



Urostomy: A Guide

Urostomy surgery is needed when the bladder is not 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, and 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 this 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. Many of the terms you will hear from your health care team use are used and defined here.

What is a urostomy?

A urostomy is an opening in the belly (abdominal wall) that is made during surgery. It re-directs urine away from a bladder that is diseased or not working as it should. The bladder is either bypassed or removed. (Surgery to remove the bladder is called a cystectomy.) The urine is passed out of the body through an opening called a *stoma*. An *enterostomal therapy (ET) nurse* or the surgeon will figure out the best location for your stoma. (An ET nurse is a specially trained registered nurse who takes care of and teaches ostomy patients. This nurse may also be called a Wound, Ostomy and Continence nurse (WOC) or 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 will not be able to start and stop urine coming out through the stoma, so a pouch will be fitted to collect the urine as it comes out. There are no nerve endings in the stoma, so it is not a source of pain or discomfort.

Getting ready for surgery

As you get ready for abdominal surgery, your doctor or your 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 the placement of the pouch, talk to the doctor or the ostomy nurse.

A special source of help is an ostomy visitor. The visitor is a person 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.

Why have a urostomy?

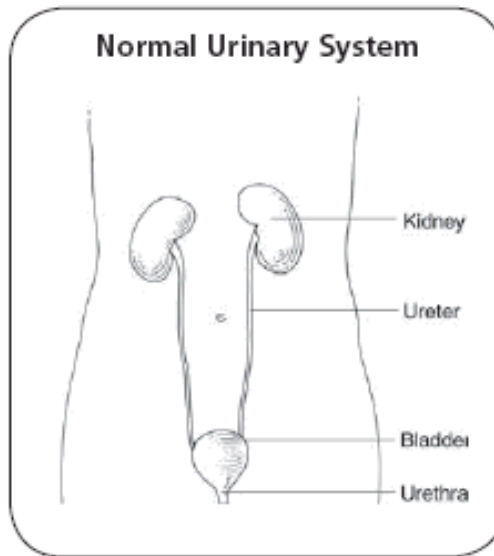
Urostomy surgery is done for some diseases and conditions that cause serious bladder problems. The bladder is part of the urinary tract – the system that removes liquid waste products from the body. The urinary tract is made up of 2 kidneys, 2 ureters, the bladder, and the urethra. Urine is made in the kidneys. It flows through the ureters to the bladder for storage. It passes out of the body through the urethra. You can live without a bladder, but you must have a certain amount of kidney function to grow and be healthy.

If there is cancer (a malignancy) in the bladder, all or part of the bladder may be removed and the urine detoured through a urostomy. This may cure the cancer.

Some people find a urostomy easier to manage 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 cannot 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.

The normal urinary system



Kidneys: The kidneys are a pair of bean-shaped organs, each about the size of a fist. They are fixed to the upper back wall of the abdominal cavity. One kidney is just to the left and the other just to the right of the spine. Both are protected by the lower ribcage. Their main job is to filter the blood to remove excess water, salt, and waste products – these become urine. They also help make sure the body has enough red blood cells by making a hormone called erythropoietin, which tells the bone marrow to make more red blood cells.

Ureters: The 2 ureters are 10- to 12-inch long tubes from the kidneys to the bladder. They carry away urine as it is made by kidneys. Muscle squeezing (called peristalsis) pushes the urine down the ureters and into the bladder.

Bladder: The bladder is a hollow pelvic organ with flexible, muscular walls that stores urine. The average adult bladder holds about 2 cups of urine. Every so often, the person releases urine through the urethra to empty the bladder.

Urethra: The urethra is the tube that carries urine from the bladder to outside of the body.

Types of urostomies

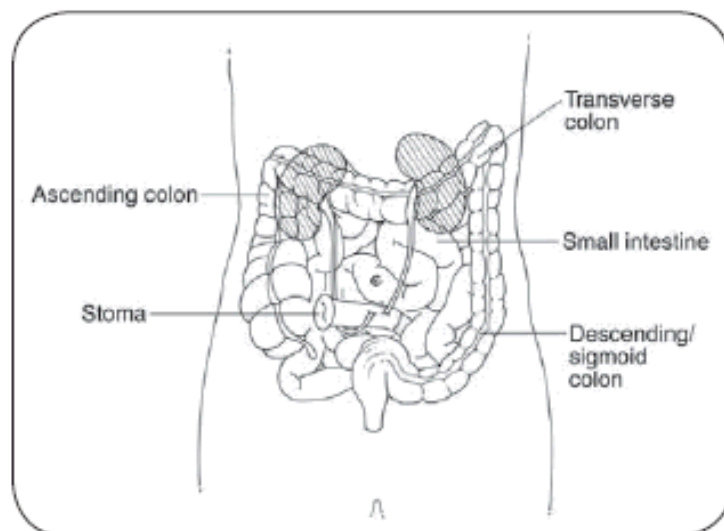
There are 2 basic options for urostomy surgery: the standard or conventional urostomy and the continent urinary reservoir. There are many factors that must be considered when deciding which type is needed. The surgeon will talk with you about which is best for you.

