Urostomy Patient Handbook

Surgery, Recovery, and Living with Your Urostomy

Rogel Cancer Center

MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

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When and how do I call my doctor?

Call your doctor if you have any of the following symptoms:

- Your incision becomes red, swollen or open, or if you experience pus-like drainage.
- The skin around your incision is warmer than elsewhere.
- You develop a fever (100.5° degrees Fahrenheit or higher) or chills.
- Your urine becomes foul-smelling.
- Your stoma becomes much darker in color (maroon, brown or black).
- You have severe pain that is not relieved by pain medication.
- You have pelvic, flank (side between ribs and hip) or calf pain that does not go away.
- You notice bright red blood or blood clots in the urine.
- There is no urine in the ostomy pouch.
- You have nausea, vomiting, diarrhea or cannot eat.
- You lose more than 10 pounds of weight.
- You are more fatigued.

What is the contact information?

- For symptom questions and non-emergency concerns, call the U-M Urologic Oncology clinic at **(734) 647-8902** Monday through Friday from 8:00 a.m. to 5:00 p.m.
- For urgent or emergency situations 24 hours a day, call the paging operator at **(734) 936-6267**. They will call the "on call" urologist for you.

Important Phone Numbers

Care Management Services	(734) 764-0589
Cancer Center Infusion Appointments (Use only for same day appointments, or if you will be late or need to cancel.)	(734) 647-8902
Endoscopy Appointments	(877) 334-2943
Guest Assistance Program	(800) 888-9825
Med Inn (hotel accommodations at University Hospital)	(734) 936-0135
Multidisciplinary Urologic Oncology	(734) 647-8902
Nuclear Medicine Department	(734) 936-5090
Nutrition Services	(877) 907-0859
Patient Assistance Center	(734) 232-2215
Patient Education Program	(734) 647-8626
Patient and Family Support Services	(877) 907-0859
Patient and Visitor Hotel Accommodations Program	(800) 544-8684
Physical Therapy	(734) 936-7070
PsychOnc Clinic Appointments	(877) 907-0859
Radiation Oncology Department	(800) 865-1125
Sexual Health Clinic	(734) 763-4963
Social Work	(800) 888-9825

Introduction

If you are reading this handbook, you or someone you love has been diagnosed with bladder cancer. With that diagnosis, your life has already changed. The days ahead will bring still more changes and challenges, but there are also many reasons for optimism. Proven, effective treatments are available for people with bladder cancer. You and your Rogel Cancer Center treatment team have decided on the best treatment plan for you, and you are starting the journey together.

As you read through this handbook, you're likely feeling overwhelmed. If so, you're not alone. Most patients and family members feel that way as they are introduced to the new concepts, tools, techniques and resources involved in cancer treatment.

You and your surgical team have decided that **a urostomy or ileal conduit** is the best urinary diversion choice for you. A **urostomy** is an **ostomy** (opening) that is surgically made to allow urine to empty out of the body once the bladder is removed. An **ileal conduit** is when a section of the small intestine is removed to function as your new bladder. This is the most common type of urostomy. You will learn new skills and routines to care for yourself. These pages have the information you will need to help you make the transition to life with a new urostomy.

People who have the greatest success with this procedure are those who choose a positive outlook, make a firm commitment to learning, practice new things, and have a support person involved in their care. Remember: You are not alone. We are here to help each step of the way. **Our best advice to you is to be patient with yourself and do not hesitate to ask any questions.**

Along with this handbook you should have also received the **Bladder Cancer Handbook**. If you would like more information about cancer, treatment options and support services, please visit the Patient Education Program website https://www.rogelcancercenter.org/support/learning-about-cancer or email the patient education team at CCC-PERC@umich.edu.

Your University of Michigan Rogel Cancer Center team is honored that you have chosen to partner with us for your treatment, and we look forward to helping you survive – and **thrive** – after bladder cancer.

Overview of Surgery

Stages of the surgery

There are two phases to your surgery.

Cystectomy

1. First, your bladder is surgically removed. This is called a **cystectomy**.
   In some cases, people have other parts removed as well as their bladder:
   - Surrounding lymph nodes
   - Prostate (in men)
   - Reproductive organs – uterus, ovaries and fallopian tubes (in women)

Ileal conduit and urostomy

2. After the cystectomy, your surgeon cuts out a segment of small intestine (the **ileum**) from your bowels, and clamps it shut on one end to create a new passageway for urine. This is the **ileal conduit (**see illustration 2 on page 11). The bowels are reconnected so you will have normal bowel movements after surgery. The surgeon then creates a **urostomy** using the ileal conduit. This will be the pathway for the urine to exit the body instead of the urethra:
   a. The ureters are connected to the ileal conduit.
   b. The end of the ileal conduit is then brought out through the abdominal wall (belly) and the stoma is formed above the surface of your skin, most often on the right side of your abdomen.
   c. Urine will drain from the kidneys, down the ureters, through the ileal conduit, and out of the stoma.
   d. The urine is collected into a pouch that sticks to your skin and is worn over the stoma. For a short time, you will have flexible tubes (stents) in the stoma that drain urine into the pouch. These tubes are temporary and usually removed before you leave the hospital.

What is a urostomy or urinary diversion?

A **urostomy** or **urinary diversion** is a surgery that is performed to allow urine to safely pass from the kidneys into a pouch on a person's abdomen (belly). It is one of the surgeries that is most often used for the treatment of bladder cancer. A urinary diversion surgery is performed in the operating room under general anesthesia. **General anesthesia** means you will be given drugs to cause a temporary loss of feeling and a complete loss of awareness that feels like a very deep sleep. The procedure can take between 5 and 6 hours.

Normal urinary system

Illustration 1 – Normal Urinary System

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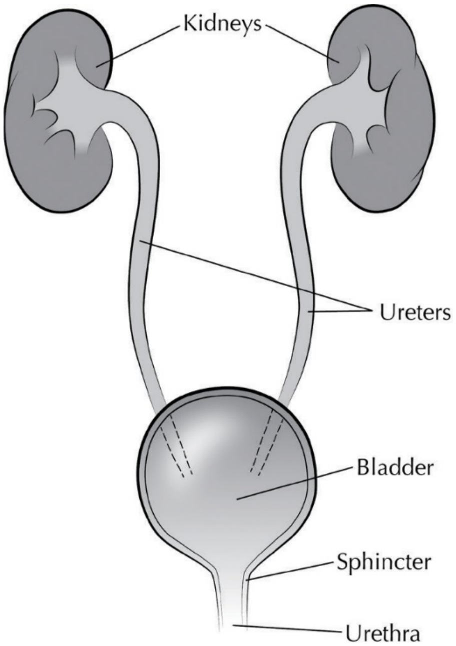


Kidneys: The kidneys are two bean- shaped organs that remove waste from blood, make urine and maintain the fluid, electrolyte and acid/base balances of the body. They are located against the back muscles in the upper abdominal cavity.

Ureters: The ureters are tubes from the kidneys. They are about 10-12 inches long. They use gravity and waves of contractions to carry urine from the kidneys and into the bladder.

Bladder: The urinary bladder stores urine.

