Treatment Handbook Neobladder

Surgery and Recovery

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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 bladder cancer patients; you and your U-M Cancer Center treatment team have decided on the best treatment plan for you, and you are beginning the journey together.

As you leaf 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 determined that a neobladder is the best urinary diversion option for you. The neobladder, or new bladder, is the alternative closest to your body's own bladder – in fact, it will be constructed from your own tissue and will occupy the same space in your body. But unlike your own bladder, your neobladder needs your help to function properly, which means you will need to develop new skills and routines. The following pages contain the information you will need to help you make the transition to life with a neobladder.

Patients who have the greatest success with this procedure are those who adopt a positive attitude and make a firm



commitment to learning and practicing new things. Remember – you are not alone. We are here to help every step of the way. Our best advice to you is to be patient with yourself and do not hesitate to ask any and all questions – as many times as you need to.

Along with this handbook you should have also received the *Bladder Cancer Handbook*. If you would like additional information about cancer, treatment options and support services, please visit the Patient Education Resource Center (PERC) on Level B2/Ground Floor of the Cancer Center.

Your University of Michigan Comprehensive 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.

The neobladder is a pouch formed from a part of your small intestine. Just like your bladder, it is a reservoir where urine collects before urination. The diagram below illustrates how your body's urinary system works. Urine flows from the kidneys through the ureters into the bladder (and after the surgery, into the neobladder), where it can then be voided (urinated).

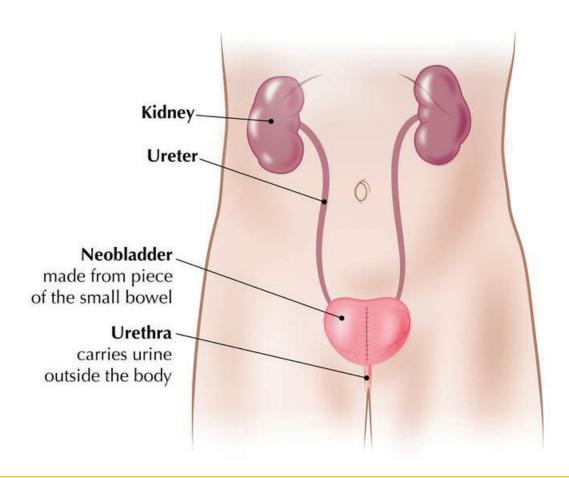
Eventually, after you have healed and your body has adjusted to the neobladder, you will be able to urinate by way of your urethra, using Credé (kree-day) Maneuver (explained later in this handbook). At first, you will have a catheter drain in your neobladder. The catheter drains your urine and allows the neobladder to heal. You will have the catheter at home for about two weeks. Once it is removed, you will retrain your body to urinate with the neobladder.

An overview of the surgical procedure

There are two phases to your surgery. First, your bladder must be surgically removed, a process called a *cystectomy*. In addition to removing your bladder, other organs may be removed during the procedure, including:

- · surrounding lymph nodes
- · the prostate (in men)
- the reproductive organs uterus, ovaries, and fallopian tubes (in women)

After the cystectomy, your surgeon will form the neobladder from a section of your small intestine and attach it to your ureters and urethra.



Preparing for your surgery

All surgical procedures are stressful. You are preparing for major abdominal surgery that will significantly change your life – it is perfectly natural to feel anxious. Information is one tool you can use to counter the anxiety and uncertainty and help you and your loved ones feel ready for the road ahead. This section of the handbook provides an overview of what will happen before, during and immediately after your surgery, and the steps you can take to safely prepare for your procedure.

Your pre-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 neobladder surgery is the best option for you. At that time, appointments with other members of your care team, including a Registered Dietitian, an ostomy nurse (ostomy nurses care for patients with wounds caused by medical treatments, diseases, or injuries. They also provide post-surgery treatment and care for patients with ostomies, which are surgical openings that allow for the elimination of bodily waste.) and an urology nurse will be scheduled for you. 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 a computerized tomography (CT) scan or magnetic resonance imaging (MRI) tests may also be scheduled.

Whenever possible, we prefer that all of these steps be completed at the

University of Michigan, but we will work with providers in your community if that is not possible.

Before your surgery, you may also speak with a U-M anesthesia provider to discuss your anesthetic options, including the risks and benefits of each. This conversation may take place by phone or in person.

The following 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, including dose and frequency. If medications are added, update your list before each appointment. Your list should include vitamins, herbal supplements and over-the-counter drugs, too.
- 3. Before you leave your preoperative appointments, a clinic staff member will give you a list of instructions to follow before you arrive at the hospital for surgery. If you have any questions about any of these details, please ask your doctor or nurse.
- 4. You will need to identify someone who can help you during the first few weeks after surgery. If possible, that person should accompany you to your pre-surgery clinic appointments.

Taking care of yourself before surgery

Developing healthy habits will help you recover and thrive after surgery. Lifestyle changes are best made several weeks before surgery to allow your body to adjust. We recommend that neobladder patients adopt the following self-care strategies in advance of their procedures:

Physical activity

- Your best strategy is to stay as active as you can both before and after surgery. 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 48 of the Appendix.
- We also recommend 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 49 of the Appendix.

Alcohol and tobacco

We strongly encourage you to quit all tobacco use and drink alcohol only in moderation. Taking these steps will make it possible for you to recover much more quickly from surgery.

Diet

- Eat plenty of fruits and vegetables.
- Eat plenty of bread, rice, potatoes, pasta and other starchy foods (choosing wholegrain varieties when possible).
- Drink/eat some milk and dairy foods (choosing 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 and whole soy foods as desired (tofu and tempeh).
- Eat just a small amount or avoid foods high in fat and sugar.
- Drink plenty of water. Your water needs depend on many factors, 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.

1. Purchase supplies

You will need to stock your home with several items to aid you in your recovery. A list of the most common items neobladder patients use can be found in the Appendix on page 40. We recommend you obtain these supplies in advance of your hospital stay. When you return home from your surgery your focus will be on resting, healing, and developing new skills and habits.