Standard or conventional urostomy

Reasons surgery may be needed:	Output:	Management:
Bladder cancer Neurologic dysfunction Birth defects Chronic inflammation of bladder	Urine and some mucus; will be continuous (non-stop) drainage	Skin protection is needed; will use a drainable, valve-end pouch that is 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 is surgically created from a small piece of bowel.

To make an ileal conduit, a 6- to 8- inch piece of the small bowel (also called the ileum) is cut out near where it attaches to the large bowel. The rest of the ileum is then re-connected to the large bowel. 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 abdominal wall to form a 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 is not controlled and this person will have to wear a collection pouch at all times.

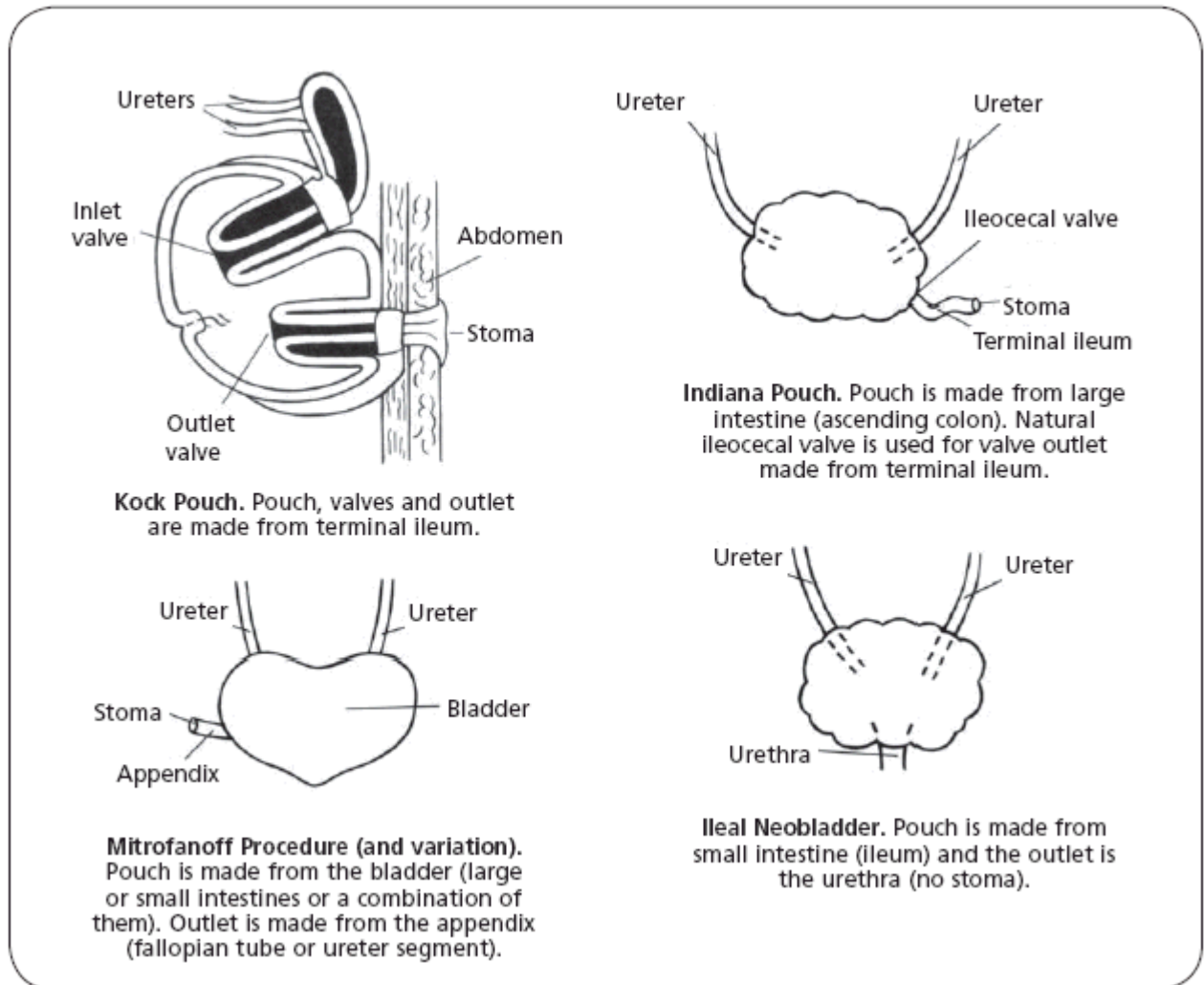


The small intestine produces mucus naturally. The segment of intestine that was used to form the ileal conduit or urine pocket will keep making mucus, too. The mucus will collect in the pouch along with the urine.

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 is also a valve to keep the urine in the pouch until it is 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 help you make a schedule to do this.