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

Illustration 2 – Urostomy without pouch

© Shayne Davidson Illustration

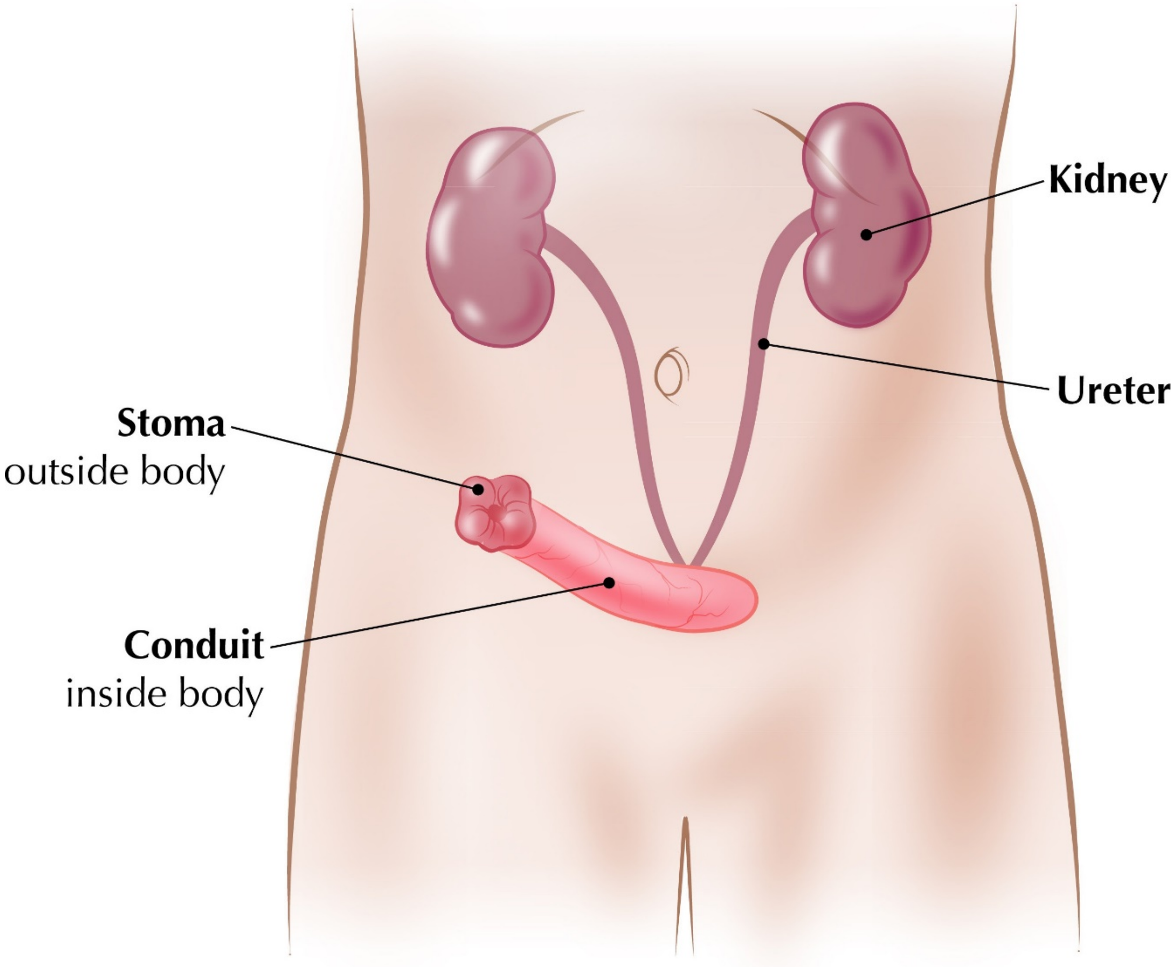
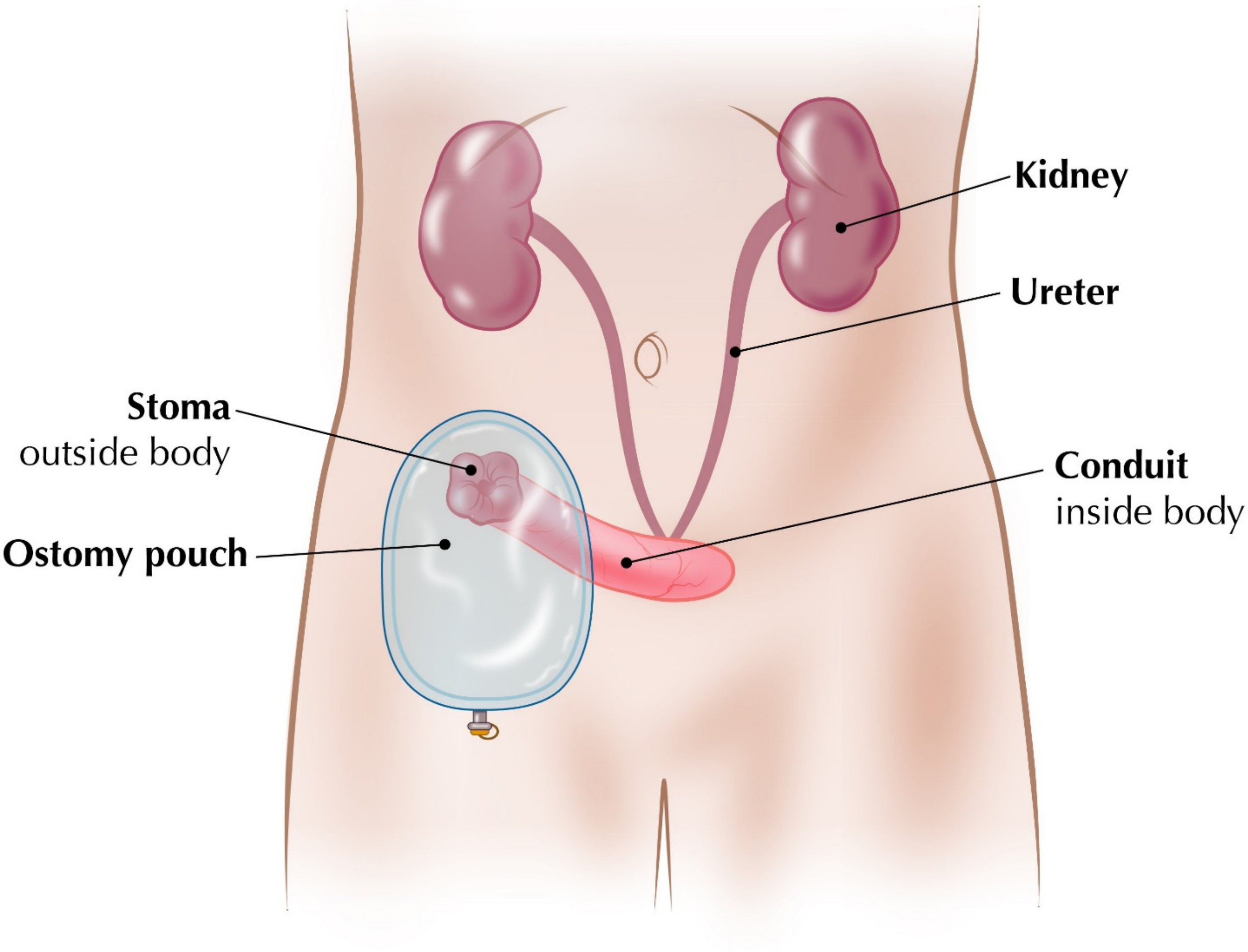


Illustration 3 – Urostomy with pouch worn over stoma

© Shayne Davidson Illustration



What is a stoma?

A **stoma** (a Greek word meaning mouth) is the end of the urostomy or urinary diversion that comes out of your abdominal wall. The stoma is red, moist and soft and has no nerve endings or feeling. Each stoma is unique. You will meet with an ostomy nurse (a nurse who gives specialized care for people with ostomies) before surgery to:

- Find the best location for your stoma
- Get education on stoma and skin management
- See samples of a pouching system that may be used to manage your stoma after surgery

Illustration 4 – Stoma

How do I prepare for my surgery?

Most people undergoing surgery have some level of stress. You are preparing for major abdominal surgery that will greatly change your life – it is perfectly normal to feel anxious. Information is one tool you can use to counter the worry and doubt and help you and your loved ones feel prepared. This section of the handbook gives an overview of what will happen before, during and right after your surgery and the steps you can take to safely prepare for your procedure.

Before surgery clinic appointments

Before your surgery is scheduled, you will meet with your surgeon in the clinic. Together, you will review your information and confirm that the urostomy surgery is the best choice for you. At that time, we will schedule appointments with other members of your care team, along with a registered dietitian and an ostomy nurse. You will also meet with hospital staff members who will gather your health history, complete a physical, and prepare the paperwork for surgical clearance. Additional testing, including computed tomography (CT) or magnetic resonance imaging (MRI), may also be scheduled.

When possible, we prefer that all of these steps be completed at Michigan Medicine; however, we will work with providers in your community if that is not possible. Before your surgery, you may see a Michigan Medicine anesthesia provider. They will talk to you about your choices for anesthesia including the risks and benefits of each. This talk may take place by phone or in person.

These tips will help you get the most out of your pre-surgery appointments:

1. Bring a list of your questions to your clinic appointment.
2. Bring a list of your medications that includes the dose and how often you take them. If you start a new medication, update your list before each visit.

Your list should have vitamins, herbal supplements and over-the-counter drugs, too.

3. You will need to find someone who can help you during the first few weeks after surgery. If possible, that person should come with you to your pre-surgery clinic appointments.
4. Before you leave your preoperative appointments, a clinic staff member will give you a list of instructions to follow before you come to the hospital for surgery. If you have any questions, please ask your doctor or nurse.

Taking care of yourself before surgery

Developing healthy habits will help you recover and thrive after surgery. It is best to make lifestyle changes several weeks before surgery to allow your body time to adjust. We suggest that you eat a well-balanced diet, get regular exercise and enough rest. Making small changes to your daily routine can have a big effect on how well you recover after surgery. The Michigan Surgical and Health Optimization Program (MSHOP) can help you maintain or improve your health in these four areas: physical activity, lung health, nutrition and relaxation. For more information on how you can prepare for surgery, consider getting started with MSHOP:

- http://www.michmed.org/jOj6o (graphically designed booklet)
- http://www.michmed.org/axyLn (printer-friendly booklet)

Physical activity

Your best plan is to stay as active as you can both before and after surgery. We suggest a simple walking program – one that focuses more on minutes rather than miles. In the table below there are 3 columns:

- Weeks 1-5 before or after surgery
- How many times you should walk that week
- How many minutes you should walk each time

You will start with Week 1 in the first row and work your way down until you have reached week 6.