2. Arrange transportation

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

3. Arrange for time off from work/school

You will be required to take time off from work or school to recover from surgery. On average, patients need to schedule about three months off. You and your doctor will determine the length of time you will need.

4. Prepare Advance Directives

- Advance Directives are legal documents that allow you to spell out your wishes regarding end-of-life care. Doctors recommend that all patients prepare these papers before surgery, regardless of their condition or the planned procedure.
- A patient's Advance Directives, which include a living will and durable powers of attorney for healthcare

- (DPOA-HC), help their family, friends and health care professionals know their wishes in advance, in the event that they become unable to communicate those wishes.
- Let your doctor know if you have an Advance Directive.
- If you do not have an Advance
 Directive, consider preparing
 them. Ask your doctor or nurse for
 information, or stop by the Patient
 Education Resource Center (on Level
 B2/Ground Floor of the Cancer Center)
 for materials.

5. Familiarize yourself with our online patient portal,

www.MyUofMHealth.org

- If you are not yet registered on the portal, you will receive instructions on how to set up your account. If you do not have access to the internet, patient instructions/education will print with your "After Visit Summary" that you receive at check-out.
- The portal has more information and tips to help you prepare for surgery and on other topics in the Health Library section.

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 indicate which medications you can and cannot take on the day of surgery. Please take any allowable medications with only a sip of water.
- You will get a phone call from pre-op surgery the night before surgery to discuss your medications.
- You may take a shower (no tub baths) before arriving for surgery.
- Do not apply lotions, perfumes, deodorants 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 legal picture ID.

At the hospital

- 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 inserted 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 awaken 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.

On average, neobladder patients stay in the hospital for five to seven days following surgery. During this time, your focus will be on:

- Taking care of yourself and beginning the healing process.
- · Managing pain.
- Maintaining lung function to reduce the risk of developing pneumonia.
- Being active to reduce the risk of blood clots and complications.

An introduction to your care team: "Rounds"

The University of Michigan is a teaching hospital, and many people are involved in your care. The department of Urology is dedicated to training resident doctors. Residents are medical doctors at various stages in their training. Residents make "rounds" with their team, visiting each patient to address immediate needs and carry out the plan of the attending doctor (your surgeon). You will see several nurses and staff members involved in your care.

At U-M, 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 post-operative care.

Communicating with your care team: the Whiteboard

Following surgery you will spend a period of time in the recovery room, after which 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 communicate with you as well.

To improve communications between patients, family and care team members, dry-erase "whiteboards" are placed in every room in University Hospital. During morning rounds, the boards are used to reinforce what is discussed with the patient, including goals for the day, leading up to discharge.

At every 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 may receive pain medication through your IV using a device called a Patient Controlled Analgesia (PCA). The device features a button you push when you need a dose of medication.
- As you progress, you will switch from the PCA to oral pain medication. Oral pain medication lasts longer and provides more consistent pain relief than IV pain medication.
- · Oral medications should be taken with crackers or food, *before* pain becomes more than you can tolerate.
- You can also use alternative therapies to help control pain, including relaxation techniques, massage, listening to music and 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. A nurse will maintain the drains during your hospital stay, monitoring and recording the amount of drainage. Your doctor will determine when the drains can be removed, usually before you are discharged from the hospital. If you are sent home with a JP drain, the nurse will instruct you on how to care for it and monitor drainage. Do not attempt to remove a drain on your own.

Stents

During surgery, ureteral stents were placed in your body. These stents are thin flexible tubes that help drain urine from the kidneys and encourage the connection between the ureters and neobladder to heal. Your stents will likely be removed prior to your discharge; however, if you are sent home with stents, your nurse will provide you with more information.

Preventing post-operative complications

After surgery, patients 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.









Your hospital care team will include different nurses and in some cases a physical therapist, who will instruct you on 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 48 of the Appendix for instructions and exercises.

To prevent falls, remember to ask for help getting out of bed. Your nurse will review the factors that put you at an increased risk of falls during your hospitalization. You will likely be required to have assistance getting out of bed and/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 to care for your catheter and neobladder

After surgery, a nurse on your unit will teach you how to care for your catheter and neobladder, and how to perform an important task called "irrigating" the catheter. The training you receive while in the hospital will be reinforced with written instructions found in this handbook.

We strongly recommend that you designate another person – someone who lives with you or will be staying with you after you are discharged – to participate in this teaching while you are in the hospital. Patients often need both assistance and reminders to perform these tasks correctly and regularly at home.

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 in order to prepare to return home.

- Be sure you have arranged for someone to drive you home. For your safety, you will not be permitted to drive until you are no longer taking narcotic pain medicines, your Foley catheter is removed, 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.
- Before you are discharged, you will be given more specific instructions about your continuing recovery, including when you can return to work and regular activities.

- Arrangements may be made for a home care nurse to visit you after discharge to continue the plan of care and education started in the hospital, assist you and your family members in learning the new skills you will need to care for yourself, and to address follow-up questions and care issues that may arise.
- If you were not able to purchase the supplies you will need at home prior to entering 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 40.

The first weeks after your hospital stay are an important transitional 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; all of these points are covered in this section of the handbook:

- You will have a surgically-placed catheter (called a Foley or indwelling catheter) in the neobladder to empty urine from your new bladder into a collection bag. The catheter and bag will both require regular draining and cleaning.
- Because mucus will build up in your neobladder, both your Foley catheter and your neobladder will require regular irrigation to flush out the mucus.
- You are still healing, so physical exercise will be limited. You will require help with some daily activities, and you will be given hygiene and dietary suggestions to follow. You may not drive until your Foley catheter is removed and you are off narcotic pain medication.

All of this may seem overwhelming at first. You are not alone – this is a challenging time for all neobladder patients. It is important to remember to relax, be patient with yourself, and do not hesitate to call the Urology Clinic at (734) 647-8903 if you have any questions or concerns.

Foley catheter

You will go home with a *Foley catheter*, also called an *indwelling urinary catheter*. The catheter is a flexible hollow tube inserted through your urethra into the neobladder during surgery. The catheter will drain urine into a drainage bag.