Different types of continent urostomies:



Urostomy management

Learning to take care of your urostomy may seem hard at first, but with practice and time it will become second nature, just like shaving or bathing.

Choosing a pouching system

Deciding what pouching system or appliance is best for you is a very personal matter. When you are trying out your first pouching system, it is 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 are getting ready to leave the hospital, be sure you are referred to an ostomy nurse, a clinic, or a chapter of the United Ostomy Associations of America. Even if you must go out of town to get such help, it is 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 the section "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 length 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:

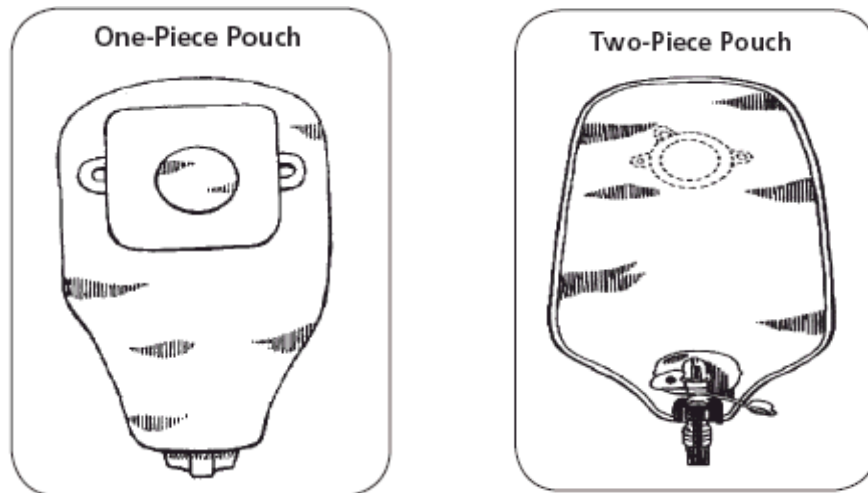
- Secure with a good leak-proof seal that lasts for 3 to 7 days
- Protective of the skin around the stoma
- Nearly invisible when covered with clothing
- Easy to put on and take off

Types of pouching systems

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

- 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

The skin barrier or faceplate of the pouch may need a hole cut out for the stoma, or it may be sized and pre-cut. It is designed to protect the skin from urine and to be as gentle to the skin as possible.



Each urostomy pouch has a drain valve at the bottom, so the pouch can be emptied as needed. It is a good idea to empty your pouch when it is about one-third 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.

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 while you sleep. Many people find a bedside drainage unit better than getting up during the night to empty the pouch. (This will be discussed later in the section called "Night drainage system.")

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 is 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.

Skin protection

The constant flow of urine from the stoma can irritate the nearby skin, so most urostomy pouches have protective skin barriers. Pouching systems come with either a pre-cut opening or they can be cut to fit your stoma size and shape.

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.

Factors that can affect the pouching system seal

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 during the summer months in warm, humid climates 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 gain or loss will also 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.

Changing the pouch

It may be easier to change the pouch in the morning before you eat or drink anything. If this is not a good time for you, try to wait at least 1 to 2 hours after you have had fluids so that urine is not getting on your skin while you change the pouch. Some people find it helpful to use rolled tissues or paper towels to absorb dribbling urine from the stoma.

You will 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 is 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.

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. Remember that your pouch should be changed on a schedule that fits your routine. In other words, do not wait for it to leak to change it.

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.

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 (see "Ordering and storing supplies").

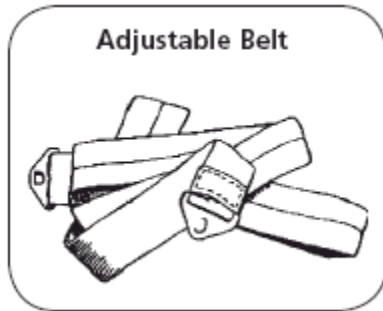
Emptying the pouch

Since bacteria grow quickly in urine, it is important to empty the pouch often, at regular times. A lot of urine in the bag also could damage the pouch seal.

During the day, you likely will need to empty the pouch 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. Try to empty it when the pouch is 1/3 to 1/2 full. 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.

Belts and tape

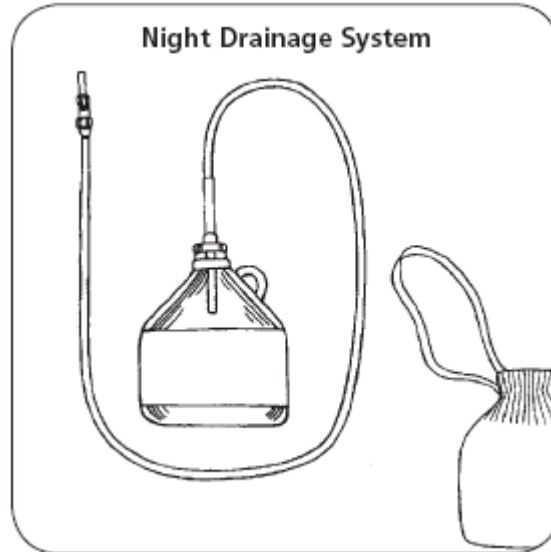


Wearing an ostomy belt is a personal choice. The belt attaches to the pouching system and wraps around your waist. Some people with urostomies wear a belt because it makes them feel more secure and it supports the pouching system, which can get heavy as it fills with urine. Others find a belt awkward 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 pressure ulcers on the nearby skin. Belts should be worn so they do not ride above or below the level of the belt tabs on the pouching system. People who are in a wheelchair may need special ostomy belts. Supply companies often carry special belts, or an ostomy nurse can talk to you about making one yourself.