Walking program

Week:	**How many times to walk per week:**	**How many minutes to walk each time:**
Week 1	Walk 3 times per week	5 minutes
Week 2	Walk 3 times per week	10 minutes
Week 3	Walk 3 times per week	13 minutes
Week 4	Walk 3 times per week	15 minutes
Week 5	Walk 4 times per week	15 minutes

Week 6 and beyond: Slowly increase both:

- The minutes each time you walk
- The number of times you walk each week

Until you reach **30 minute** walks, **5–7 days** of the week.

- If you already have a regular exercise routine that your primary care doctor has approved, we hope you will maintain it. Check with your doctor if you make changes to your routine.
- It is very important to practice coughing and deep breathing before your surgery. You will find descriptions of these exercises on Page 61 of the Appendix.
- We also suggest that you practice doing a log roll to get out bed. You will find descriptions on how to do a log roll and a link to a YouTube video on Page 64 of the Appendix.

Tobacco and alcohol

Smoking can greatly impact your surgical risk and recovery. If you smoke, we strongly encourage you to quit. We do not suggest that you simply stop smoking ("cold turkey") without help, as this can be harmful to your health too. There are many programs available to help you stop smoking. Talk to your health care team about quitting smoking. If you need help to quit smoking or to quit the use of other tobacco products, please call the MHealthy Tobacco Consultation Service at **(734) 998-6222** or visit: https://michmed.org/G264z. Along with quitting smoking, we suggest that you drink alcohol only in moderation.

Diet

- Eat plenty of fruits and vegetables.
- Eat plenty of starchy foods (choosing wholegrain varieties most often):
  - bread
  - rice
  - potatoes
  - pasta
  - other starchy foods

- Drink milk and eat dairy foods (choose lower-fat varieties when possible).
- Eat other sources of protein for healing such as:
  - lean meats (including fish, chicken and turkey)
  - eggs
  - nuts and nut butters (if tolerated)
  - beans
  - whole soy foods (tofu and tempeh)

- Eat a small amount of foods high in fat and sugar.
- Drink plenty of water. Your water needs depend on many things, including your health, how active you are and where you live. The general rule of “8 by 8” is easy to remember - drink eight 8-ounce glasses of fluid a day. All fluids count toward the daily total.
- If you are diabetic and your blood sugar is not well managed, work with your primary care doctor or a registered dietitian on strategies to improve your blood sugar control.

What do I need to do before going to the hospital?

1. Buy supplies

You will need to stock your home with some supplies to help you recover. We suggest getting these supplies before you leave for the hospital. You will find a list of useful items in the Appendix on Page 51. This is a good time to check with your insurance company to find out the specific coverage you have for ostomy supplies, as well as which medical supplier you can use.

2. Arrange transportation

Before surgery, you will need to find someone who can drive you for the first few weeks of your recovery.

3. Arrange for time off from work/activities

You will need to take time off from work or other activities to recover from surgery. Your doctor's office will help with paperwork. For the most part, people need to schedule about 6 weeks off. You and your doctor will decide the length of time you will need.

4. Prepare Advance Directives

- Advance Directives are legal documents that allow you to write out your wishes about end-of-life care. Doctors suggest that all people prepare these papers before surgery, no matter their condition or the kind of surgery/ procedure.
- A person’s Advance Directives, which include a living will and durable powers of attorney for health care (DPOA-HC) help their family, friends and health care professionals know their wishes in advance, if they become unable to communicate those wishes.
- Be sure to tell your health care team that you have completed an Advanced Directives document. Bring a copy of it with you to the hospital.
- If you do not have Advance Directives, think about preparing them.

  - You can download and complete them by visiting Care Guides From Your Clinician and clicking "Advance Directive Booklet and Forms": https://careguides.med.umich.edu/advance-directives
  - Ask your doctor or nurse for information, or contact the Patient Assistance Center at (800) 888-9825 (on Level 2 of the Cancer Center) for materials.

5. **Get to know the online patient portal,** www.MyUofMHealth.org
   - If you are not yet registered on the portal, you will get instructions on how to set up your account. If you do not have access to the internet, patient instructions or education will print with your "After Visit Summary" that you get at checkout.
   - The portal has more information and tips to help you prepare for surgery and other topics in the Health Library section.
   - You can access your own medical records, talk with your health care team and learn how to care for your urostomy on the Having an Ostomy page at: https://careguides.med.umich.edu/ostomy .

The Day of the Surgery

Preoperative instructions: before you leave for the hospital

- It is very important that you follow the directions from your preoperative appointment about when to stop eating and drinking fluids. **Your surgery may be canceled if you do not follow these directions.**
- Your preoperative instructions will also point out which medications you can and cannot take on the day of surgery. Please take any allowable medications with only a sip of water.
- On the night before surgery and the morning of your surgery, take a shower using anti-bacterial soap such as Dial®, Safeguard® or Lever 2000®.
    - Do not take a tub bath.
    - After you shower on the day of surgery, do not put anything on your skin or hair, including: make-up, lotion, powder, hairspray, perfume, aftershave, deodorant, antiperspirant or nail polish.
    - Do not shave the surgical site.
- Remove all jewelry, piercings and contact lenses.
- Leave all valuables at home.
- Bring your driver's license or other picture ID.

At the hospital

- Check-in on the first floor of University Hospital at the Admissions desk 2 hours before your scheduled surgery.
- Before surgery you will be asked to repeat information, including your full name, the part of your body being operated on and the type of surgery you are having.
- A nurse or staff member may mark the area of your body where the surgery will be performed.
- A small tube (called an intravenous tube or IV) will be placed into a vein to give you fluids and medicine to help you relax.
- Your anesthesia provider will keep you comfortable and safe before

and during the procedure.

- As you wake up in the recovery room after the surgery, a nurse will check to be sure you are stable and comfortable. It is important to let your doctors and nurses know how you feel and that you share any questions or concerns you may have.

Recovering from Surgery in the Hospital

Most people having a urostomy stay in the hospital for 4–5 days after surgery. During this time, your focus will be on:

- Taking care of yourself and starting the healing process.
- Learning how to care for your new ostomy by yourself.
- Managing pain.
- Maintaining lung function to reduce the risk of developing pneumonia.
- Being active to reduce the risk of blood clots and problems.

You will be discharged when:

- You are able to eat and drink.
- You are off IV’s (intravenous fluids and medications).
- You have no signs of infection.
- You and your caregiver understand basic ostomy care.

“Rounds”: An introduction to your care team

During your hospital stay you will meet many people who are involved in your care. University Hospital at Michigan Medicine is a **teaching hospital,** meaning that the Department of Urology is dedicated to training resident doctors.

Residents are medical doctors at various stages in their training. Residents make “**rounds**”: seeing each patient to address immediate needs and carrying out the plan of the attending doctor (your surgeon). You will also see several nurses, including an ostomy nurse, along with other staff members after your surgery.

At Michigan Medicine, we believe strongly in a team approach to medicine. The nurses, residents and other medical professionals all work together with you to carry out the attending doctor’s plan and ensure safe, high-quality postoperative care.

Communicating with your care team: The Whiteboard

After surgery you will spend some time in the recovery room, then you will be transferred to your room. Your primary job is to play an active role in your recovery. Over the course of your stay, you will have questions for your care team, and they will need to talk with you as well.

To improve communications between patients, family and care team members, dry-erase whiteboards are placed in all rooms at Michigan Medicine. During morning rounds, the boards are used to support what is discussed with you. This includes goals for the day and scheduled times for ostomy teaching before discharge.

At each shift change, boards are updated with the names and contact numbers of care team members on duty. You and your family members can also use the board to write questions for your care team. We encourage you to refer to the whiteboard in your room often. Do not hesitate to write questions, comments or concerns on it for follow-up by your care team.

Managing pain

- After surgery you will get pain medication. Your health care team will use a variety of pain medications tailored to control your pain so that you can help in your recovery.
- Take oral medications **before** pain becomes more than you can stand.
- You can also use alternative therapies to help control pain, including:
    - relaxation techniques
    - massage
    - listening to music
    - using a heating pad and warm blanket
- Avoid any bending, stretching or reaching that causes pain.

Drains

A **drain** (called a Jackson Pratt or JP drain) will be placed in your abdomen or side during surgery to drain excess fluid from the surgical site. It is not unusual for there to be a lot of fluid coming out of the JP drain. A nurse will maintain the drains during your hospital stay and record the amount of drainage. Your doctor will decide when the drains can be removed, usually before you are released from the hospital. The fluid coming from the drain may be tested before it is removed. If you are sent home with a JP drain, the nurse will teach you how to care for it and check drainage. **Do not remove a drain on your own.**

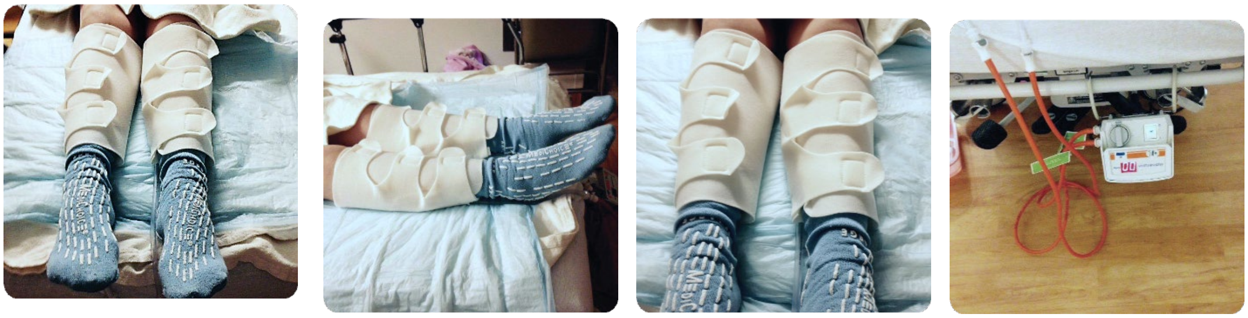
Stents

During surgery, ureteral stents were placed in the opening of your stoma. These **stents** are thin flexible tubes that help drain urine from the kidneys and allow the connection between the ureters and urostomy to heal. Your stents will likely be removed before you go home. However, if you are sent home with stents, your nurse will give you more information on how to care for it.

