it run out of the pouch, through the tubing, and into the collection container. Then pour it out and hang up the night drainage tubing so it can air dry.

Caring for a Urostomy

As you learn more, you may have questions about caring for your urostomy. This section has many tips that come from others. But remember, no two people are alike. There’s no one right answer, only suggestions and ideas for you to try.

Changing the pouch

Different pouching systems are made to last different lengths of time. Some are changed every day, some every 3 days or so, and some just once a week. It depends on type of pouch you use.

Your pouch should be changed on a schedule that fits your routine. In other words, don’t wait for it to leak to change it. It may be easier to change the pouch in the morning before you eat or drink anything. If this isn’t a good time for you, try to wait at least 1 to 2 hours after drinking fluids so that urine doesn’t get on your skin and supplies while you change the pouch.

You’ll want to find the best position for putting on your pouch – sitting, standing, or lying down. The position you use should allow you to see your stoma and be easy for you to be in when making a change. Some people stand facing the toilet so the urine dripping from the stoma falls in the toilet. When changing while sitting in a wheelchair, it’s helpful to slide your buttocks toward the front of the chair and lean back a little. Using a mirror may help you center the pouch over the stoma.

Before changing your pouch, clean your hands well and put all your supplies on a clean surface. Clean pouches decrease the chances of germs (bacteria) getting into your urinary system. Bacteria can multiply quickly even in the tiniest drop of urine. These germs may travel up the ureters and cause a kidney infection. Bacteria can also cause foul-smelling urine. Some people find it helpful to use rolled tissues, paper towels, or tampons to absorb dribbling urine from the stoma.
You don’t have to use sterile supplies – the stoma and nearby skin are clean, but not sterile. But keeping all your supplies clean and organized will save you time and money. Always have at least 2 complete pouches, one on your body and one ready for your next change.

At first you may find that changing your pouch can take up to 30 minutes. With time and practice you may be able to change it in 10 minutes or less.

**Factors that can affect the pouching system seal**

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Here are some other things that may affect how long a pouch sticks:

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- Physical activities may affect wearing time. Swimming, very strenuous sports, or anything that makes you sweat may shorten wearing time.

**Protecting the skin around the stoma**

The skin around your stoma should always look the same as the skin anywhere else on your abdomen. But urostomy output can make this skin tender or sore. As you get stronger and get better at handling your equipment, skin irritation may become less of a problem. Here are some ways to help keep your skin healthy:

- **Use the right size pouch and skin barrier opening.** An opening that’s too small can cut or injure the stoma and may cause it to swell. If the opening is too large, urine could get to and possibly irritate the skin. In both cases, change the pouch or skin barrier and replace it with one that fits well.
- **Change the pouching system regularly** to avoid leaks and skin irritation. Itching and burning are signs that the skin needs to be cleaned and the pouching system
should be changed.

- **Do not rip the pouching system away from the skin or remove it more than once a day** unless there’s a problem. Remove the skin barrier gently by pushing your skin away from the sticky barrier rather than pulling the barrier from the skin.

- **Clean the skin around the stoma** with water. This can be done in the shower or tub. Pat the skin dry before putting on the skin barrier or pouch.

- **Watch for sensitivities and allergies** to the adhesive, skin barrier, paste, tape, or pouch material. They can develop after weeks, months, or even years of using a product because you can become sensitized over time. If your skin is irritated only where the plastic pouch touches it, you might try a pouch cover or a different brand of pouch. Pouch covers are available from supply manufacturers, or you can make your own.

- You may have to **test different products to see how your skin reacts to them**. If you feel comfortable testing yourself, follow the directions under “Patch testing” that follow. If you’re not comfortable doing this on your own and the problem continues, talk to your doctor or ostomy nurse.

### Patch testing

Patch testing can be done to see if you’re sensitive to or allergic to a product used as part of your ostomy care. Place a small piece of the material to be tested on the skin of your belly, far away from the urostomy. If the material is not self-sticking attach it with an adhesive tape that you know you’re not allergic to (Figures 21 and 22). Leave it on for 48 hours.
Shaving hair under the pouch
Having a lot of hair around the stoma can make it hard to get the skin barrier to stick well and may cause pain when you remove it. Shaving with a razor or trimming hair with scissors is helpful. Extreme care should always be taken when doing this. It’s recommended that you dry shave the skin around your stoma using a stoma powder, since soap and shaving creams have lotions and oils that may cause the skin barrier not to stick. After shaving, rinse and dry the skin well before applying your pouch.

**Spots of blood on the stoma**

Spots of blood are no cause for alarm. Cleaning around the stoma as you change the pouch or skin barrier may cause slight bleeding. The blood vessels in the tissues of the stoma are very delicate at the surface and are easily disturbed. The bleeding will usually stop quickly. If it doesn’t, call your ostomy nurse or your doctor.

