

About Your Urostomy

This information will help you learn about your urostomy and urostomy pouching system.

Table of Contents

About Your Urostomy	2
About Your Urostomy Pouching System.....	2
In the hospital.....	3
At home	3
Ordering supplies	4
Ostomy accessory products.....	4
Night drainage system.....	5
Leg drainage bag.....	5
Finding out about new products	5
Changing Your Urostomy Pouching System.....	6
Showering with Your Urostomy.....	7
Problems Related to Your Urostomy	7
Skin problems.....	7
Urinary tract infections (UTIs)	9
Hernias	9
Traveling with Your Urostomy	10
Preparing for Medical Tests	10
Imaging scan with contrast.....	10
Chemotherapy	11
Other procedures.....	11
Resources	11

About Your Urostomy

A urostomy is an opening in your abdomen (belly) where urine leaves your body. After your bladder surgery with a urostomy (ileal conduit), your urine (pee) will flow from your kidneys, through your ureters and ileal conduit, and out of a small opening in your abdomen called a stoma (see Figure 1).

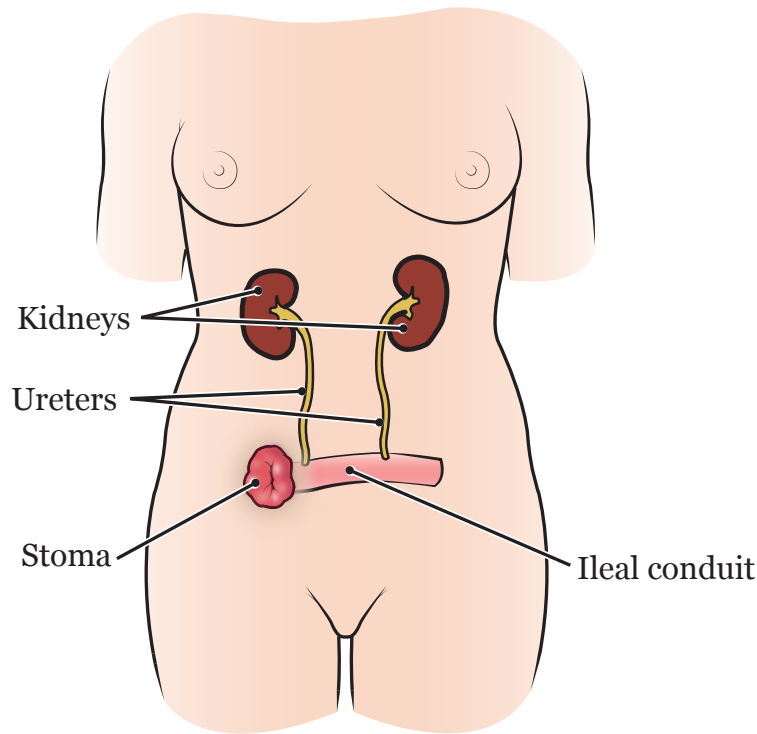


Figure 1. Your urinary system after your bladder surgery with a urostomy (ileal conduit)

Your stoma should be a deep pink or red color all the time. If your stoma looks grey, brown, or black, contact your doctor right away.

You won't be able to control the flow of urine from your stoma. You will wear a urostomy pouching system (appliance) over your stoma to catch and hold the urine.

There are a few different types of urostomy stomas. Your wound, ostomy, and continence (WOC) nurse will tell you which type you have and answer your questions.

About Your Urostomy Pouching System

A urostomy pouching system has 2 parts: a wafer (the part that sticks to your skin) and a pouch (the bag that holds your urine). With a 2-piece pouching system, the wafer and the pouch are separate pieces that can be taken apart. With a 1-piece system, the wafer and pouch are connected.

You will use different types of pouching systems in the hospital and at home. This is because your stoma will get smaller as it heals. It usually takes about 6 to 8 weeks for your stoma to get to its permanent size.

In the hospital

While you're in the hospital, you will learn how to care for your urostomy stoma and pouching system.