To lower your risk of infection, it is important to keep the connection area clean. A nurse will teach you how to wash around the urethral opening (meatus) using soap and water. Men should also place a small amount of bacitracin ointment around the meatus. Continue to clean this area at home four times a day until the Foley is removed by a nurse in the clinic.

Note that you will also need to irrigate (or flush out) the catheter regularly (as explained starting on page 19).

Urine drainage bags

After surgery, a drainage bag (or urinary catheter bag) will be attached to your catheter to collect urine. You will continue to rely on the catheter and drainage bags for about two weeks after you leave the hospital.

You will be given two types of urine collection bags:

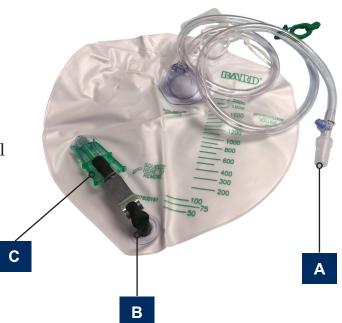
- A larger bag for drainage when you are stationary and at night.
- · A leg draining bag for use during the day when you are more active.

Bedside Collector

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

This allows the urine to flow into a bedside collector while you sleep.
Always keep the night bag below the level of your bladder.

Many people find a bedside collector preferable to getting up during the night to empty the pouch.



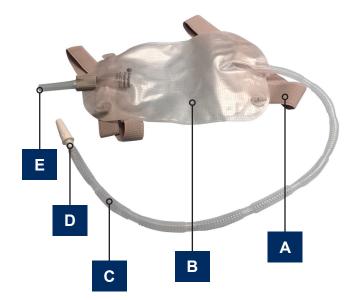
Using your large/nighttime drainage bag

To empty urine from the bag:

- **A.** This is where the bag's tubing connects to the Foley catheter.
- **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.

Using your leg drainage bag

- Position the bag with soft backing against your skin. Adjust the straps until they are comfortable. You may trim excess strap length with scissors.
- · Wear the leg bag below your knee. This will help your catheter drain.
- Make sure that the valve at the bottom of the bag is firmly closed before connecting it to your Foley catheter.
 To close the valve, flip it upward toward the bag until it snaps firmly in place.
- Attach the bag to the end of the catheter by inserting the tapered connector snugly into the catheter port.
- To drain the bag, flip the clamp downward. The flexible outlet tube can be directed to control the outflow of urine. You do not have to disconnect the leg bag from the tubing in order to empty it.



Small/Daytime Drainage Bag

A = Leg Straps

B = Collection Bag

C = Drainage Tube

D = Tapered Connector

E = Valve

Maintaining your drainage bags

- Each time a bag is emptied, wash the connector with soap and water and cover it with the cap provided. The cap can be soaked in soap and water when not being used and rinsed with warm water before being placed back on the connector.
- If maintained properly, urinary collection bags can be reused for two weeks to up to one month. See page 47 of the Appendix for instructions on keeping reusable urinary collection bags clean and free of bacteria and odor.

Mucus

Your neobladder is constructed from a segment of your small bowel. Because the cells lining the intestines produce mucus, you will notice mucus draining out with your urine. The mucus may become so thick that it can prevent urine from passing.

It is very important that you closely watch the build-up of mucus and take these steps to make sure it does not obstruct your catheter or your neobladder:

- 1. Drink plenty of liquids to dilute your urine to make draining easier.
- 2. Consider using over-the-counter (OTC) Zantac®, 250 mg twice daily or Guaifenesin OTC as directed by your doctor. Studies have shown that these can reduce mucus production.
- 3. Irrigate your Foley catheter (following the instructions in this section).

Irrigation refers to gently pushing sterile water into the catheter and thereby the neobladder, then gently pulling out the fluid along with mucus and urine. Irrigating your neobladder is an important process you will begin while in the hospital and continue at home while your Foley catheter is still in place. Once your Foley is removed, you will continue to irrigate your neobladder regularly using a catheter you put in place yourself (instructions for this are found later in this handbook). This process helps reduce mucus build-up that might lead to infection or problems with neobladder healing.

Irrigating your Neobladder

Your neobladder should be irrigated three times a day or more often if needed to prevent mucus build-up, with **sterile** water. While in the hospital, this will be done more frequently. Your nurse will show you the proper procedure and review it with you until you are comfortable doing it yourself.

Use only **sterile water** for the irrigation at home. **Do not use tap or well water.**

Supplies needed:

You will be given these supplies when you are discharged from the hospital:

- Sterile water
- · Tommey (catheter tip) syringe
- · Alcohol wipes
- Bacitracin ointment (men only)
- · Blue clamp
- · Clean measuring cups
- · Blue pads



Directions for irrigating your catheter

- 1. Wash your hands with soap and water, and dry well.
- 2. Have everything ready on a blue pad or clean towel before you begin. Before irrigating, sit in a comfortable position. If someone else is going to irrigate your catheter, it will be easier for them to do if you lean or lie back.
- 3. Pour the sterile water into the cup provided.
- 4. Draw 40-60 ml's of sterile water into the Toomey syringe.
- 5. Clamp the Foley catheter with the blue clamp.
- 6. Wipe the part of the Foley catheter that connects into the tubing with an alcohol wipe.
- 7. Gently roll the cap off of the catheter with your thumb; do not pull on the catheter. Make sure you anchor the catheter with one hand so you do not pull the catheter too far forward. (Have someone help you if needed.)

- 8. Remove the tube from the catheter and wipe the tubing tip with alcohol and cap with the clean cap.
- 9. Unclamp the clamp.
- 10.Gently push the sterile water into the catheter. Do not force the water; it can cause discomfort.
- 11.Gently pull the water out of the catheter with the same syringe. Note how much mucus is in the syringe. If there appears to be a significant amount of mucus, irrigate again using the same syringe. You can repeat the process several times until you are comfortable that the amount of mucus seen has decreased.
- 12. You may not pull as much liquid out as you pushed in. This is normal; it will drain out. The Foley may stick to the neobladder wall, making it difficult to pull out. Do not force it.
- 13.Uncap the Foley tubing connected to the large bag or leg bag. Wipe with an alcohol wipe before reinserting the tubing into the Foley.
- 14.Men: Cleanse around the tip of the penis where the catheter enters the urethra with soap and water, and then pat dry. Apply bacitracin ointment to the area for comfort.
- 15. Women: Clean around the Foley catheter with soap and water, using a spray bottle or shower hose, then pat dry. If there is discomfort around the Foley catheter, apply a lubricant such as KY Jelly® (do not use petroleumbased products).