Preventing postoperative complications

After surgery, people are at risk for several serious complications including pneumonia and blood clots. To reduce your risk of these complications during your hospital stay, it is important that you maintain good lung function and circulation in your legs.

Sequential Compression Devices (SCDs) may be used while you are in the hospital to prevent blood clots and maintain good circulation in the legs. Shaped like sleeves, **SCDs** wrap around each leg. Alternating between the right and left leg, SCDs are inflated and deflated with air, imitating the circulation that occurs while walking and helping to prevent blood clots. You will wear SCDs while in bed the entire time you are in the hospital. The images below show how SCDs are wrapped around the legs.



Swelling

After surgery, you may have swelling for up to 1 month in the groin (between the thighs) and genital area. If you have had lymph nodes removed from your groin area, you may have swelling in the legs. If you have any swelling in the legs, contact your doctor.

Incentive Spirometer

Your hospital care team will include nurses, and in some cases, a respiratory therapist, who will teach you how to reduce your risk of developing. pneumonia by performing exercises and using a device called an Incentive Spirometer. You can also refer to Page 61 of the Appendix for instructions and exercises.

To prevent falls, ask for help getting in and out of bed. Your nurse will review the factors that put you at an increased risk of falls during your hospital stay. You will likely be required to have help getting in and out of bed or with toileting after surgery. For more information on preventing falls, see the handout, **"How to Prevent Falls: Tips for Patients and Caregivers"** in the Appendix of this handbook.

Learning about urostomy care

After surgery, an ostomy nurse will teach you how to care for your urostomy. You will learn how to empty and change the pouching system and how to use the night drain bag system. We encourage you to take advantage of this so that you are comfortable managing your urostomy before you go home. You will receive some ostomy supplies to get you started at home, along with helpful ostomy resources that will help reinforce what you have learned.

We strongly recommend that you designate another person to participate in this teaching while you are in the hospital. This could be someone who lives with you or someone who will be staying with you after you are discharged. You may need both assistance and reminders to change the appliance on a set schedule (twice per week) when first starting out. The goal is for you to become independent managing your own urostomy.

Before going home

Once your doctor has determined that you are ready to be discharged from the hospital, there are a few more steps you'll need to take to get ready to go home.

- Be sure you have arranged for someone to drive you home. For your safety, you will not be allowed to drive until you are no longer taking narcotic (opioid) pain medicines and you can move and react normally while driving.
- Arrange for extra help at home after surgery, especially if you live alone or provide care for another person.
- Decide where you want your prescriptions filled and bring your insurance card. For your convenience, we suggest getting your medications at the Ambulatory Care Pharmacy Taubman Center the day before you are discharged. This is located on the First Floor, in Reception F.
- Before you are discharged, you will receive more specific instructions about

your continuing recovery, including when you can return to work and regular activities.

- A nurse case manager will meet with you while you are in the hospital to assist with discharge planning. They will help arrange for a home care nurse to continue your plan of care and ostomy teaching. Based on your specific needs and your support system at home, arrangements could be made to stay at a rehabilitation facility to provide you with additional support while you recover.
- If you were not able to purchase the items needed before going to the hospital, arrange for someone to shop for these items for you. You will find a list of useful items in the Appendix on Page 53.

Recovery at home

The first weeks after your hospital stay are an important time in your recovery. You will have many new skills to learn and new tasks to complete one or more times each day.

Here's a summary of what to expect when you first return home:

- Don't be surprised if you feel very tired when you get home. You have had a major operation with general anesthesia. You will need help with some daily activities.
- It is normal to have vaginal or penile drainage for 4 – 8 weeks. For this reason, you may want to wear a pad in your underwear to absorb the drainage. Please call the clinic if you saturated more than 3 pads in a 24-hour period.
- For men with a swollen scrotum, try applying ice packs with this schedule: 20 minutes on, 20 minutes off. It can also be helpful to elevate your scrotum while lying down or sitting. You can do this by placing a folded hand towel under your scrotum.
- Your homecare nurse will visit you and can be helpful in guiding you through the process of caring for yourself independently. They will call your doctor's office if any medical issues come up.
- Your primary care doctor may suggest that you take a multi-vitamin.
- Follow the hygiene and dietary suggestions that you received at discharge. A registered dietitian can help make sure you know which foods are healthy and promote healing.
- **Do not** drive until you are no longer taking narcotic pain medication.

Physical Activity

- To help you build strength, continue the walking program from page 16 when you return home.
- Gradually increase the distance you walk.

- Listen to your body and do not become overly tired. Plan to take time for regular rest periods during the day.
- You may walk up and down stairs when you return home, but go slowly. Plan your activities so you only need to go up and down stairs a few times a day.
- Avoid heavy lifting (greater than 10 pounds) or strenuous activity for about 4 weeks. Heavy lifting can cause increased abdominal pressure which can strain your incision. This could possibly lead to a hernia at your incision or around your stoma.
- Avoid bending for 4 weeks. If you must pick something up, bend at the knees (not at the waist) and squat to pick up the object.

Driving

- Do not drive if you are taking narcotic pain medications. A good rule is: do not drive until you are pain-free. Pain can be distracting and may slow your reaction time.
- When riding in a car for long periods of time, take a break every 2 hours to stretch your legs. This will help you avoid circulation problems.

Mucus Production

Your urostomy is constructed from a segment of your small intestine. Because the cells lining the intestines produce mucus, you will notice mucus draining out with your urine. This is normal. It is important to drink plenty of fluids to dilute (thin) the mucus. This prevents mucus from clogging the spigot on the bottom of your ostomy pouch. If the mucus production is large, contact your doctor for suggestions on taking over-the-counter (OTC) medication to control mucus production.

Other activities to avoid

- Do not operate any motorized vehicle, make major decisions or sign legal documents while taking narcotic pain medications. These medications may affect your judgment.

Preventing blood clots and pulmonary embolism

Following major surgery, people are at an increased risk of developing blood clots. Blood clots can lead to serious complications, including **deep vein thrombosis (DVT)** and **pulmonary embolism**.

Based on risk, you may be sent home on Lovenox® to prevent blood clots and pulmonary embolism. People are usually on subcutaneous heparin (given through an IV) while in the hospital.

- A **DVT** is a blood clot in a vein of the leg, pelvis or arm. Without prompt attention, DVTs can enlarge, break loose and travel through the bloodstream to the lungs.
- A **pulmonary embolism** is a sudden blockage of an artery in the lung by a blood clot and can be life-threatening.

Please review the detailed information on blood clots pulmonary embolism and related complications in the appendix of this handbook.

Bathing:

- Once your surgical dressing has been removed, you will be able to take a shower.
- Do not take a tub bath, soak in a hot tub or swim. Avoid these activities until your incision has fully healed and you are cleared by your doctor.
- Use fragrance free anti-bacterial soap. Scented soaps can irritate the incision.
- Do not put any kind of ointment on the incision.
- Keep the incision clean, dry and open to air.
- **Cleaning your incision:** Gently wash your incision with unscented antibacterial soap by wringing a soapy wash cloth over the incision,

rinsing and patting dry.
  - Do not apply ointments or bandages.
  - If you have white strips called “steri-strips” on your incision, they should fall off in about 7 days. If they do not, you may remove them after 7 days.

Diet

- Drink plenty of water to avoid dehydration and keep your kidneys healthy.
- The general rule of “8 by 8” is easy to remember: drink eight, 8-ounce glasses of fluid a day. All fluids count toward the daily total.
- See page 58 of the Appendix to learn more about dehydration.

Preventing constipation

After surgery, people frequently experience **constipation** (when bowel movements are less frequent than usual or stools are so firm that they are difficult to pass). Constipation can be caused by chemotherapy, narcotic pain medications, the things you eat and drink and lack of physical activity. Make sure to let your doctor know if you are experiencing constipation.

To prevent constipation and keep your bowels working easily, we recommend the following:

- Staying hydrated.
- Drinking prune juice or eating prunes.
- Eating whole wheat/whole grain bread.
- Eating rolled or steel-cut oatmeal.
- Eating bran cereals.
- Eating a variety of fruits and vegetables.
- Drinking six to eight 8-ounce glasses of water every day.
- Walking to stimulate bowel activity.