Most people use a 2-piece pouching system and an extender called a low-pressure adaptor while they're in the hospital. The low-pressure adaptor goes between the wafer and pouch to create extra space. This makes it easier for your doctor and nurses to take the pouch off the wafer and put it back on without pushing hard on your abdomen. It will help you be more comfortable when your doctor checks your stoma.

At home

After you're discharged from the hospital, you will use either a 2-piece or a 1-piece pouching system. A home care nurse will visit you to help you keep learning how to care for your stoma and pouching system.

You may use different pouching systems as your body heals and your stoma gets smaller. You will have appointments with an outpatient WOC nurse. They will look at your stoma with you, keep track of how your stoma is healing, and help you choose the pouching system and ostomy accessory products (products that you can use along with your pouching system) that are best for your body.

Follow-up appointments

Your first appointment with your outpatient WOC nurse will be 2 weeks after you're discharged from the hospital. It's also helpful to schedule follow-up appointments with your outpatient WOC nurse 2 to 3 months and 6 months after your surgery. You should also contact your WOC nurse if you have skin issues or questions about your pouching system.

You may lose some weight when you're first recovering after surgery. Over the 3 to 6 months after surgery, you will probably gain back some of this weight. During this time, you may notice some small changes in the shape of your abdomen. These changes can cause your pouching system to fit differently and be uncomfortable. If this happens, contact your WOC nurse. They can recommend a pouching system that's more flexible and moves with your body.

You may also want to choose a more flexible pouching system if your pouching system is uncomfortable when you bend, twist, or work out. Your WOC nurse will help you find a system that works best with your body and activities.

Always contact your doctor's office to tell them about your questions or concerns and to make an appointment with your WOC nurse.

Positioning your pouching system

Position your pouch so it points down and can be tucked into your pants or underwear. You can also fold it, if you prefer. You can also try special underwear or concealment bands such as those from www.ostomysecrets.com or www.steathbelt.com.

After you're discharged from the hospital, contact your doctor's office if you need to speak with your WOC nurse.

If your WOC nurse isn't available when you contact your doctor's office, your doctor's office will give them your message and they will contact you.

Wearing a belt or suspenders

You can wear a belt or suspenders on your pants when you're wearing your pouching system. If you choose to wear a belt, wear it above or below your stoma. If the belt is directly on your stoma, it may cause irritation, bleeding, or an overgrowth of tissue.

Preparing an emergency kit

Prepare a small emergency kit with a pre-cut wafer, a pouch, and several gauze pads. Keep the emergency kit with you at all times so you can change your pouch if it leaks.

Keep your emergency kit out of direct sunlight or heat.

Ordering supplies

Ostomy supply companies

There are 2 main types of ostomy supply companies.

- **Ostomy supply distributors** are companies that sell ostomy products. They sell supplies made by many different manufacturers. You will order your urostomy supplies from an ostomy supply distributor.
- **Ostomy supply manufacturers** are companies that make ostomy products. You can call an ostomy supply manufacturer for information about their products or to ask for a sample of their products. You can't buy products right from the manufacturer.

When to order supplies

Order more supplies when you have only 1 box of pouches or wafers left. You can order from one of the following ostomy supply distributors:

180 Medical
877-688-2729

Edgepark Medical Supplies
800-321-0591

Byram Healthcare
877-902-9726

McKesson
800-451-6510

Choose an ostomy supply distributor that accepts your health insurance. You can find out by calling the distributor.

Ostomy accessory products

There are many different ostomy accessory products. Examples of ostomy accessory products include:

- **Barrier ring:** This goes around the base of your stoma and helps the wafer fit better. It can help keep urine from leaking underneath the wafer.
- **Elastic barrier strips:** These go over the wafer and help keep it from coming off your skin. They also help to waterproof the wafer.
- **Ostomy belt:** This attaches to the wafer and wraps around your waist. It helps to secure the pouching system.
- **Stoma guard:** This goes over your stoma and pouching system to provide extra protection. It can be helpful if you play contact sports.

You probably won't need to use all of these accessory products. Your WOC nurse will give you more information about the accessory products that may be most useful for you.