Signs that your catheter needs additional irrigation

If you experience leaking around the catheter, it may indicate a mucus plug and you should irrigate.

 If you notice a decrease in urine or urine that is dark yellow or tea colored, or if you see mucus in the tubing, you should irrigate.

If you develop pelvic discomfort or cramps, or if the catheter is not draining freely, you must irrigate the catheter immediately to prevent blockage caused by mucus that is collecting in your neobladder.

Clean-up after each irrigation

- 1. Wash your hands using warm water and soap.
- 2. Clean the syringe with a small amount of the sterile water.
- 3. Wash the tip of the syringe with soap and hot water.
- 4. Cleanse the tip of the syringe with alcohol and replace the cap.
- 5. Wash the measuring cup and cap.
- 6. Store supplies in a clean place. A plastic container with a lid works well.

"On-the-Go" Kit

To irrigate your catheter when away from home, keep a supply of these items in a clean container or re-sealable plastic bag. Store the kit in your purse, backpack or vehicle glove box.

- 2 syringes pre-drawn with sterile water and capped.
- · Alcohol wipes.
- · Bacitracin (for men).
- · Hand sanitizing wipes.

Physical Activity

- To help you build strength, continue walking when you return home, gradually increasing the distance you walk.
- Listen to your body and do not become overly tired. Plan to take time for regular rest periods throughout the day.
- You may walk up and down stairs when you return home, but go slowly.
 Plan your activities so you need only go up and down stairs a few times a day.
- Avoid heavy lifting (greater than ten pounds) or strenuous activity for about four weeks. Heavy lifting can cause increased abdominal pressure which can strain your incision, possibly leading to a hernia.
- Avoid bending for four 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 or while your Foley catheter is in place. A good rule is to not drive until you are pain free, as pain can be distracting and may slow your reaction time.
- When riding in a car for an extended time, take a break every two hours to stretch your legs. This will help you avoid circulation problems.

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

Following major surgery, patients 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 and can be life-threatening.

To lower your risk of developing these complications, learn the risk factors and the steps you and your doctor can take to reduce your risk.

Please review the detailed information on blood clots, related complications, and when to call for help at the beginning of this handbook.

Hygiene

- 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 tub or swim. These activities should be avoided until your incision has fully healed and you are cleared by your doctor. We recommend using unscented bacterial soap, as scented soaps can irritate the incision.
- 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 seven days. If they do not, you
 may remove them after seven days.

Diet

- Return to your normal eating habits.
 A healthy, well-balanced diet promotes healing.
- Drink plenty of water. 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.

Preventing constipation

- After surgery, patients 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:

- · Stay 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.

A Few Final Words on Home Self-Care

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.

- Be sure to make and keep all clinic appointments, and call your care team if you are having problems.
- 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, and write down any questions or concerns as they come up so that you can review them with your care team.

Your first follow-up

Two weeks after your surgery you will have your first follow-up visit at the U-M Urology Clinic. At that time you can expect the following:

- Your Foley catheter will be removed.
 (You may have a Cystogram prior to catheter removal.)
- You will have any surgical skin staples removed.
- If you still have stents, they may be removed.

Before you come to the clinic, you will be given a prescription for an antibiotic to prevent a urinary infection when removing the catheter. Take your first dose, in the morning, the day before your appointment. Take this medication as directed until you have finished all of it.

Additional follow-up appointments

You will be seen in the clinic again in six 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 diagnostic scans.
- You will meet with a Registered Dietitian.

As time goes on, you may still wish to be seen by your primary care doctor to address any additional concerns. In addition, we would like you to keep in touch with the U-M Urology Clinic so we can follow your progress.

For survivors like you who had their bladders removed due to cancer, the neobladder is the closest thing to a natural bladder. However, your neobladder requires you to take a much more active role to ensure it functions properly – we call that *managing your neobladder*.

Now that you have recovered from surgery and the Foley catheter has been removed, it's time to shift your focus to developing the skills and routines you will need to manage your neobladder. This section of the handbook focuses on those skills and daily routines. Specifically, developing new daily bathroom and hygiene routines, including:

- Alternative methods for passing urine (voiding).
- Tracking urination frequency and volume.
- Handling urinary leakage (incontinence) which is a common occurrence in neobladder patients.

With so many new skills and habits to master, it's natural to feel overwhelmed – all neobladder patients feel this way. With patience and practice, you, too, will adapt to these changes and develop a routine that feels right for you.

Passing Urine (voiding)

How to pass urine

The process of urinating is different with your neobladder. To safely and efficiently pass urine from your neobladder, you must do two important things which are explained in this section:
Relax your pelvic floor muscles.
Place pressure on the neobladder, either by contracting your abdominal muscles or by pushing down on the neobladder.

About the pelvic floor muscles

Your pelvic floor is the surface of your body that touches the seat of a chair when you are sitting. The pelvic floor muscles support the urinary and reproductive organs and surround the urethra.

You put your pelvic floor muscles to work when:

- You tighten them to stop your urine flow when urinating.
- You tighten them around your anus to prevent the passage of gas.
- You tighten or squeeze them while sitting in order to lift the area between the anus and genitals (called the perineum) up and away from the surface of the chair.

When the pelvic floor muscles are contracted or tightened, the urethra is pinched off and urine cannot pass through. When the pelvic floor muscles are relaxed, there is little resistance to passing urine from the neobladder.

Relaxing your pelvic floor muscles is an essential part of emptying your neobladder. To get used to relaxing your pelvic floor muscles, try the exercises on page 50 of the Appendix.