Night drainage system

At night the bottom of the pouch is connected to a night drainage system which will carry the urine away from the stoma while you sleep. This lets you sleep undisturbed. Gravity drains the urine to a bedside container. Your pouch will not get so full and heavy that it pulls away from your body, and your stoma will be protected 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 drainage. The drainage container can be hung on the side of the bed, or put in another container on the floor. A wastebasket may be used for this purpose.

Clean the tubing and bedside drainage collector every morning. Pour about 2 ounces of a vinegar/water solution into the emptied pouch that is attached to the night drainage system. (Use 1 part of white vinegar to 3 parts of water.) Let it run out of your pouch, through the tubing, and into the collection container. Then pour it out and hang up the night drainage system so it can air dry.

Ordering and storing supplies

Keep all your supplies together on a shelf, in a drawer, or in a box in a dry area away from hot or cold temperatures.

Order supplies a few weeks before you expect to run out to allow enough time for delivery. But don't stockpile supplies -- they can be ruined by moisture and temperature changes.

To order pouches, skin barriers, and other ostomy products, you will need the manufacturer's name and product numbers. 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, talk with your nurse about reputable dealers who can supply you with what you need. You will also want to check with your health insurance to be sure that they work with the company in question. You may want to compare prices when using mail order and Internet (remember to include shipping costs). For information and help

ordering, you may contact a local ostomy nurse, the product manufacturer, your local phone book's business pages, or the Internet (try the search words "ostomy supplies").

Helpful hints

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

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. Use the following tips to help keep your skin healthy:

- Use the right size pouch and skin barrier opening. An opening that is 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 leakage 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 is a problem. Remove the face plate 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. If needed, use a mild soap and rinse well. 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. These are available from many manufacturers, or you can make your own.
- You may have to test different products to see how your skin will react to them. If you feel comfortable testing yourself, follow the directions under "Patch testing" that follow. If you are 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 are 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 are not allergic to (Figures 21 and 22). Leave it on for 48 hours.

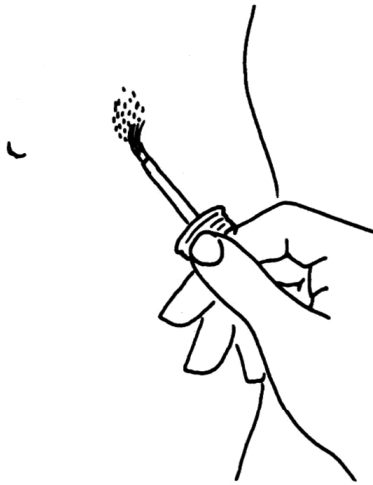


Figure 21
Patch Testing without Adhesive Tape

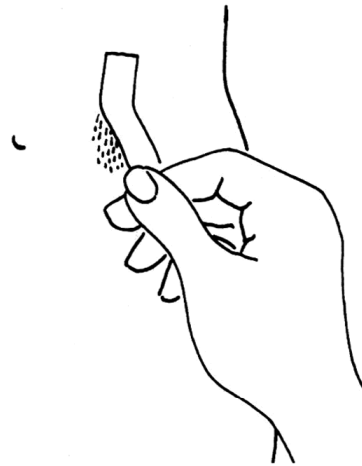


Figure 22
Patch Testing with Adhesive Tape



Figure 23
Reaction to the Tested Material



Figure 24
Reaction to the Tape Only

Gently remove the patch at the end of 48 hours and look for redness or spots under the patch. If there is no redness after 48 hours, it is generally safe to use the product. But, in a few cases, reactions that took longer than 48 hours to show up have been reported (Figure 23).

Itching or burning before 48 hours pass is a sign of sensitivity. Remove the material right away and wash your skin well with soap and water.

A reaction to the tape is also possible. If this is the case, the redness or other irritation will only be in the area outlined by the tape (Figure 24).

If you seem to be allergic to a certain product, try one made by another company and patch test it, too. It may take a few tries to find one that works for you. Keep in mind that allergies are not as common as is irritation caused by using a product the wrong way. For this reason, before using a product, always read the directions that come with it. When in doubt, check with your ostomy nurse or doctor.

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 does not, call your ostomy nurse or your doctor.

Urine pH balance

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 alkalized ash and tend to make the urine alkaline. Meats and cereals will 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.