Night drainage system

A night drainage system is a pouch or bottle that connects to the bottom of your pouch. It holds more urine than your normal pouch.

It's important to use a night drainage system when you sleep to keep your pouch from getting too full. If your pouch gets too full, it may leak, or urine may flow back into your stoma and cause an infection. Using a night drainage system can also help you avoid needing to get up at night to empty your pouch.

You will need to use an adaptor to connect the night drainage system to your pouch. The adaptor will be included in your box of pouches.

Caring for your night drainage system

Each morning, empty the urine from the night drainage bag or bottle into the toilet. After you empty the bag or bottle, wash the night drainage system. You can use warm water or a mixture of 1/4 cup white vinegar and 1 cup water. You can also buy cleansers such as M9™ Crystallizer cleansing system. After you wash the night drainage system, let it air dry.

Replace your night drainage system every 2 to 4 weeks.

If you're having problems with your night drainage system tubing coming loose, you can tape the connections between the night drainage system and your pouch. If you move around a lot while you sleep, use a leg stabilizer or Foley® catheter holder. You can order these accessories when you order your supplies.

Leg drainage bag

A leg drainage bag is a pouch that holds more urine than your normal pouch. You may want to use a leg drainage bag if you're traveling or if you may not be able to get to a toilet to empty your pouch (such as when you're golfing or in a traffic jam).

Leg drainage bags may not be covered by your insurance plan. You can call the ostomy supply distributor to find out if leg drainage bags are covered by your insurance.

Caring for your leg drainage bag

When the pouch is getting full, empty the urine from the leg drainage bag into the toilet. After you empty the bag, wash it. You can use warm water or a mixture of 1/4 cup white vinegar and 1 cup water. You can also buy cleansers such as M9™ Crystallizer cleansing system. After you wash the drainage bag, let it air dry.

Replace your leg drainage bag every week, no matter how many times you use it.

Finding out about new products

You can find out about new products by asking your WOC nurse, calling ostomy supply manufacturers and asking for samples of their latest products, or searching for urostomy products online. If you contact an ostomy supply manufacturer or search online, make sure you're looking at urostomy products, not fecal pouches.

You can also find out about new products by joining an online chat room or local support group for people with urostomies. Often, other people dealing with the same issues know of products that might meet your needs. Read the “Resources” section of this resource for a list of online support groups and websites to help you find local support groups. Make sure you talk with your WOC nurse before trying any new urostomy products.

Changing Your Urostomy Pouching System

You should change your pouching system about every 3 to 4 days. If urine is leaking from your pouching system, change it right away. It’s best to change your pouching system in the morning before you drink any liquids. There’s usually less urine coming out of your stoma in the morning.

The first few times you change your pouching system, you will be in your hospital bed. As you heal, you can start changing your pouching system wherever you’re most comfortable. Many people like to stand in the bathroom in front of the mirror. You can also remove your pouching system and clean around your stoma as part of your normal shower routine.

For more information about changing your pouching system, read the resource *Changing Your Two-Piece Disposable Urostomy Appliance* (www.mskcc.org/pe/2_piece_urostomy_appliance).

What to do if you see blood on your stoma

Your stoma has many blood vessels and may bleed easily. It’s normal to see a small amount of blood on the gauze or tissue when you’re cleaning the stoma. The bleeding should stop on its own within a few minutes. If you take a blood thinner or aspirin, you may bleed more easily and for a longer time. Apply pressure to your stoma to help stop the bleeding.



Call your doctor if the bleeding doesn’t stop after 10 to 15 minutes. You may need to go to MSK’s Urgent Care Center or your local emergency room. Your doctor will tell you what to do.

Call your doctor right away if there’s blood in your urine or coming from the inside of your stoma.

About wearing gloves

You can decide if you want to wear gloves when you change your pouching system. Just as you didn’t wear gloves when urinating (peeing) before your urostomy, you don’t need to wear them now. However, you may prefer to wear gloves when you change your pouch because some urine could get on your fingers.

Showering with Your Urostomy

It's very important that you shower every day. This will help keep your skin clean.