Emptying your neobladder

Once you have relaxed your pelvic floor, you can proceed to put pressure on your neobladder in order to empty it. There are two methods of exerting pressure on the neobladder:

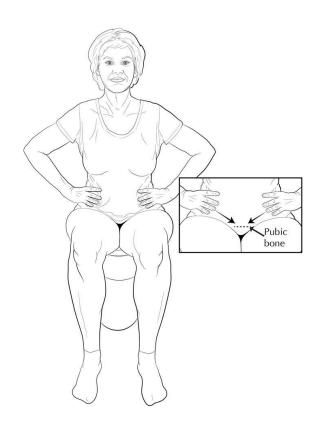
- 1. By contracting your abdominal muscles.
- 2. By pushing down on your neobladder with your hands.

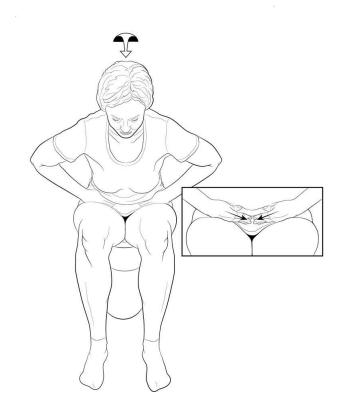
Tips for emptying your neobladder

- 1. Sit all the way back on the toilet seat with feet supported; don't hover over the seat. Relax and release pelvic floor muscles while breathing deeply; do not rush or strain.
- 2. Lean forward in order to move urine out of a pocket where it might collect.
- 3. Practice double voiding: Wipe, stand up, shake your hips, sit down, lean forward and see if more urine comes out.
- 4. Keeping your lips, jaw, and mouth open will help with relaxation of the pelvic floor during urination.
- 5. Breathe in through nose and breathe out through mouth or gently hiss through the teeth. Gently direct the air down and forward toward your neobladder, while contracting your abdominal muscles (bearing down). Urine should begin to flow.
- 6. Try whistling. A sustained outward breath may help to increase pressure within the abdomen.

If you cannot empty your neobladder by contracting your abdominal muscles, try pushing down on your muscles using the Credé maneuver as described on page 29.

The Credé maneuver





- 1. Place your right thumb on your right hip bone and your left thumb on your left hip bone.
- 2. Extend your fingers towards your midline, at the level of your belly button, and gently press in on your abdominal wall.
- 3. Lean forward.
- 4. Move your hands down smoothly towards your pubic bone, while pushing in on your abdominal wall.
- 5. Once you get to the level of your pubic bone, push deeply inward and downward. Urine should begin to flow.

Note: Patients often find it easier and more efficient to empty the neobladder when sitting down; however, if you prefer, you can try emptying your neobladder while standing.

When to pass urine (void)

In the beginning, the capacity of your neobladder is small. By following the steps outlined below, you will gradually increase your neobladder's storage capacity. You should start this program once your urinary catheter has been removed.

Week 1 – Urinate <u>every two hours</u> around the clock (you will need to set an alarm to wake you at night).

Week 2 – Urinate <u>every three hours</u> around the clock (you will need to set an alarm to wake you at night).

Week 3 – Urinate <u>every three hours</u> while awake and every four hours at night (if you urinate right before going to bed and first thing in the morning, you should only have to get up once in the night).

Week 4 – Urinate <u>every four hours</u> during the day and night (if you urinate right before going to bed and first thing in the morning, you should only have to get up once in the night).

After Week 4 – Continue to urinate every four hours during the day. You may want to get up at least once during the night in order to help prevent leaking. If you do not get up at night, you will not injure the neobladder, but you are likely to have some leakage and may be wet in the morning.

Once you have completed this cycle, your goal is to store no more than 400-cc's (about 14 ounces) of urine in your neobladder before emptying it.

The frequency at which you pass urine should be determined by that volume or quantity of urine. Holding too much urine in the neobladder may make it more difficult to empty it.

Self-Catheterization and Neobladder Irrigation

In addition to passing urine with one of the methods outlined previously, on a regular basis you will need to pass a catheter into your neobladder to help with the following:

- 1. To check how completely you are emptying your neobladder.
- 2. To drain any urine you are unable to pass on your own.
- 3. To irrigate mucus from your neobladder.

Before your surgery, you were taught how to self-catheterize. Once your indwelling Foley catheter is removed, you will learn more about self-catheterization and receive a patient education handout outlining the steps in the process.

Supplies for self-catheterization

- Catheters you will be given two different catheters:
 - A curved-tip Coude catheter.
 - A straight-tipped (#16 FR Regular) catheter.
- · Sterile packet of lubrication.
- 60cc Toomey syringe.
- Saline solution.
- "Urinal" (for men) or "Hat" (for women) to capture urine in the toilet for measurement.

About the catheters

- Try each type of catheter and use whichever inserts the easiest.
- If using a Coude, remember to insert it with the tip curving up.
- You can re-use your catheter as long as you wash it with antibacterial soap and water, rinse it well, and allow it to completely air dry.
- We recommend that you use a new catheter each week. If your insurance covers the use of a new catheter daily, do so.

Self-catheterization and irrigation schedule

Weeks one and two after Foley removal:

Self-catheterize to void and irrigate the neobladder twice per day, once in the morning and again at bedtime. Call the Urology Clinic at the end of week one to review your results. You may need to return to the clinic within one week for follow-up; this will be determined at discharge.

Weeks three and four after Foley removal:

Self-catheterize to void and irrigate the neobladder once per day at bedtime, or more often if needed due to mucus buildup.

Week five and beyond:

Your voiding diary will be reviewed by a member of your care team either in person or by phone. If your urine residual volume is less than 100 ml for three consecutive voids, then you can stop catheterizing.

Important:

If the catheter is not draining well, it may be due to mucus plugging the tip. Try irrigating the catheter using the same technique used for the Foley catheter (outlined on page 20). If irrigating doesn't help, pull the catheter out, clean off the mucus, and reinsert it.

Do not allow your neobladder to hold too much urine before voiding. You should maintain a volume of 400 cc's of urine or less in your neobladder at any time.