Home self-care tips

1. Watch closely for any changes in your health, and be sure to contact your doctor if you are having problems or are not improving as expected.
2. Be sure to make and keep all clinic appointments, and call your care team if you are having problems.
3. To make sure you and your care team are working with the same up-to-date information:
    - Keep track of your test results
    - Maintain an updated list of all medications you are taking
    - Write down any questions or concerns as they come up so that you can review them with your care team.

All of this may seem overwhelming at first. **You are not alone** – this is a challenging time for **all** urostomy patients. It is important to remember to **relax and to be patient** with yourself. Do not hesitate to **call the Urology Clinic** at (734) 647-8902 if you have any questions or concerns.

Getting ostomy supplies

You will be discharged with 1-2 weeks of ostomy supplies. You will get a copy of the ostomy supplies that will be ordered for you. If you have Medicare and are receiving home care services, the supplies will be ordered by your home care nurse.

- If you have private insurance or you choose not to receive home care services, you will be responsible for getting your own supplies from a durable medical equipment (DME) company. The nurse case manager can also help you find one that takes your insurance before you leave the hospital.
- If you go home without identifying a supplier, use the list of DME suppliers that was provided in your yellow folder to help you find one.

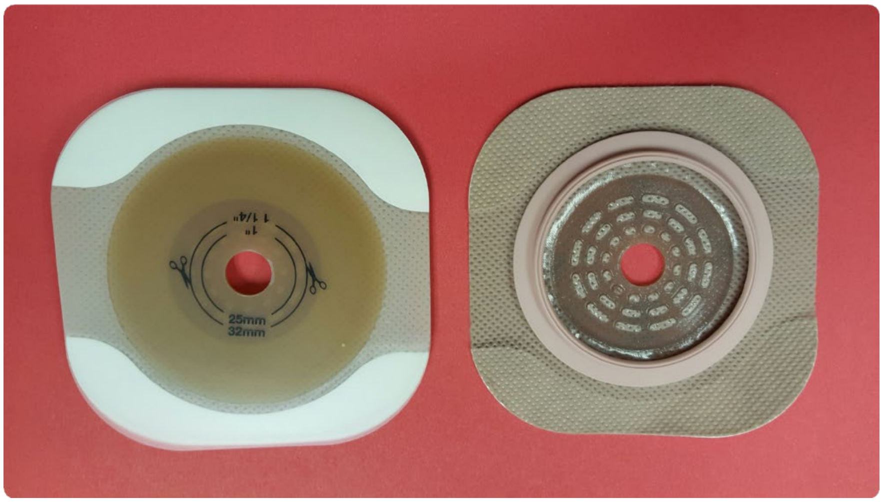
You may also contact your insurance company to find out which one is in your network.

Ostomy pouching systems

The pouching system that you will use in the hospital is a basic two-piece system. It consists of a pouch and skin barrier (see figure). After you are home you may want to try some different styles or brands to find out the one that works best for you. Although there are different styles, they will all have a **skin barrier,** which is the adhesive portion that helps protect your skin and helps your pouch stick to your abdomen. All of the urostomy pouches have a spigot at the bottom. Empty your pouch when it is one third to half full. The pouching system is used typically for about 3-4 days and is then thrown away.

It is **not** recommended that you clean them out and re-use them.

Skin Barrier



Urinary Pouch

Assembled pouching system with stoma

Night/bedside drainage bags

The bedside drainage bag can be attached to your ostomy pouch to allow for the collection of a larger amount of urine. This can be helpful for:

- Travel home
- Long car rides
- When you are inactive
- At night time

Using your large/nighttime drainage bag

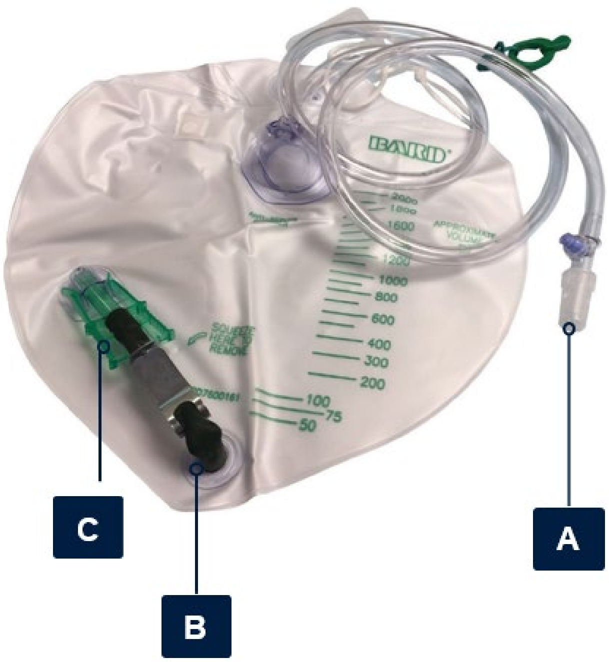
To empty urine from the bag:

A. This is where the bag's tubing inserts into the ostomy pouch connector.

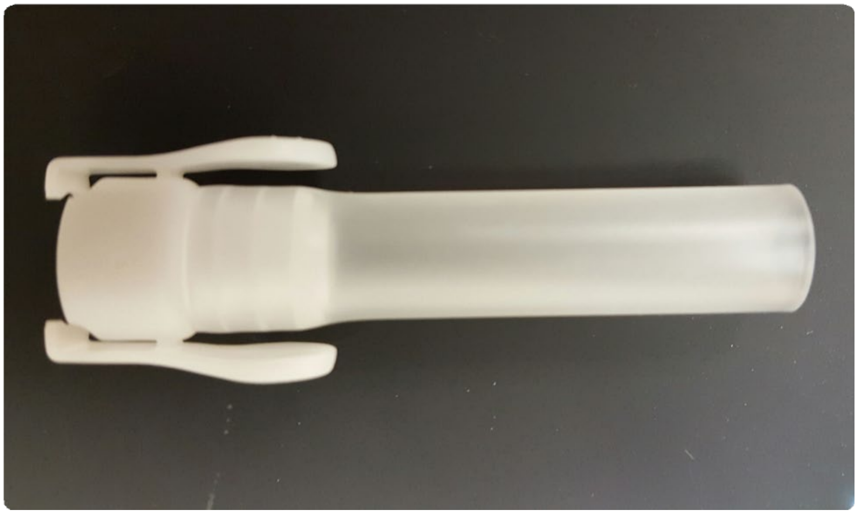
B. The "clip port" works like a clothes pin to pull the tube out of the holder.

C. The "snap port" flips open to empty the urine.

D. The ostomy pouch connector (see photo below on Page 38) connects the end of the tubing to the ostomy pouch spigot.



D. Ostomy pouch connector



- At night, you can attach a length of flexible tubing to the spigot on your pouch. This allows the urine to flow into a bedside collector while you sleep so you don't have to get up to empty the pouch at night.
- Always keep the night bag below the level of your hip to help gravity drain the urine.
- You may want to secure your tubing using a leg strap which will prevent the tubing from twisting at night.
- If maintained properly, urinary collection bags can be reused for up to one month. See Page 56 of the Appendix for instructions on keeping reusable urinary collection bags clean and free of bacteria and odor.

Follow-up appointments and ongoing monitoring

Your first follow-up

2 weeks after your surgery, you will have your first follow-up visit at the Michigan Medicine Urology Clinic. At that time you can expect the following:

- Your nurse will make sure you are recovering well after your surgery.
- You will have your blood drawn.
- Your surgical incision will be assessed and the skin staples removed.
- If you still have stents, they may be removed.
- The nurse will answer any questions you have.
- If you are having any issues with your ostomy, please call ahead so arrangements can also be made to see an ostomy nurse.

Additional follow-up appointments

You will be seen in the clinic again in 6 weeks. At that time you can expect the following:

- You will have a consultation with your doctor.
- You will have blood drawn.
- You will have one or more test scans.
- You will meet with a registered dietitian.
- You will have a consultation with an ostomy nurse.

As time goes on, you should be seen by your primary care doctor to address any additional concerns. In addition, we would like you to keep in touch with the Michigan Medicine Urology Clinic so we can follow your progress.

Managing your urostomy

For cancer survivors like you who had their bladders removed, having a urostomy will allow you to continue living your life to the fullest.

Your stoma will be swollen after surgery. It will take about 6 to 8 weeks for the stoma to shrink to its permanent size. It is necessary to measure your stoma, making sure the ostomy appliance is fitting correctly to protect the surrounding skin. The ostomy nurse will show you how to do this. The stoma is red in color, moist and very vascular (has blood vessels inside). It is normal for your stoma to bleed slightly after pouch changes.

Call your doctor if:

- The stoma color becomes purple, blue or black
- Bleeding continues

There is no pain associated with the stoma.