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. Extra care should always be taken when doing this. A mild soap or shaving cream may be used. Rinse well.

Bathing

You may take a bath or shower with or without your pouch in place. If you do not wear the pouch, keep in mind that urine may keep draining out. Soap cannot harm the stoma. Just rinse it well. Do not use bath oil around the stoma -- it can make it hard to get the pouch to stick well. If you bathe with your pouch off, be sure your skin is cool and dry before you replace the 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.

Urostomy problems

Severe skin problems

Large areas of skin that are red, sore, and weeping (always wet) will keep you from getting a good seal around your stoma. It is important to treat minor irritations right away. If you have a large irritated area that does not go away in a few days, or crusty skin around the stoma (called encrustation), contact your doctor or ostomy nurse. They may prescribe medicine to help dry out and heal your skin.

Remember that a well-fitted pouching system, drinking enough fluids, and good skin care, can help prevent problems.

Urinary crystals

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 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 also 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.

When you should call the doctor

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

- A deep cut in 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 ulcers (sores)
- An unusual change in your stoma size or color
- Fever or strong urine odor (may be a sign of a kidney infection)

Hospitalization

Take your ostomy supplies with you if you have to be in the hospital. The hospital may not have the same type that you use. Be ready to do some explaining and teaching, especially if you are in a hospital where urostomy patients are rare, or if you go for a problem not related to your ostomy.

Do not assume all hospital staff know a lot about urostomies. Do not let hospital staff do anything you think may be harmful. If you are in doubt about any procedure, ask to talk to your doctor first.

Also ask to have the following information listed on your chart:

- Your type of ileal conduit or continent diversion
- Details of your management routine and the products you use
- A reminder to not take a urine specimen from the urostomy pouch. (To get a specimen, a catheter should be put into the stoma.)

Living with a urostomy

Learning to live with a urostomy may seem like a big project. It is a lot like any other major change in your life. Starting a new job, moving to a new city, marriage, and having children are all examples of life changes that get easier over time. At first, you have to get used to the new aspects of these experiences and be open to the changes that are taking place. Having a positive outlook, patience, and a sense of humor are keys to adjusting to any life changes.

There may be times after surgery when you feel discouraged. You may feel alone and isolated. Because the whole experience is so new to you, you may feel awkward, frustrated, and uncertain. Feeling discouraged is real and normal. You might cry, be angry, and react in ways that are unusual for you. Talking to a trusted friend, nurse, clergy, and certainly another person with a urostomy may help you work through those feelings.

Your social life can be as active as it was before surgery. You can enjoy all the things you did before, such as travel, sporting events, and eating at restaurants. The first time you go out of the house after surgery, you may feel as if everyone is staring at your pouch even though it cannot be seen under your clothes. Remember, you may feel your pouch on your body, but no one can see it.

You may also worry about your pouch filling with urine and bulging under your clothes. A quick trip to the rest room can take care of this problem. You are likely to find that you need to empty your pouch about as often as you needed to urinate before.

Telling others

You might be worried about how others will accept you and how your social role may change. It is natural to wonder how you will explain your surgery. Your friends and relatives may ask questions about your operation. Tell them only as much as you want them to know. Do not feel as if you have to explain your surgery to everyone who asks. A clear, brief answer would be that you had abdominal surgery or that you had your bladder removed or bypassed.

If you have children, answer their questions simply and honestly. A simple explanation is often enough for them. Once you have explained what a urostomy is, they may ask questions and want to see your stoma or the pouch. Talking about your surgery in a natural way will help get rid of any wrong ideas they may have. They will accept your urostomy much the same way you do.

If you are single and dating, pick the time to tell a partner, but it seems better to do so early in a relationship. Stress the fact that this surgery was necessary and managing your urostomy does not affect your activities and enjoyment of life. This not only lessens your anxiety, but if there is an issue that cannot be overcome, the letdown is not as harsh as it might be later. Do not wait until intimate sexual contact leads to discovery.

If you are considering marriage, talking with your future spouse about life with a urostomy and its affect on sex, children, and family acceptance will help to correct any wrong ideas your partner may have. Going to an ostomy support group meeting together may also be helpful. Talking to other couples in which one partner has a urostomy will give you both an experienced point of view. See the section called "Intimacy and sexuality" for more information.

Clothing

You will not need special clothes, though some people may need looser pants. Urostomy pouches are fairly flat and hard to see under most clothing. The gentle pressure of undergarments with elastic will not harm the stoma or keep the urostomy from working. Do not wear tight-fitting pants that may cause problems with the urine drainage.

Cotton knit or stretch underpants may give you extra support and security. A simple pouch cover adds comfort by absorbing sweat and also keeps the plastic pouch from resting against your skin. Men can wear either boxer or jockey-type shorts.

Diet and nutrition

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 is not changed by the surgery. The urinary tract and digestive tract are separate systems. Be aware that some foods and medicines may cause urine odor or change the color of your urine. Drink plenty of liquids each day as your doctor or ostomy nurse recommends.