Your pouching system is waterproof. Keep your pouching system on while you shower, except on the days you're changing your pouching system. On the days you're changing your pouching system, you can take your pouching system off and shower without it, if you choose. Urine will keep flowing from your stoma while you shower.

Shower the same way you did before your surgery. Don't use perfumed or oil-based soaps around your stoma.

Problems Related to Your Urostomy

Contact your doctor's office if you have any of the problems below. They will share your message with your WOC nurse, and your WOC nurse will reach out to you.

Skin problems

Tell your WOC nurse if you have any problems with the skin around your stoma (peristomal skin). The most common skin problems happen if urine gets under the wafer or if you have allergies to your ostomy products.

- If urine is leaking under your wafer, change the wafer right away. Don't use tape to stop the leakage.
- If the leakage doesn't stop after you change your wafer, contact your WOC nurse. You may need a different system that fits better to avoid leakage.

Tissue build-up

One common skin problem is a build-up of tissue on the skin around your stoma. The tissue may look greyish, purplish, wart-like, or have white spots (see Figure 2). It can cause pain around your stoma. The build-up is caused when your skin is exposed to urine all the time. If you have tissue build-up, call your doctor's office to make an appointment with your WOC nurse.

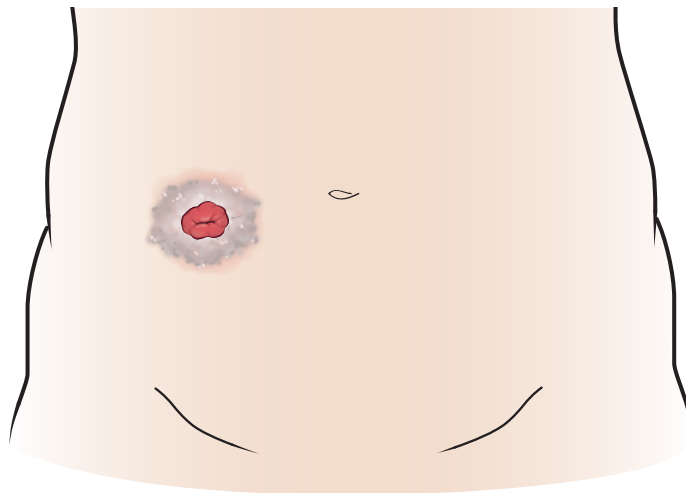


Figure 2. Tissue build-up around your stoma

If you're having problems with tissue build-up around your stoma, you may need to:

- Cut or mold your wafer or get a different pre-cut wafer.
- Use a different type of wafer.
- Apply a barrier to your wafer (such as a Colly-Seel™ disc, Coloplast Brava® Protective Seal, or Coloplast Brava moldable ring).

You may also need to treat the skin right around your stoma each time you change your pouching system. To do this:

1. Mix ¼ cup of white vinegar with ¾ cup of water.
2. Soak a gauze pad in the mixture. Place the gauze pad on your skin for 20 minutes.
3. Rinse your skin with water.
4. Dry your skin well and apply a new wafer.

Allergic reaction

Another common skin problem is an allergic reaction. If you're allergic to one of the ostomy products you're using, you may have redness or welts on the skin around your stoma (see Figure 3). You may also have itching, burning, or discomfort. If you think you're having an allergic reaction, call your doctor's office. You may need to see a dermatologist (skin doctor).

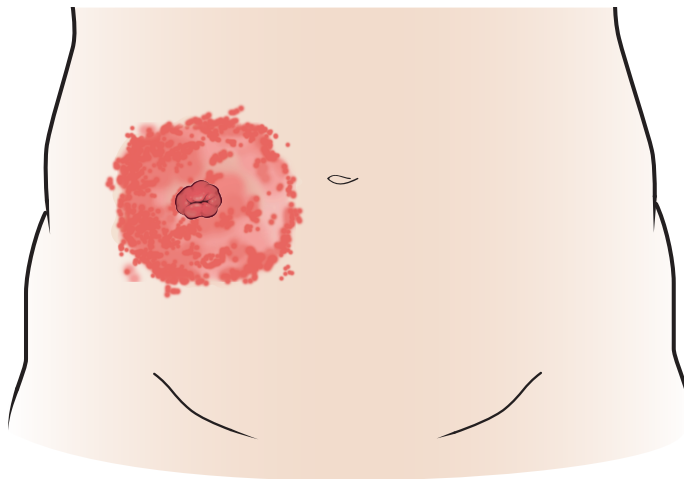


Figure 2. Tissue build-up around your stoma

If you're having an allergic reaction, you will need to try a different brand of wafer and pouch.