Helpful ostomy care tips:

- Be sure to wash your hands before and after the care of your ostomy.
- Empty the ostomy pouch when it is about one third to half full. Always empty before you change the pouching system.
- When planning your appliance change, first organize the supplies you will need so they are within easy reach.
- Make sure you have good lighting and a tilt-style mirror. If needed, wear glasses so that you can see your stoma. It is best to stand while changing your appliance.
- To keep your skin healthy, it is important to change the pouching system on a regular basis about twice per week.
- Change your pouching system if you have discomfort, itching, burning or leakage, even if it is not your scheduled day to change. This will help prevent skin irritation.

- It is recommended that you carry an “on-the-go” or travel kit with you that has all of your basic ostomy supplies, just in case you need to change your pouching system when you are away from home.

With many new skills and habits to master, it’s **natural** to feel overwhelmed – most people with a urostomy feel this way at first. With patience and practice, **you, too, will adapt to these changes** and develop a routine that works best for you.

Caring for the skin around your stoma

Each time you change your pouching system, thoroughly check the skin around the stoma. It is not unusual for the skin to turn slightly red after you remove the adhesive barrier; however, this redness will disappear in a few minutes.

Helpful skin care tips:

- When the pouching system is changed, the skin surrounding the stoma should be gently cleansed with plain water.
- If you choose to use soap for cleansing, it should be mild and pH balanced. We do not recommend using soaps that contain moisturizing creams or lotions. They can leave a residue on your skin that may interfere with the appliance adhesion. Rinse well and dry the skin before the new appliance is replaced.
- After you apply your new pouching system, gently press and mold the skin barrier against your body for 30-60 seconds. The warmth and pressure of your hands will help activate the adhesive.
- If your skin becomes red, irritated or sore, or your pouching system is not staying in place, call your home care nurse or call the Urology Clinic

for more instruction.

- You should check the sutured area around the stoma as well. The skin should be snug against the stoma. If there is a gap, you should contact your home care nurse or the Urology Clinic for more instruction.
- The best ways to keep your skin healthy are to:
    - Keep the skin clean around the stoma
    - Cut the skin barrier to the correct size
    - Maintain a good seal

Preventing peristomal (around the stoma) skin irritation

It is not normal to get skin irritation, but it can occur if there is moisture underneath your barrier, called **peristomal skin irritation.** This is often caused by a poor-fitting pouching system or changes in the stoma and skin surrounding it as your abdominal swelling decreases after surgery. It is important that you:

- Keep the skin clean around the stoma by cleaning with water, then drying thoroughly before applying a new pouch.
- Measure your stoma at each pouch change and cut the skin barrier to the size of the stoma. The skin barrier should "hug" the stoma leaving no skin showing.
- Change your pouching system at least twice weekly.

The most common form of peristomal skin irritation looks like a rash. This type of red or pink rash is caused by urine coming into contact with the skin. The skin around the stoma may turn gray or white and it may be moist. You may feel a burning sensation or it may even bleed. You received stoma powder and skin prep (barrier film) to treat it if it occurs. To use:

1. Apply a light dusting of stoma powder onto the affected area.
2. Rub it into the skin, then brush off the excess.
3. Next, dab skin prep (barrier film) over the powder to seal it in.

4. Allow to dry completely.
5. You may repeat the process to form a “crust,” which will produce a dry pouching skin surface. Then replace the appliance.

Whenever there is a rash present, you may need to change your appliance more often to retreat the skin. Only use powders and skin prep when your skin is irritated. Once the skin rash has improved, you do not need to keep using these products.
If a skin rash lasts more than 2 weeks without improvement, you should call the Urology Clinic. You may need more recommendations for care. An appointment may be necessary with your ostomy nurse to address any skin or pouching issues.

Odor

Odor from urine is a concern for many people. The urostomy pouches are made with odor-barrier film, so there is no noticeable odor when the urine is contained in the pouch. Urine is normally very acidic and has a mild odor. If you notice a strong ammonia odor, your urine may have lost its acidity. When this happens, it will irritate the skin around your stoma. It may also cause white, crystalline deposits to form on or around the stoma. These deposits can be dissolved by using a watered-down solution of half vinegar and half water to wash the stoma and the surrounding skin.

Drinking cranberry juice or taking a vitamin C supplement can help maintain the natural acidity of your urine and help control odor. Check with your doctor whether it is okay for you to take vitamin C. Some foods, nutritional supplements or medications can cause urine odor. Be mindful of what you are taking and eating that may cause an odor in your urine.

Urinary tract infections

Urinary tract infections can be a problem for people who have a urostomy. You will want to take some precautions, such as washing your hands before and after ostomy care, drinking plenty of water and emptying and changing your pouch regularly. It is important to replace your night drain bag at least monthly and clean it daily (See Page 60 in the Appendix for cleaning reusable urinary drainage systems).

It is also important to be aware of some of the warning signs of a urinary tract infection. They are:

- Cloudy, strong-smelling urine.
- Back or flank (side between ribs and hips) pain.
- Fever or chills.
- Loss of appetite.
- Nausea or vomiting.

If you notice these warnings, please call the Urology Clinic. You may be instructed to give a urine sample from a clean pouch so it can be tested for an infection. If you come into the clinic for the nurse to collect the urine, it may be obtained by using a clean catheter placed into the stoma. Do not give a urine sample from an old pouch as you will not have accurate results.

Troubleshooting

If you are having any issues with leaking or with your appliance sticking, first call your home care nurse for help. They are your closest resource at home. If you are having ongoing issues, do not hesitate to call the Urology Clinic for more direction. The clinic works closely with the outpatient ostomy nurses and can determine whether an appointment is needed.

Overcoming challenges

Support and coping

Having support after surgery can be a major source of your healing. Our goal for you is to live a normal, active life and to go back to doing all of the things that you enjoyed doing before your surgery. Having an ostomy should not change that.

The Michigan Medicine Department of Urology hosts a Bladder Cancer Support Group for newly diagnosed people or people undergoing treatment and their caregivers. The group actively participates in roundtable discussions and educational seminars to provide information and guidance on living and coping with bladder cancer. Registration is not required.

The **bladder cancer support group** meets **every other month on a Sunday**. Please call the University of Michigan Rogel Cancer Center Urology Clinic at (734) 647-8902 for more information, dates and times.

There are also many support groups for ostomates (people with ostomies) across the country. Talk with your ostomy nurse about how to locate a group in your area.

Sexual Health

No two people are alike, and it is not possible to predict exactly how bladder cancer surgery will affect your sexuality and sex life. Your desires and abilities may change or you may have new feelings about your body image after having a urostomy. How you choose to treat these changes is a very personal decision. If you have a spouse or partner, this surgery will affect both of you. Give yourself and your partner time to adjust to the “new normal.”

At first it may be difficult to believe that an intimate relationship is still possible. Do not assume your partner is "turned off" by your stoma or pouch. Talk about your feelings and your new urostomy. Let your partner know that being intimate and resuming sexual activity will not hurt you or your stoma, although you never want to use your stoma for intercourse.

Intimacy and sexuality after surgery – tips for success:

- Empty your pouch first.
- Be sure that your pouching system is secure.
- You may choose to wear a beige pouch or pouch cover to hide the pouch contents.
- Intimate apparel can hide the pouch and keep it close to your body. Ask your ostomy nurse about options and where to find resources.

Please speak with your ostomy nurse or doctor about any sexual concerns you have. They will be most helpful in assisting you through some of these very important issues and questions.

It is important to maintain a dialog with your doctor about how bladder removal is affecting your sexuality. Begin that conversation before your surgery and address the topic again when you return to the clinic for your first post- surgery check-up. Be sure to ask your doctor or nurse any questions you have about body image or function. They may refer you to a program at the U-M Rogel Cancer Center dedicated to sexual health after cancer surgery or to a support group.

For women:

When surgeons remove a woman's bladder, they may also remove the uterus, fallopian tubes, ovaries, and part of the vagina. Physical comfort, arousal and orgasm can all be affected by these changes. If sexual activity is important to you, talk to your surgeon before the operation about the possibility of organ-sparing surgery and vaginal reconstruction. Even without these options, intercourse can still be satisfactory by adapting to more comfortable positions or stretching the vagina with a series of dilators, or using lubricants. Your doctor will discuss sexual function with you at your postoperative visit.

For men:

When a man's bladder is removed, the prostate gland and seminal vesicles are also removed. All men experience erectile dysfunction after surgery. However, this is not always permanent, especially for men under 60. Talk to your surgeon about the possibility of surgical techniques which may improve the chance of getting an erection after surgery. Even with erectile dysfunction, there are options to get an erection including oral medicines, penile injections, implants, or penile pumps. Your doctor will discuss sexual function with you at your postoperative visit.

Where can I find out more?

To learn more about sexuality after bladder cancer, visit the Rogel Cancer Center Patient Education Program website: https://www.rogelcancercenter.org/support/learning-about-cancer. You will find links to information guides. The Sexuality and Cancer guide can help you locate information including:

- Sexuality for the Woman and Man with Cancer (American Cancer Society)
- University of Michigan Health System's Center for Sexual Health

In addition, the patient education resource specialist can do a customized search for you. For more information, please email CCC-PERC@med.umich.edu or call (734) 647-8626.