Returning to work

As your strength returns you can go back to your regular activities. If you go back to work, you may want to tell your employer or a good friend about your urostomy. Being open about it will help educate others. Keeping it a complete secret may cause practical problems.

People with urostomies can do most jobs. But heavy lifting may cause a stoma to herniate (the whole thing bulges outward) or prolapse (the inside falls outward). A sudden blow in the pouch area could cause the face plate to shift and cut the stoma. Still, people with urostomies do heavy lifting when they work as mechanics, fire fighters, and truck drivers. There are athletes who have stomas, too. Check with your doctor about your type of work. As with all major surgery, it will take time for you to regain strength after your operation. A letter from your doctor to your employer may be helpful should your employer have doubts about what you will be able to do.

Sometimes people with a urostomy find that their employer thinks the urostomy will keep them from doing their job. This also may happen to people with ostomies who are applying for a new job. You should know that your right to work may be protected by parts of the US Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1992, and sometimes by sections of your state and local laws. If you feel you are being treated unfairly because of your urostomy, check with the United Ostomy Associations of America or with a local legal resource about protecting your rights.

Intimacy and sexuality

Sexual relationships and intimacy are important and fulfilling aspects of your life that should continue after ostomy surgery. But there is a period of adjustment after surgery. Your attitude is a key factor in re-establishing sexual expression and intimacy. Sexual function in women is usually not changed, but sexual potency of men may sometimes be affected. (If so, this is usually only for a short time.) Talk to your doctor and/or ostomy nurse about any problems or concerns you or your partner might have.

Any sexuality concerns you have are best discussed openly between you and your partner. A stoma on your belly is quite a change in how you look and can make you feel anxious and self-conscious. It is likely that your partner will be anxious about sexual activities, too, and may be afraid of hurting your stoma or dislodging the pouch. Talk to your partner about the fact that sex is not likely to harm the stoma. Try to be warm, tender, and patient with each other.

The first time you become intimate after surgery, things may not go perfectly. Men may have trouble getting and keeping an erection and women sometimes have pain during sex. These problems usually get better with time. Your interest in sex is likely to return as your strength returns and you get better at managing your pouch system. Body contact during sex will usually not harm the stoma or loosen the pouch. If the pouch or stoma covering seems to be in the way during sex, try different positions or use small pillows to take pressure off the stoma.

If possible, empty the pouch beforehand. Women may consider wearing crotchless panties, "teddies," or a short slip or nightie. Men may consider wearing a cummerbund around the midsection to secure the pouch. There are many types of pouch covers that can be purchased or you can make your own.

Ostomy surgery may present more concerns for single people. When you choose to tell that special someone depends on the relationship. Brief casual dates may not need to know. If the relationship grows and is leading to physical intimacy, your partner needs to be told about the ostomy before a sexual experience.

For more information, see our documents *Sexuality for the Man with Cancer*, or *Sexuality for the Woman with Cancer*.

Pregnancy

Pregnancy is possible for women who have had urostomy surgery. But before you plan to get pregnant you should talk about it with your doctor. The urostomy itself is not a reason to avoid pregnancy. If you are healthy, the risk during childbirth appears to be no greater than for other mothers. Of course, any other health problems must be considered and discussed with your doctor.

Exercise, play, and sports

Everyone needs daily exercise to keep good health and body function. A urostomy should not keep you from exercising and playing sports. But there are a few safety measures you should think about. Many doctors do not recommend contact sports because of possible injury to the stoma from a severe blow, or because the pouching system may slip. But special protection can help prevent these problems. Weight lifting could cause a hernia at the stoma. Check with your doctor about such sports. Indeed, people with urostomies are distance runners, skiers, swimmers, and take part in most other types of athletics.

Bathing and swimming

Water will not hurt your urostomy. You may take a bath or shower with or without a pouching system in place. Normal exposure to air or contact with soap and water will not harm the stoma. Soap will not irritate it and water will not flow in.

You can swim with your pouching system in place. Remember these points:

- If you use a support ostomy belt, you can leave it on if you want to.
- You may want to protect the barrier by taping the edges with waterproof tape.
- You may want to choose a swim suit with a lining for a smoother profile. Dark colors or busy patterns can also help hide the pouching system. Women may want to choose a suit with a well-placed skirt or ruffle. Men may want to try a suit with a higher waist band or longer leg.

- Women may wear stretch panties designed for swim suits.
- Men may want to wear bike shorts or a support garment sold in men's underwear departments or athletic wear departments under their bathing suits.
- Men may prefer to wear a tank top and trunks if the stoma is above the belt line.
- Empty your pouch before going into the water.