If you experience any of the following:

- · You are unable to void
- · You are drawing out a significant amount of mucus when irrigating
- · You feel your neobladder is bloated or over-distended
- · You experience back or side pain

You may need to self-catheterize and irrigate your neobladder more often than the schedule recommended above.

Recording Frequency and Volume: Voiding Diary

To evaluate your neobladder function and assess how well you are recovering from surgery, fill out your voiding diary as completely as you can.

The chart on page 34 tells your care team how much fluid you are drinking (fluid intake), how much urine you make (urine output), and how often you empty your neobladder each day. It also documents the storage capacity of your neobladder and tells the team how efficiently you are voiding your neobladder, and if you have any urinary leakage (incontinence). Bring the chart with you to your follow-up appointments.

You will be given a container that fits under the toilet seat (called a "urinal" for men and a "hat" for women) to capture urine for measurement. You can also purchase an inexpensive measuring cup for use when you are away from home. For the remainder of your first year with the neobladder we ask that you measure and record your fluid intake and urine output for two full days before each clinic visit. The numbers that you provide will help us to identify problems early and take steps to correct them.

- · Choose days which will be convenient for you.
- They do not have to be two days in a row.
- On the days that you measure and record, you should also use the self-catheterization procedure at bedtime to check for and record any residual urine.

Reviewing your results

It is essential that you complete the chart and bring it with you to each appointment, whether it is with the doctor or the nurse practitioner.

In general, the volume of fluid you drink should be greater than the volume of urine that you void. If the volume of urine that you void is consistently greater than the volume of fluid that you drink, you will become dehydrated.

Call the Urology Clinic at the end of week 1 to review your results. The clinic staff may adjust your instructions, depending on how efficiently you are emptying your neobladder. Bring your chart from week 2 with you to your clinic visit.

Urinary Leakage (incontinence)

Initially, all neobladder patients experience some urinary incontinence. This improves as your body heals and you retrain your bladder function. Urinary incontinence typically resolves during the daytime hours, but may persist at night when your body is most relaxed.

You will need to purchase pads or briefs to protect your clothing. At night, you may initially need a larger, more absorbent pad or combination of a pad and a brief. If you choose to wear a brief, use a pad inserted in a brief at night.

| Fluid intake and type | | 8oz tea, 4oz OJ | | | | | | | | | | | | |
|--|-----------------|-----------------|--|--|--|--|--|---|--|--|--|--|--|--|
| Sensation and/or pain 1=mild 2=moderate 3=severe | 1 | | | | | | | | | | | | | |
| Urgency 1=mild 2=moderate 3=severe | 2 | | | | | | | | | | | | | |
| Activity during leak | Running | | | | | | | | | | | | | |
| Pad change? Yes/no | Yes | | | | | | | | | | | | | |
| Amount leaked 1=drops/damp 2=wet-soaked 3=emptied bladder | 2 | | | | | | | | | | | | | |
| Catheterized urine volume (cc or ounces) | | | | | | | | < | | | | | | |
| Voided urine volume (cc or ounces) | 250 сс | | | | | | | | | | | | | |
| Time (am/pm) | 7:00 am 7:30 am | 8:00 am | | | | | | | | | | | | |
| Date | 01/01/20 | 01/01/20 | | | | | | | | | | | | |

Frequency and Volume Chart

Strengthening your pelvic floor muscles

As discussed earlier, relaxing your pelvic floor muscles is an important step in voiding with your neobladder. It is equally important to strengthen those muscles in order to improve urinary control and reduce urinary incontinence.

The Kegel exercises are done to strengthen pelvic floor muscles. Initially, we encourage you to set aside specific times during the day to do these exercises. Once you have gained expertise, you will find that you can do Kegels virtually any time and in any place, even while doing other activities. Don't do any Kegels if you have a catheter in place.

Key points to remember

- If you drain more than 150 cc's of residual urine through the catheter, call us.
- Constipation makes it harder to empty your neobladder. See page 24 for tips on preventing constipation.
- You may be prescribed a drug that will help decrease mucus production in the bowel. This is because part of your small bowel was used to create your new bladder, and that tissue will continue to produce mucus for some time. You may take this medication for up to a year.

- Relaxing your pelvic floor muscles is the key to emptying your neobladder completely. For men, sitting on the toilet seat rather than standing to urinate may help you to relax. For women, facing the back of the toilet seat as opposed to facing forward may help you relax. Don't be afraid to experiment.
- Be vigilant about your new bathroom habits, especially the first year of your recovery. Don't let your neobladder become overly full. Empty your neobladder routinely and completely.
- Keep yourself well-hydrated to keep the mucus thin. Irrigate your neobladder if you notice that mucus production has increased, or if you have to strain more to void urine.
- Remember, your neobladder grows stronger and more efficient during the first one to three years after surgery. *Practice* and *patience* are the keys to adjusting to your neobladder routine.

Support and Coping

The U-M Department of Urology hosts a Bladder Cancer Support Group for newly diagnosed patients, patients undergoing treatment or family members. The group actively participates in activities such as 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 Cancer Center Urology Clinic at (734) 647-8903 for more information, dates and times.

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, and/or you may have new feelings about your body after surgery. How you choose to treat these changes is a very personal decision.

It is important to maintain a dialog with your doctor about how bladder removal may affect your sexuality. Begin that conversation before your surgery, and address the topic again when you return to the clinic for your first post-surgery checkup. Be sure to ask your doctor or nurse any questions you have about body image or function. He or she may refer you to a program at the U-M Comprehensive 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.

To learn more about adapting sexually after bladder surgery, you can visit the Patient Education Resource Center (PERC) on level B2 of the Comprehensive Cancer Center. They have two brochures: Sexuality for the Woman with Cancer (American Cancer Society) and the University of Michigan Health System's Center for Sexual Health. The PERC also has books on the subject that you may check-out. To contact the PERC, call (734) 647-8626.

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 or implants.

Find out more

For more information about adapting sexually after bladder surgery, visit the Patient Education Resource Center (PERC), located on level B2 of the Comprehensive Cancer Center or call them at (734) 647-8626.