The Michigan Medicine Department of Urology has certified sexual counselors and sexual therapists who are available for consultation. Ask your doctor or nurse for a referral.

The Patient Assistance Center (PAC)

The Patient Assistance Center (PAC) helps connect people to resources within Michigan Medicine including:

- Clinic social workers.
- Michigan Medicine Financial Services, which handles billing concerns and payment programs.
- Michigan Medicine Patient and Visitor Accommodations, which helps families find lodging in the Ann Arbor area.

The PAC is also there to help when people require resources above and beyond those offered by the Michigan Medicine Health System. For example, the PAC can help you determine whether you qualify for financial assistance from cancer-oriented or other charitable organizations. These help pay for:

- Prescriptions
- Wigs
- Transportation, Parking
- Lodging, Meals
- Other unforeseen needs

What is the contact information?

Contact the PAC by calling (723) 232-2215; or visit the PAC on Level 2 of the Rogel Cancer Center.

Additional resources

There are many resources available to patients and families receiving care at the University of Michigan Rogel Cancer Center. All of the programs available to you are described online at https://www.rogelcancercenter.org/support. Phone numbers for some of these resources appear on Page 6 of this handbook.

Online resources

- American Cancer Society: https://www.cancer.org/ or 1-800-227-2345
- Bladder Cancer Network (BCAN): https://bcan.org or 1-888-901-BCAN
- United Ostomy Association of America: https://www.ostomy.org
- University of Michigan Rogel Cancer Center website: https://www.rogelcancercenter.org
- Care Guides from your Clinician *Having an Ostomy*: https://careguides.med.umich.edu/ostomy

Ostomy Resources

How do I find an ostomy nurse closer to home?

- Visit the Wound Ostomy and Continence Nurses Society (WOCN): https://member.wocn.org/page/Nurse_Referral
- *Visit Learning Center" then "View Patient Resources"* Type in your zip code to find a nurse.

Shopping for ostomy apparel:

- Finding ostomy clothing is easy using the Internet. Many companies sell briefs with built-in pouches, lingerie and other types of intimate clothing. Type in the key words **"Ostomy Apparel"** in your web browser.

Sites for travel tips:

- United Ostomy Associations of America Inc. *Air Travel Tips from UOAA and the TSA:* http://www.ostomy.org/Ostomy_Travel_Tips.html

- Hollister: Type “Travel” into the search box: www.hollister.com/us/

Other ostomy products:

If you are interested in additional ostomy product samples or information, below are some helpful web sites:

- Hollister, Incorporated: www.hollister.com/us/ (800) 323-4060
- Convatec, Incorporated: www.convatec.com (800) 422-8811
- Coloplast, Incorporated: www.coloplast.fr (800) 533-0464
- Marlen: www.marlenmfg.com (216) 292-7060
- NuHope: www.nuhope.com (800) 899-5017

Patient to patient

You can also benefit from the experience of others who are successfully recovering and managing their urostomy. See “Recovery Tips for Patients from Patients” found on Page 51 of the Appendix.

Appendix

Before surgery shopping list

To make the transition easier when you return home from the hospital, you may want to purchase the following items **before** your surgery:

- ☐ Larger size pants, pants with an elastic waist or with some stretch as your abdomen will be swollen
- ☐ Loose dresses or yoga-style pants may be more comfortable
- ☐ Suspenders to avoid a tight belt around your midsection
- ☐ An electric razor to shave the hair around the stoma
- ☐ Slip-on shoes to avoid bending at the waist
- ☐ Waterproof, washable mattress pad(s) to protect your mattress from accidental leaking
- ☐ A shower chair or bath tub bench if standing is difficult.
- ☐ Plain, white paper towel or several less expensive washcloths for ostomy care
- ☐ Tilt-style mirror to help you see your stoma during ostomy care
- ☐ A handheld device for picking things up without bending or reaching
- ☐ A watch, timer or phone with alarm to remind you to stand and move around often
- ☐ Friends and family email or phone list so you can keep them updated on your progress
- ☐ Miralax® to help relieve constipation
- ☐ Food items that help relieve constipation (see Page 32)
- ☐ Nutritional oral supplements such as Boost® or Ensure®

Recovery tips for patients from patients

Chances are that other survivors have already dealt with many of the challenges you will face after bladder cancer surgery.

Below are some practical tips from people treated for bladder cancer at the Rogel Cancer Center. From recovering at home, to getting used to new equipment, to developing new habits, we hope you can learn from their experiences:

- Wear your ostomy appliance on the outside of your pants or skirt with a longer shirt to cover the pouch. This will help you empty the urine while you are adjusting to having an ostomy.
- Make sure you always have ostomy supplies on hand. You do not want to run out as you cannot buy them at your local drug store.
- While in bed, you can hang the night drain bag from a plastic coat hanger slid between the mattress and box spring or you can place the bag in a small, clean trash can on the floor.
- To steady yourself when getting out of bed, place a chair next to the bed with the back facing the bed so you can hold onto it. Practice getting in and out of bed with chair support before your surgery to make sure that you have the right chair placed in the right position.
- Keep a pillow handy to hug when you laugh, cough or sneeze.
- Purchase or borrow grab bars to position along the sides of the toilet.
- Prepare enough easy-to-make, healthy food to last the first 2 or 3 weeks after surgery.
- Get a digital thermometer (that you can read) to keep track of your temperature.
- Use a cane or walking stick for support.
- Make plans to find and attend bladder cancer support group meetings.

Blood clots, DVT and pulmonary embolism:

Following major surgery, you are at an increased risk of developing blood clots. Blood clots can lead to serious complications including, deep vein thrombosis (DVT) and pulmonary embolism.

- A **DVT** is a blood clot in a vein of the leg, pelvis, or arm. Without prompt attention, DVTs can enlarge, break loose and travel through the bloodstream to the lungs.

- A **pulmonary embolism** is a sudden blockage of an artery in the lung by a blood clot. This can be life-threatening.

Risk factors for blood clots:

- Recent surgery that involved the legs or belly.
- Staying in bed for 72 hours or more after surgery or a serious illness.
- Remaining inactive for long periods of time, or remaining seated for 6 or more hours, such as during a long flight or car trip.
- Illnesses such as cancer, heart failure, stroke or a severe infection.
- Smoking.
- Being overweight.
- Having blood that tends to clot easily, a condition that may be hereditary (passed down from your parents).
- Taking birth control pills or hormone therapy.
- Pregnancy and childbirth (especially following a cesarean section).

Preventing blood clots, DVT and pulmonary embolism:

- If you are prescribed anticoagulant medicines, take them exactly as directed.
- Get up out of bed as soon as possible after your surgery.
- Exercise to keep blood circulating in your legs.
- Do not stay seated for long periods of time.
  - » If traveling by car, stop every 2 to 3 hours, get out and walk around.
  - » If traveling by bus, train or plane, walk up and down the aisles every hour or so.
  - » Do leg exercises while seated. Pump your feet up and down by pulling your toes up toward your knees and then pointing them down.

- Ask your doctor about wearing compression stockings to help prevent blood clots in your legs. You can buy these with a prescription at medical supply stores and some drugstores.
- Do not smoke. If you need help quitting, talk to your doctor about stop-smoking programs and medicines that can increase your chance of quitting for good.
- Check with your doctor before using birth control pills or hormone replacement therapy.

How to prevent falls while you are at home:

- Set up your furniture so that you can walk around without anything blocking your way.
- If your lighting is dim, use brighter light bulbs. Use a nightlight or keep a flashlight close to you at night.
- Secure electrical cords.
- Remove throw rugs or other loose items from your floor. If you have an area rug covering a slippery floor, make sure the rug does not have any loose or fringed edges.
- Add handrails to stairways.
- Install raised toilet seats.
- If your bathroom is not close to your bedroom (or where you spend most of your time during the day), get a commode. Place it near you so you do not have to walk to the bathroom.
- Install grab bars and handrails next to your toilet and inside your shower. Never use towel racks to pull yourself up because they are not strong enough to hold your weight.
- Apply anti-slip stickers to the floor of your tub or shower.
- Buy a shower chair and a hand-held shower head so you can sit while taking a shower.
- When getting up from a lying position, always sit at the side of the bed or couch for a few minutes before you stand.

- Arrange items in your kitchen and bathroom cabinets at shoulder height so that you don't have to bend too low or reach too high.
- Wear shoes with low heels and slip resistant soles inside and outside the house; avoid going barefoot or wearing slippers.
- Be careful of pets. Have them wear metal tags or bells so that you can hear them.

Other things you can do to prevent falls:

- Exercise regularly. Exercise makes you stronger and improves your balance and coordination. Eat nutritious foods and stay well-hydrated.
- Avoid alcohol.
- Have your doctor or pharmacist look at all the medicines you take, including over-the-counter medicines, herbs and supplements. Some medicines can make you sleepy or dizzy.
    - Have your vision checked at least once a year by an eye doctor. Poor vision can increase your risk of falling.

Other Safety Tips:

- Keep emergency numbers in large print near each phone.
- Put a phone near the floor in case you fall and can't get up.
- Think about wearing an alarm device that will bring help in case you fall and can't get up.