Rash

If you develop a rash, tell your doctor or WOC nurse. They will give you suggestions for how to treat it.

Urinary tract infections (UTIs)

The signs and symptoms of a UTI are:

- Urine that smells worse than usual
- Cloudy urine
- Back pain
- Nausea (feeling like you're going to throw up) and vomiting (throwing up)
- Loss of appetite
- Temperature of 100.4 °F (38 °C) or higher (fever)

If you think you have a UTI, call your doctor's office.

To keep from getting a UTI:

- Drink 6 to 8 (8-ounce) glasses of liquids every day. It's best to drink water.
- Limit the amount of alcohol and caffeine you drink.
- Use a pouch that has an antireflux valve, and use a night drainage system. This keeps urine from sitting on your stoma and causing an infection.
- Empty your pouch when it's $\frac{1}{3}$ to $\frac{1}{2}$ full.

You can also ask your doctor if you can take vitamin C (about 500 to 1,000 milligrams) and a sugar-free cranberry pill daily. These will make your urine more acidic and may help prevent UTIs, decrease your urine's odor (smell), and keep your skin from being damaged.

Hernias

A hernia is when a loop of bowel (intestine) pokes through a weak area of muscle. This causes a bulge to form. Hernias often don't cause any symptoms. If you see a bulge around your stoma, contact your doctor or WOC nurse.

Tips to avoid getting a hernia

Often, the abdominal muscle around your stoma is weak. To minimize the risk of developing a hernia, avoid constipation (straining to pass bowel movements), coughing a lot or very strongly, heavy lifting, or straining.

It takes up to a year for the inside of your body to heal after surgery, so pay attention to how your body feels. If you feel pain during any activities, stop doing them. Call your doctor's office if the pain doesn't go away.

Treating a hernia

If you have a hernia, your WOC nurse can suggest a hernia support belt. These belts are made to fit your body. You can also use a girdle or biking shorts to support the hernia. If you use these, you will need to cut out a hole for your urostomy pouch.

Using a hernia support belt, girdle, or biking shorts won't cure the hernia or keep it from getting worse. But, they can make you feel more comfortable and pull in the bulge to help your clothes fit better.

Hernias usually aren't treated unless they become blocked, twisted, or cause pain or other problems. Call your doctor right away if you have:

- Nausea
- Vomiting
- Pain in your abdomen
- Swelling in your abdomen

Traveling with Your Urostomy

Your travel decisions shouldn't be based on the fact that you have a urostomy. Here are some tips to help you manage traveling with your pouching system:

- Bring extra supplies, just in case you have trouble getting them while you're away.
- If you're taking an airplane, train, or bus, carry your supplies with you. Don't put them in your checked luggage. This will help you be prepared if you're separated from your luggage.
- Avoid driving a car for 4 to 6 weeks after your surgery, unless your doctor tells you otherwise. You may wear a seat belt loosely or place a small pillow over your stoma and under your seat belt. You can also use an ostomy seat belt protector. Check with your distributor or ask your WOC nurse for more information.
- Discuss travel options with your WOC nurse. You may want to use a leg bag if you think you may have trouble getting to a toilet to empty your bag.
- If you're traveling by airplane, you may want to get a travel card from the United Ostomy Associations of America (UOAA) by visiting www.ostomy.org/uploaded/files/travel_card/Travel_Communication_Card.pdf.

For more information, visit the UOAA webpage at www.ostomy.org or call 800-826-0826.

Preparing for Medical Tests

Always bring extra urostomy supplies with you. Many pharmacies and medical centers don't have urostomy supplies, and you may need an extra set.