In addition, the U-M Department of Urology has certified sexual counselors and sexual therapists who are available for consultation. Your doctor or nurse can refer you to these counselors.

The Practical Assistance Center (PAC)

The Practical Assistance Center (PAC) helps connect patients to resources within the U-M Health System, including:

- · Clinic social workers.
- UMHS Financial Services, which handles billing concerns and payment programs.

The PAC is also there to help when patients require resources above and beyond those offered by the U-M Health System. For example, the PAC can help patients and families determine if they qualify for financial assistance from cancer-oriented or other charitable organizations to help pay for:

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

Contact the PAC by calling 877-907-0859; or visit the PAC on Level 1 of the Cancer Center.

Additional resources

There are many resources available to patients and families receiving care at the University of Michigan Comprehensive Cancer Center. All of the programs available to you are described in the *Patient & Family Support Services Handbook*. A copy of the *Handbook* is included in your *New Patient Toolkit* and at the Patient Education Resource Center (PERC) on level B2 of the Cancer Center. The PERC also has a complete list of events and resources to assist you during your cancer treatment and recovery. Phone numbers for some of these resources appear on the inside cover.

Online resources

- American Cancer Society: www.cancer.org or 1-800-227-2345
- Bladder Cancer Network (BCAN): www.bcan.org or 1-888-901-BCAN
- U-M Cancer Center website: www.mCancer.org

Patient to patient

You can also benefit from the experience of other patients who are successfully recovering and managing their neobladders. See "Recovery Tips for Patients from Patients" found on page 41 of the Appendix.

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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:

- · Pants and shorts with elastic waistbands.
- · Slip-on shoes.
- Rubberized flannel-backed sheeting (at least two yards) to use as mattress pads and/or to cover furniture.
- Reusable/washable bed pads to reduce the need to change bed sheets during the night.
- · Disposable bed pads (blue pads).
- · A shower chair or bath tub bench.
- · Two or more thermal blankets.
- · A reclining chair (you can expect to take multiple naps during the day).
- · Antibacterial wipes.
- · Hand sanitizing wipes.
- · A five-gallon bucket to keep your leg bag in while showering, etc..
- · Several dozen inexpensive washcloths.
- · An electric razor to use the first few days after surgery.
- · Incontinence pads for use after your catheter has been removed.
- · A handheld device for picking things up without bending or reaching.
- · A watch or timer to remind you to stand and move around often.
- · A phone or e-mail list for updating family and friends on your progress.
- · Zantac® to help relieve indigestion and reduce the production of mucus.
- Milk of Magnesia® or Miralax® to help relieve constipation.
- · Food items that help relieve constipation (see page 6).
- · Nutritional oral supplements such as Boost® or Ensure®.

In addition, check with your insurance provider to determine where you should obtain your catheter supplies.

You Are Not Alone: Recovery Tips 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 bladder cancer patients treated at U-M. From recovering at home to getting used to new equipment to developing new habits, we hope you can learn from their experiences:

- While using a catheter, wear oversized athletic warm-up pants with snaps or leg zippers, or convertible hiking pants (with lower legs that can be zippered off to create shorts) for discrete access to the catheter and bag. Make sure the pants can accommodate the night bags, which are larger than the walking bags.
- A five-gallon plastic bucket is a very useful night-time receptacle for the larger catheter bag. It may become your constant companion around the house.
- Get a shower chair, bench or use a lawn chair (make sure it's the right height) in your shower. You may feel lightheaded when showering and need to sit down.



- While showering, use the five-gallon bucket to hold the bag on the floor next to the shower, or hang the bag on a hook that can be temporarily attached (with adhesive) to the wall next to the shower.
- While in bed, you can hang the bag from a plastic coat hanger slid between the mattress and box spring, or you can place the bag in the bucket on the floor.
- Even if you are using a rubberized protector above your sheets, also protect your mattress with a plastic sheet placed under the bed sheets. A large plastic garbage bag can work in a pinch.
- 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. Experiment with 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.
- Put a pillow between your knees while sleeping on your side.
- · Purchase or borrow grab bars to position along the sides of the toilet.
- Have enough easy-to-prepare, healthy food on hand for the first two or three weeks after surgery.
- Use an alarm on a watch or cell phone or a kitchen timer to remind you not to remain seated for too long.

- An inexpensive (\$10) digital thermometer is a convenient way to keep track of your temperature.
- A cane or walking stick might be useful for support.
- Pack a travel bag with supplies like wipes and paper towels. Keep it ready for when you leave the house.
- Make plans to find and attend bladder cancer support group meetings.

Preventing Blood Clots and Other Complications

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 lifethreatening.

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 six or more hours, 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.
- 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 remain seated for an extended length of time.
 - If traveling by car, stop every two to three 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: Tips for Patients and Caregivers

What are the risk factors for falling?: Anyone can fall, but some factors can make it more likely for you to fall. Some risk factors for falls are:

- · If you have fallen before
- · Being fearful of falling
- · Feeling weak, tired, or forgetful
- Numbness or tingling in the feet or legs
- · Difficulty walking or unsteady walking
- · Having poor vision
- Feeling lightheaded, disoriented or dizzy
- Being dehydrated and having poor nutrition
- · Using a cane or walker
- · Having anxiety or depression
- · Taking many medications
- · Taking certain medications such as:
 - Medications that make you feel sleepy, such as Nyquil®, Tylenol PM®, Sudafed®, and other over-thecounter medications and herbal supplements
 - Sleeping pills
 - Fluids into a vein (called IV or intravenous fluids)
 - Laxatives
 - Medications to prevent seizures
 - Pain medications
 - Some antidepressants
 - Water pills (diuretics)
- Mixing alcohol and certain medications

How to Prevent Falls While You Are Receiving Treatment:

- Bring someone with you who can help you get around.
- · Ask for a wheelchair to use while you are receiving treatment.
- Have someone help you while you're in the dressing room or bathroom.
- When getting up from a lying position, always sit at the side of the bed or exam table for a few minutes before you stand up.
- If you use a cane or walker, bring it with you and use it when you come for treatment.