**Eating restrictions**

There are no eating restrictions after urostomy surgery. If your kidneys have been damaged, your doctor may have you watch your protein and salt intake, but your kidney function isn’t changed by the surgery. The urinary tract and digestive tract are separate systems. Some foods and medicines may cause urine odor or change the color of your urine. The pH balance in urine may also change. Urine pH is a measure of how acid or alkaline it is.

When the food you eat is used by the body, it leaves a mineral residue called ash. This ash can be either acidic or basic (alkaline) depending on the type of food. Most fruits and vegetables give an alkalinized ash and tend to make the urine alkaline. Meats and cereals usually lead to an acidic ash residue.

Unless you are told otherwise, your urine should be kept in an acid state. Drink cranberry juice in place of orange juice or other citrus juices (these tend to make the urine more alkaline), and take vitamin C daily (check with your doctor first). Some of the acid ash foods include: most meats, breads and cereals, cheese, corn, cranberries, eggs, macaroni, nuts, pasta, prunes, fish, and poultry.

Urinary crystals on the stoma or skin are caused by alkaline urine. The crystals look like white, gritty particles. They may lead to stoma irritation and/or bleeding. Proper cleaning, keeping your urine acidic, and careful fitting of the skin barrier will help prevent urinary crystals.

To help reduce urinary crystals, you can make a vinegar compress and apply it to the
stoma for a few minutes when the pouch is changed. To do this, soak a bath cloth or small towel in a mixture of equal parts of water and white vinegar and hold the moist cloth on the stoma.

**Bathing**

You can take a bath or shower with or without your pouch in place. If you don’t wear a pouch, keep in mind that urine may keep draining out. Soap will not irritate your stoma, but soap may interfere with the skin barrier sticking to the skin. It’s best to only use water while cleaning the skin around your stoma. If you do use soap, be sure to rinse your skin well. Don’t use bath oil around the stoma – it can make it hard to get the pouch to stick.

If you bathe with your pouch off, be sure your skin is cool and dry before you put on a pouch. Otherwise the heat from a hot bath or shower can keep the skin warm and make you sweat under the barrier, this makes it hard to get a secure seal.

**When you should call the doctor**

You should call the doctor or ostomy nurse if you have:

- A cut in the stoma or injury to the stoma
- A lot of bleeding from the stoma opening (or a moderate amount in the pouch that you notice several times when emptying it)
- Bleeding where the stoma meets the skin
- Bad skin irritation or deep sores (ulcers)
- An unusual change in your stoma size or color
- Fever or strong urine odor (may be a sign of a kidney infection)

**Ordering and storing ostomy supplies**

Supplies may be ordered from a mail order company, from a medical supply store, or from a local pharmacy. If you want to order supplies online. For additional help ordering, try contacting the product manufacturer, check your local phone book’s business pages, or check the Internet (try searching for “ostomy supplies”).

- To order pouches, skin barriers, and other ostomy products, you’ll need both the manufacturer’s name and the product numbers
• Talk with your ostomy nurse about reputable dealers who can supply you with what you need
• Before ordering your supplies, check with your health insurance to be sure that they work with the company in question
• Compare prices when using mail order and the Internet (remember to include shipping costs)
• Keep all your supplies together on a shelf, in a drawer, or in a box in a dry area away from moisture and hot or cold temperatures.
• Order supplies a few weeks before you expect them to run out to allow enough time for delivery. DO NOT stockpile supplies – they can be ruined by moisture and temperature changes.

Choosing a pouching system

A pouching system is needed to collect urine that comes out of the stoma. It must have a skin barrier that protects the surrounding skin.

Deciding what pouching system or appliance is best for you is a very personal matter. When you're trying out your first pouching system, it's best to talk with an ostomy nurse or someone who has experience in this area. There should be someone in the hospital who can get you started with equipment and instructions after surgery.

As you're getting ready to leave the hospital, be sure you are referred to an ostomy nurse, a clinic, an ostomy manufacturer, or a chapter of the United Ostomy Associations of America. Even if you must go out of town to get such help, it's worthwhile, as you want to get a good start and avoid mistakes. Even with help, you may have to try different types or brands of pouching systems to find the one that best suits you. (See Getting Help, Information, and Support.)

There are a few things to think about when trying to find the pouching system that will work best for you. The size of the stoma, abdominal firmness and shape, the location of the stoma, scars and folds near the stoma, and your height and weight all must be considered. Special changes may have to be made for stomas near the hipbone, waistline, groin, or scars. Some companies have custom-made products to fit unusual situations.

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