Imaging scan with contrast

If you're having a scan with contrast, bring an extra set of urostomy supplies, as well as a leg bag or night drainage system. For the scan, you will need to drink more liquids than usual. This will help the contrast leave your body, but it will also increase the amount of urine your body makes. You may need to change your pouching system if you have a leak because you're making more urine than usual.

If you live an hour or more away from the hospital, empty your bag before leaving. You may also need to empty it on the trip home or use a leg bag. You may also want to keep a portable urinal or other container in your car in case of an emergency.

Chemotherapy

If you're having chemotherapy, bring an extra set of urostomy supplies. Chemotherapy may cause your body to make more urine. It may also make your skin more sensitive or change the way the wafer sticks to your skin. You may need to change your wafer more often during chemotherapy to protect your skin and prevent leakage.

Other procedures

If you're having a procedure where the doctor or nurse needs to access your stoma, you may need to switch to a different type of pouching system. For example, you may need to switch from a 1-piece system to a 2-piece system. Your doctor or nurse will talk with you before the procedure.

If you have any problems, contact your WOC nurse.

Resources

MSK Support Groups

Bladder Cancer Support Group

646-422-4628 or 646-888-8106

This is a live, in-person support and education group for people who have bladder cancer or who have been treated for bladder cancer. People share their personal experiences and provide practical and emotional support for one another. Discussions are led by a social worker, nurse, and WOC nurse.

This group meets the 2nd Thursday of each month from 12:00 to 1:30 PM. For more information, or to register, call the numbers above or email RLAC@mskcc.org.

Online Bladder Cancer Support Group

This is a live, online support and education group for people undergoing treatment for bladder cancer. People share their personal experiences and provide practical and emotional support for one another. Discussions are led by a social worker and a WOC nurse.

This group meets the 4th Thursday of each month from 4:00 to 5:00 PM. For more information, or to register, email virtualprograms@mskcc.org.

Resources for Finding WOC Nurses

Wound Ostomy and Continence Nurses Society

www.wocn.org/patients

Visit this website to find a WOC nurse in your area.

You can also call your ostomy supply manufacturer or distributor to ask for information about WOC nurses in your area.

Please note that many WOC nurses can only see you if there's an outpatient clinic at their hospital or if you have a doctor at their hospital.

Resources for Finding Urostomy Support Groups

United Ostomy Associations of America (UOAA)

www.ostomy.org

Visit this website to find an ostomy support group, including both online support groups and groups in your area. You can also find tips for traveling with an ostomy and download the UOAA's Travel Communication Card.

Bladder Cancer Advocacy Network (BCAN)

www.bacn.org

Visit this website for information about bladder cancer. To join an online support group sponsored by the BCAN, go to www.inspire.com/groups/bladder-cancer-advocacy-network.

Inspire

www.inspire.com

Visit this website to find online ostomy support groups.

Resources for Managing Skin Irritation Around Your Stoma

Peristomal Skin Assessment Guide

<http://psag-consumer.wocn.org>

Visit this website if the skin around your stoma is irritated. On the website, you will answer a series of questions to find out more about the type of skin irritation you have and what you can do to manage it. **Remember to always contact your WOC nurse if you think the skin around your stoma is irritated.**

Resources for Ostomy Supplies

Contact the ostomy supply manufacturer that makes the pouching system you're using. Every ostomy supply manufacturer has an assistance program for their supplies. Some manufacturers also have WOC nurses that can help you.

Some ostomy supply distributors also have a WOC nurse who can help you. Call your distributor for more information.

Resources for Ostomy Concealment Garments

Ostomy concealment garments are clothes to make your pouching system less noticeable.

Ostomysecrets

www.ostomysecrets.com

Visit this website to buy ostomy garments.

Stealth Belt

www.stealthbelt.com

Visit this website to buy ostomy garments.

C&M Ostomy Supplies

www.cmostomysupply.com

Visit this website to buy ostomy garments, including pouch covers and stoma guards.

Safe n' Simple

www.sns-medical.com/products/support-belts

Visit this website to buy a hernia support belt.