If you feel dizzy or weak, let someone know you need help!

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.

Caring for Reusable Urinary Drainage Systems

Urinary drainage bags require routine cleaning to dissolve deposits that build up and to help reduce bacterial growth and odor.

Follow these steps to keep bags clean:

- 1. Wash your hands. Caregivers should also wash their hands and wear sterile gloves.
- 2. Drain the urine from the bag into the toilet or container.
- 3. Fill the bag with clean water and shake vigorously to rinse, then drain. Perform this step twice.
- 4. Make a diluted solution of chlorine bleach using 1 part bleach to 10 parts water (another acceptable mix is 4 ounces of bleach to 1 gallon of water). To make a 1:10 solution, you need 1 part bleach for every 9 parts water. A good amount to start with is:
 - · ¼ cup bleach
 - · 2 ¼ cup water

Carefully pour the bleach into a jar first, then add the water. Mixing the solution in this order will prevent the bleach from splashing on you. If you do get any bleach on your skin, wipe it off immediately with a damp cloth. If you need to make a larger amount of disinfectant solution, increase the amounts of bleach and water accordingly, using the same proportions as above (½ cup bleach with 4½ cups water, ¾ cup bleach with 6¾ cup water, etc..).

- 5. Pour the solution onto the drainage spigot, spigot hub, cap and connector.
- 6. Using a funnel or a water bottle with a spigot, pour the bleach solution through the tubing and into the empty drainage bag and shake for 30 seconds to one minute, then allow it to drain out the drainage pot. Allow to air dry thoroughly.
- 7. Wash and dry your hands well when cleaning is complete.
- 8. Remember to cover the end of the tubing after it is dry to prevent contamination.

It is recommended that the above cleaning process be done at least every other day. If the bags are routinely cleaned, they can be used for two weeks to a maximum of 1 month.

After Surgery Exercises and Tips

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 three to five 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 following 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 the 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.

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 one to two days of 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 promotes breathing, improves circulation, prevents joint stiffness, relieves pressure and 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

Relaxing Your Pelvic Floor

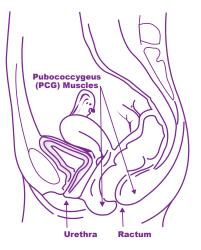
Pelvic floor relaxation exercise

- 1. Roll a towel up like a tube. Position the towel-tube between your legs so that one end of the tube is in front of you and one end behind. Sit on the tube.
- 2. Inhale.
- 3. Exhale. As you do, attempt to lightly lift the pelvic floor up and off of the towel.
- 4. Inhale. As you do, relax your pelvic floor so that it lowers back down to rest on the towel.
- 5. Exhale. As you do, gently push your pelvic floor further down onto the towel.

Strengthening Your Pelvic Floor Kegel exercises

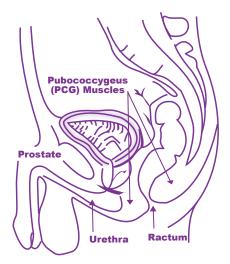
Kegels are pelvic floor muscle exercises that help to prevent urinary and fecal incontinence. They are usually started four to six weeks after the Foley catheter is removed.

Before you can exercise your pelvic floor muscles, you must locate the muscles and become familiar with squeezing or tightening them:



Women:

- 1. Imagine that you are stopping the flow of urine midstream. (Do Not perform as an exercise on the toilet.)
- 2. At the same time, imagine you are also trying to stop passing gas.
- 3. Squeeze or tighten your pelvic floor muscles by imagining you are pulling the muscles up and in. Some women find it helpful to imagine trying to pick up a marble with your vagina, or trying to keep a tampon in or draw it further into your body.
- 4. Gently close the vaginal/anal openings.
- 5. Lift, close and squeeze.
- 6. Imagine bringing your tail bone towards your pubic bone.
- 7. Do not hold your breath while squeezing pelvic floor muscles, and avoid tightening the inner thigh and buttock muscles.



Men:

- 1. Imagine that you are stopping the flow of urine midstream. (Do Not perform as an exercise on the toilet.)
- 2. At the same time, imagine that you are also trying to stop passing gas.
- 3. Gently close the anal opening, squeezing and lifting.
- 4. Some men find it helpful to imagine pulling the penis back into the body ("pulling the turtle back into the shell"), walking into cold water, or trying to pick a raisin up with your anus.
- 5. Imagine bringing your tail bone towards your pubic bone.
- 6. Do not hold your breath while squeezing pelvic floor muscles and avoid tightening the buttock muscles.

With these basic skills, you can perform both endurance and short/quick Kegel exercises.

Endurance Kegels

- 1. Contract (tighten) your pelvic floor muscles and hold the contraction for 3-5 seconds. Remember to exhale while you are doing this.
- 2. Relax for 3-5 seconds.
- 3. Repeat steps 1 and 2 for a total of 10 repetitions.
- 4. As your strength and control improve, you will be able to hold the contraction for a longer time interval. Gradually, try to work your way up to tightening your pelvic floor muscles and holding the contraction for 10 seconds followed by resting your pelvic floor muscles for 10 seconds. It may take several weeks to work up to a 10-second hold.
- 5. Once you are able to hold the contraction for a longer time interval, try to increase the number of repetitions from 10 to 15.

Each session of endurance Kegels should be followed by a session of short/quick Kegels.

Short/Quick Kegels

- 1. Contract your pelvic floor muscles and hold the contraction for one or two seconds.
- 2. Relax your pelvic floor muscles for one or two seconds.
- 3. Repeat steps 1 and 2 for a total of five repetitions.

Frequency and Duration of Kegel Exercises

Endurance Kegels should be held for 5 to 10 seconds, followed by a 10 second rest before repeating. Repeat this combination 5 to 10 times, 3 times per day. Short/Quick Kegels should be held for 2 seconds, followed by a 5 second rest before repeating. Repeat this combination 10 times, 3 times per day.

Note that excessive Kegels will fatigue your pelvic floor. Perform as instructed by your Physical Therapist or health care provider.

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

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