Travel

All methods of travel are open to you. Many people with urostomies travel just like everyone else, this includes camping trips, cruises, and air travel. Here are some travel tips:

- Take along enough supplies to last the entire trip, plus some extras. Double what you think you may need, because supplies may not be easy to get where you are going. Even if you don't expect to change your pouch, take along everything you need to do so. Plastic bags with sealable tops may be used for pouch disposal. Leave home fully prepared. Find out if and where you can get supplies before a long trip. A local ostomy support group may be able to help you find ostomy supplies and local medical professionals.
- Seat belts will not harm the stoma when adjusted comfortably.
- When traveling by car, keep your supplies in the coolest part of the car. Avoid the trunk or back window ledge.
- When traveling by plane, remember that checked-in luggage sometimes gets lost. Carry an extra pouching system and other supplies on the plane with you. Small cosmetic bags with plastic linings or shaving kits work well. These should be kept in your carry-on luggage. Air travel security will generally let you take on all medical supplies. You may want to review the Transportation Security Administration's information at: www.tsa.dhs.gov/travelers/airtravel/specialneeds/index.shtm
- To avoid problems with customs or luggage inspection, have a note from your doctor stating that you need to carry ostomy supplies and medicine by hand. Further problems might be avoided by having this information translated into the languages of the countries you are visiting.
- Before traveling abroad, get a current list of English-speaking doctors in the areas you will be visiting. The International Association for Medical Assistance to Travelers (IAMAT) at 716-754-4883 or www.iamat.org publishes lists of English speaking doctors who were trained in North America or Europe and are available in over 90 countries around the world.
- Traveler's diarrhea is a common problem for tourists in foreign countries, whether you have an ostomy or not. The most common cause of diarrhea is impure water and/or food. It may also be caused by changes in water, food, or climate. Do not eat

unpeeled fruits and raw vegetables. Be sure drinking water is safe. If the water is not safe, do not use the ice either. Bottled water or boiled water is recommended, even for brushing your teeth.

For parents of children with urostomies

If your child has a urostomy, you probably have many questions and concerns. When the surgeon said your child needed this surgery, your first reaction may have been, "Is this the only choice?" Your doctor no doubt assured you that the urostomy was needed to save your child's life. You may have felt shock. You may have asked yourself, "Why did this happen to us?"

It helps to talk to a good friend, the doctor, clergy, an ostomy nurse, or the parents of a child who has a urostomy. This will prepare you to help your child adjust to the urostomy. Deal with your own feelings first, then you will be more able to give your child the emotional support he or she needs.

You may be feeling guilty or responsible for your child's illness and surgery. These are normal feelings. You may think that your dreams have been shattered and may wonder if your child will be able to do the things that others do. Most parents worry about their child's life span, ability to work, adjustment to living with a urostomy, and in later years, marriage and family. These are normal concerns of all parents facing major changes in their child's life.

When your child is in the hospital, be there as often as possible. Being in the hospital and having surgery are frightening at any age. Your child may feel very helpless and scared at this time and needs the love and comfort you can give. You being there makes him or her feel safe.

Be prepared for how you will feel when you see an opening on your child's abdomen with urine running into a pouch. The first reaction your child sees from you is vitally important and must be as positive and casual as possible.

If your child has a fever or other symptoms, don't panic. He or she will have all the aches and pains that other children have. When in doubt, call the doctor.

Psychosocial issues

As your child begins to recover from urostomy surgery, there are many ways you can be a source of strength and support.

Your son or daughter may be afraid that young friends and relatives will not want to be around them. Your acceptance is key. Encourage your child to talk to you about these feelings. If you are open and natural about the urostomy, he or she will be, too.

Try to understand how your child feels. Your child needs to feel that you understand what it is like to have a urostomy. Still, too much sympathy is not good and can take away a

sense of independence. Listen, try to understand feelings, be encouraging, and be tactful. It is hard not to overprotect and pamper a child who is recovering from major surgery.

Very young children will probably accept the urostomy more easily than you. Children who grow up with it often find that it becomes a natural part of them. For a teenager who is facing all the problems that come with puberty and adolescence, this surgery comes at an especially difficult time. The changes in body image caused by the urostomy may make the stresses of adolescence worse. Your teenager may feel unattractive, rejected, and different because of the urostomy.

You may notice short-term changes in your child's behavior. Your acceptance and support are very important. Try to understand the feelings and listen to the complaints. Give encouragement and try to help your child find realistic solutions to his or her problems.

Your child's urostomy care

Take an interest in your child's urostomy care. If he or she is old enough, you will need to help your child learn to take care of the ostomy and pouching system on his or her own. Your child may need some help and support at first. He or she may be unsure about how to use the new supplies, feel physically weak, and tire easily.

A very young child can be taught to empty the pouch. An older child can get supplies together and learn the steps of changing the pouch, until the whole process can be done alone. You may want to use a teaching process that begins with your child helping you. Later on you can help them; then over time, stand by to help only if you are needed.

It is very important that your child have an ostomy nurse help out at this time. This is a person who has special training in ostomy management and the emotional needs that may come at this time of change. To find an ostomy nurse in your area, call the Wound, Ostomy and Continence Nurses Society at 1-888-224-9626 or visit their Web site at www.wocn.org.