For more information on preventing falls, visit:

- Check for Safety: A Home Fall Prevention Checklist for Older Adults (CDC): https://www.cdc.gov/HomeandRecreationalSafety/pubs/English/booklet_Eng_desktop-a.pdf
- What YOU Can do to Prevent Falls (CDC): https://www.cdc.gov/steadi/pdf/STEADI-Brochure-WhatYouCanDo-508.pdf
- Fall Prevention (Care Guides from your Clinician): https://careguides.med.umich.edu/subject/fall-prevention

Cleaning reusable urinary drainage systems

Why do I need to clean out my urinary drainage bags?

Urinary bags need to be cleaned to dissolve deposit buildup to reduce bacterial growth and odor.

How do I clean out my urinary drainage bags?

1. Wash your hands. Caregivers should wear non-sterile gloves after washing their hands.
2. Drain the urine from the bag into the toilet.
3. Fill the bag with clean water and vigorously shake to rinse and then drain.
4. Choose and make one of the cleaning solution from the list below for use at home:

- **Diluted bleach solution:** use standard household, unscented chlorine bleach (5.25% sodium hypochlorite) mix 1part bleach with 9 parts water (1:1 solution):

Bleach:	**Water:**
1/4 cup	2 1/4 cups
1/2 cup	4 1/2 cups
3/4 cup	6 3/4 cups
1 cup	9 cups
1 1/4 cups	11 1/4 cups
1 1/2 cups	13 1/2 cups
1 3/4 cups	15 3/4 cups
2 cups	18 cups

- **Diluted vinegar solution:** Using distilled, white vinegar (4% acetic acid) mix 1 part vinegar and 3 parts water.

Vinegar:	**Water:**
1/4 cup	3/4 cup
1/2 cup	1 1/2 cups
3/4 cup	2 1/4 cups
1 cup	3 cups
1 1/4 cups	3 3/4 cups
1 1/2 cups	4 1/2 cups
1 3/4 cups	5 1/4 cups
2 cups	6 cups

Multiple studies have shown that a bleach solution kills more bacteria than the vinegar solution. However, a vinegar solution dissolves the gritty deposits that collect inside the tubing better than bleach.

5. Using a water or squirt bottle with a tapered end, pour the cleaning solution through the tubing to fill the empty drainage bag.
6. Shake for 30 seconds to one minute, then allow solution to drain through the drainage port into your toilet or container. Be sure to clean the drainage spigot, spigot hub, cap and connector. Rinse with clean water and allow to air dry thoroughly.
7. Remove gloves, if worn, and wash your hands well when you are finished cleaning.
8. Remember to cover the end of the tubing after it's dry to prevent contamination.

How often should the urinary bags be cleaned?

Perform the cleaning process daily. If the bags are routinely cleaned, they can be used for two weeks to a maximum of 1 month.

Preventing Dehydration

What is dehydration?

Dehydration happens when your body loses too much fluid. This might happen when you do not drink enough water or you lose large amounts of fluids from your body because of diarrhea, vomiting, or sweating. Severe dehydration can be life-threatening. But, even moderate dehydration can be serious and might lead to another hospital stay.

Water and minerals called **electrolytes** help put your body fluids back in balance. Learn the early signs of fluid loss, and drink more fluids to prevent dehydration.

What are the signs and symptoms of dehydration?

- A dry, sticky mouth.
- Dark yellow or amber-colored urine
- Less than 500mls of urine in 12 hours
- Feeling very tired.
- Dizziness or feeling light headed or nausea

If you experience signs of dehydration, you need to drink more fluid and call the clinic.

How do I prevent dehydration?

To prevent dehydration, drink plenty of fluids, enough so that your urine is light yellow or almost clear like water. Choose water and other caffeine-free clear liquids until you feel better. Stay away from drinks with alcohol or caffeine.

If you do not feel like eating or drinking, try taking small sips of water, sports drinks, or Gatorade. Your body has been through a shock, and may need some time for the feelings of hunger and thirst to return. It is important to take in food and drink, so try to coax yourself. Also, get plenty of rest.

If you have kidney, heart, or liver disease and have to limit fluids, talk with your doctor before you increase the amount of fluids you drink.

After discharge from your operation, it is a good idea to record your liquid intake and urine output each day until the first post-operative appointment.

Urine output

You will receive at least two measuring devices at discharge:

- For males: urinal and 2 graduated triangular containers.
- For females: 2 white "hats" for urine and 2 graduated triangular containers.
- If you do not receive these items, please ask for them! You can use a household measuring cup as well.
- Urine should be pale yellow (if it is more amber or dark in color, you need to drink more).
- You should have about 4 cups (approximately 1000ml) urine output every 24 hours.

Liquid intake

Record all liquids in "cc" or "ml", which are the same volume/amount.

- Drink at least 2000 ml or 64 ounces of fluid daily. Best choices are:
  - Water
  - Gatorade or sport drinks
  - Juices
  - Tea - non-caffeine drinks only
  - Protein drinks such as: Boost®, Ensure® or Carnation® instant shakes

  - Ounces can easily be converted to cc or ml by multiplying by 30 (1 ounce=30cc or 30ml).

Remember to read the “cc” or “ml” on a liquid container label to help you.

Follow-up care is important for your health and safety!
Be sure to keep all appointments. Call your doctor if you are having problems. It’s also a good idea to know your test results and keep a list of the medicines you take.

When should I call for help?

Call your doctor now or seek immediate medical care if you have any of the following symptoms:

- Confused and cannot think clearly.
- Dizzy or lightheaded, or you feel like you may faint.
- Signs of needing more fluids: sunken eyes and a dry mouth, and you pass only a little dark urine.
- Cannot keep fluids down.
- Not making tears.
- Skin is very dry and sags slowly back into place after you pinch it.
- Mouth and eyes are very dry.

Who do I call?

If you have any of the signs or symptoms listed above, and for any questions or concerns please contact the University of Michigan, Department of Urology at (734) 647-8902 during business hours (8:00 am – 5:00 pm).

- After business hours and on weekends, please call (734) 936-6267 and ask to speak with the Urology Resident on call.
- If you need to see a doctor right away, please go to the nearest Emergency Room (ER). Ask the ER doctor to contact the University of Michigan urology

resident on call for assistance

After surgery exercises, tips, and tricks

Coughing and deep breathing help to prevent pneumonia after surgery.

Coughing exercise

1. Take a low, deep breath through your nose, expanding your chest and your back as much as you can.
2. Breathe out through your mouth.
3. Repeat steps one and two.
4. Take a third breath, again expanding your chest and back.
5. Hold this breath for 3 to 5 seconds, then cough hard, forcing the air out of your lungs. Hold a folded blanket or pillow over your incision to provide support while coughing.
6. Repeat this exercise three times.

Using an incentive spirometer

An incentive spirometer is a device that helps you keep your lungs clear. During the days immediately after surgery, you will be less active than normal; the spirometer provides exercise for your lungs until you can resume your daily activities.

1. Sit on the edge of your bed if possible, or sit up as straight as you can in bed.
2. Hold the incentive spirometer in an upright position.
3. Place the mouthpiece in your mouth and seal your lips tightly around it.
4. Breathe in as slowly and deeply as possible.
5. As you inhale, a yellow piston will rise toward the top of the column. The yellow indicator should reach the blue outlined area.
6. Hold your breath for 3 to 5 seconds to achieve full lung expansion.
7. Slowly exhale, allowing the piston to fall to the bottom of the column.

8. Rest for a few seconds, then repeat steps 1-7 at least 10 times every hour.
9. After each set of 10 breaths, cough to be sure that your lungs are clear. If you have a surgical incision, support your incision when coughing by placing a pillow firmly against it.

Incentive Spirometer

Plantar extension/flexion exercise

This exercise will help you maintain muscle tone in your legs.

1. While lying in bed, point your toes toward the end of the bed.
2. Next, point your toes up toward your face.
3. Repeat at least 100 times an hour while you are awake.

Walking

Within 1 to 2 days after surgery, a member of the physical therapy team will come to your room and evaluate you to make sure it safe for you to begin walking. Walking soon after surgery has many benefits:

- Promotes breathing
- Improves circulation
- Prevents joint stiffness
- Relieves pressure
- Encourages the return of bowel function

You will be instructed to get out of bed and walk at least six times a day during your hospital stay and to continue a walking regimen when you return home.

Getting out of bed

To get up safely from a lying position, we recommend doing a “log roll.” Here are the log roll instructions:

- Roll over onto your side.
- Bend your knees until your legs are almost hanging over the side of the bed.
- Use your arms to lift your upper body up so that you are sitting on the edge of the bed.
- Push off with your arms to help you stand up.

To view a video of log roll, go to YouTube:
www.youtube.com/watch?v=1xioiSDHaWM

Notes:

Faculty and staff of these programs supplied facts for this handbook: Ambulatory Care Ostomy Nursing Services, Cancer Patient Education, HomeMed, Nursing, Medical Urology Oncology, Urology Oncology Nursing.
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