Be prepared for trial and error in caring for, or helping to care for, your child's urostomy. There are some changes that will happen in the beginning that will not happen later. There may be skin or pouching system problems. The important thing to remember is that all of these changes will become more comfortable over time. A sense of humor and a positive attitude will help you and your family through this time.

Going back to school and everyday living

Be flexible as your child adjusts to school and everyday living. Have a plan in place in case there are problems. Maybe the pouch will leak at school. If that happens, your child can go to the school nurse. Or you might pick up your child for a pouching system change at home; then he or she can return to school. One youngster tells this story: he noticed that his pouch was leaking and had wet his pants. Instead of rushing out of the class as everyone else did, he calmly waited until everyone had left the room. In this way, he very wisely avoided embarrassment and then called home so that his mother could

pick him up. You may want to visit the principal, the classroom teacher, the physical education teacher, and the nurse to explain your child's needs.

You will find that your child can take part in most sports, go on overnight trips, camp, and, in fact, still enjoy the same activities as before. At first, it may be hard to let your child go away on his or her own. Talk about what can be done if any problems come up while your child is away from home. If you can help your child know how to best handle any problems that may come up, he or she will not need any "special" treatment or seem different from any other children.

Talk with your child about how they will talk about the surgery to others. He or she may want to tell close friends and loved ones. Naturally, people will be curious. Once the surgery is explained, chances are your child will be accepted as before. Your child will likely repeat what you say. If you talk about the surgery in a natural way with others, your child will, too.

Remind your child to think about others, too. For example, cleaning up the bathroom after urostomy care is important. You and your child are facing a new situation in your lives. If it is approached with openness, firmness, and a sense of humor, you will find that a urostomy will not stop your child from taking part in life's everyday activities. Parents find that a healthy child with a urostomy can once again be a happy child.

Being around other kids with ostomies can also be a great help. Each summer, a camp for young people ages 11 to 17, with ostomies or any other bowel or bladder changes, is held at a college campus. This camp is called The Youth Rally. Planned learning sessions on self esteem, body image, hygiene, and ostomy issues, plus discussion sessions, craft projects, tours, and sports are offered. Visit www.rally4youth.org for more information.

Getting help, information, and support

There are many ways to gain a greater understanding of your life with a urostomy. Your doctor and ostomy nurse are important sources of information and support. A lot of information can also be found at various Web sites, such as those listed in the "To learn more" section.

Taking part in an ostomy support group can be very helpful. It allows you to share your feelings and ask questions as you learn to live with your urostomy. It also lets you share your successes with others who may need the benefit of your experience. Most ostomy visitor programs and support groups are sponsored by local chapters of the United Ostomy Associations of America (UOAA).

A number of cancer centers have ostomy rehabilitation programs which include all types of ostomies, whether or not they are caused by cancer. Ask about services that may be available, such as educational pamphlets, ostomy supplies for people without insurance coverage, or assistance in contacting the local UOAA chapter. You can also contact the American Cancer Society (1-800-227-2345) for information on ostomy support groups.

To learn more

More information from your American Cancer Society

We have selected some related information that may also be helpful to you. These materials may be ordered from our toll-free number.

After Diagnosis: A Guide for Patients and Families (also available in Spanish)

Bladder Cancer: A Detailed Guide (also available in Spanish)

Caring for the Patient With Cancer At Home: A Guide for Patients and Families (also available in Spanish)

Sexuality for the Man With Cancer (also available in Spanish)

Sexuality for the Woman With Cancer (also available in Spanish)

National organizations and Web sites*

United Ostomy Associations of America, Inc. (UOAA)

Toll-free number: 1-800-826-0826

Web site: www.uoaa.org

For local support group information; the interactive Web site includes discussion boards

International Ostomy Association (IOA)

Web site: www.ostomyinternational.org

Advocates for and outlines the rights of ostomates

Wound, Ostomy and Continence Nurses Society (WOCN)

Toll-free number: 1-888-224-9626

Web site: www.wocn.org

The WOC nurse is a specialist in ostomy care and rehabilitation. These nurses care for and teach people with ostomies, coordinate patient care, teach nursing staff in hospitals and clinics, and work closely with the nursing and medical professions to improve the quality of ostomy rehabilitation programs. The WOCN Society can help you find a WOC nurse in your area.

Centers for Medicare & Medicaid Services

Toll-free number: 1-800-633-4227

Web site: www.cms.hhs.gov

Ostomy care and supplies are covered under part B of Medicare. These same supplies and care may be covered under Medicaid (this is state regulated and varies). Check with an ostomy nurse about which health department or other agency in your state may be able to help you.

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

In its original form this document was written by the United Ostomy Association, Inc. (1962-2005) and reviewed by Jan Clark, RNET, CWOCN and Helen DuBois, RNET. It has since been updated and modified by the American Cancer Society.

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For additional assistance please contact your American Cancer Society
1 · 800 · ACS-2345 or www.cancer.org