Kingston Health Sciences Centre

Centre des sciences de la santé de Kingston

A New Beginning…Orthotopic Neobladder Care

Information for patients who are preparing for neobladder surgery (or who have a neobladder).

Hôpital Hotel Dieu Hospital

Hôpital Général de Kingston General Hospital

Contents

Introduction

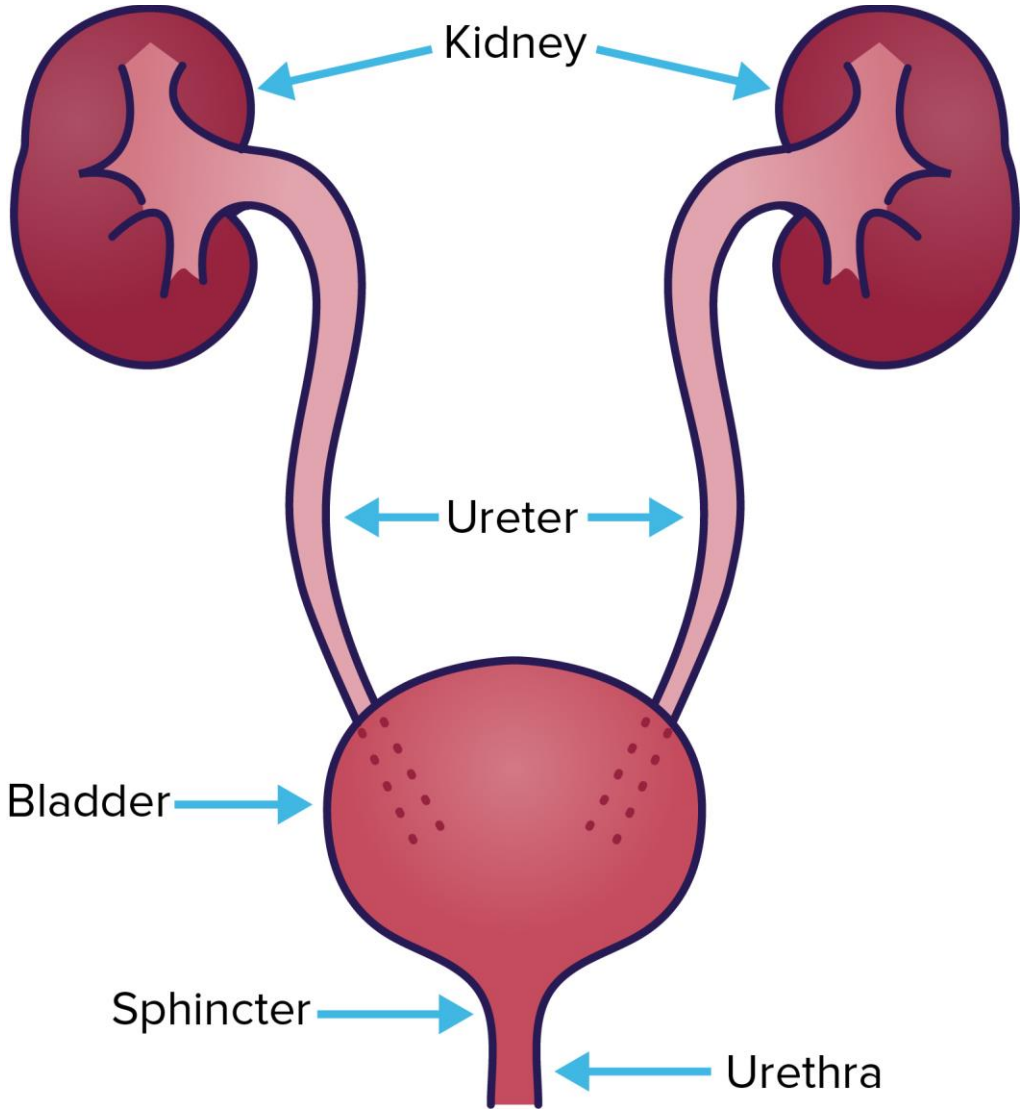
Your surgeon has told you that you need to have your bladder removed. This surgery is called a cystectomy. An orthotopic neobladder is an alternative to having an ileal-conduit urinary diversion. You may have a lot of questions, but cannot find the words to ask them. This booklet will try to answer them. Many people feel this way before their neobladder surgery. You are not alone in feeling this way. Many people live long and full lives after their neobladder surgery. For them and for you, a neobladder is a new beginning.

This book is yours to keep. It tells you about the surgery and the neobladder. This book tells you how to care for your neobladder. It also tells you how to return to your usual way of life.

There is space for you to write notes or questions on pages 42-43. Many health care providers are available to assist you and your family such as nurses, surgeons, social workers, physiotherapists, dietitians and pharmacists (and others) as you prepare and recover from surgery.

The urinary tract

The urinary tract consists of two kidneys, two ureters, one bladder and one urethra.
The kidneys filter waste from the blood and the kidneys get rid of this waste from the body by producing urine. The urine is made in the kidneys and flows down the ureters to enter the bladder. The urine is stored in the bladder. The bladder is a muscular organ that stretches as it fills with urine and contracts when it is emptied. The urine passes out of the bladder through the urethra. The sphincter muscle at the base of the bladder controls the flow of urine out of the bladder.



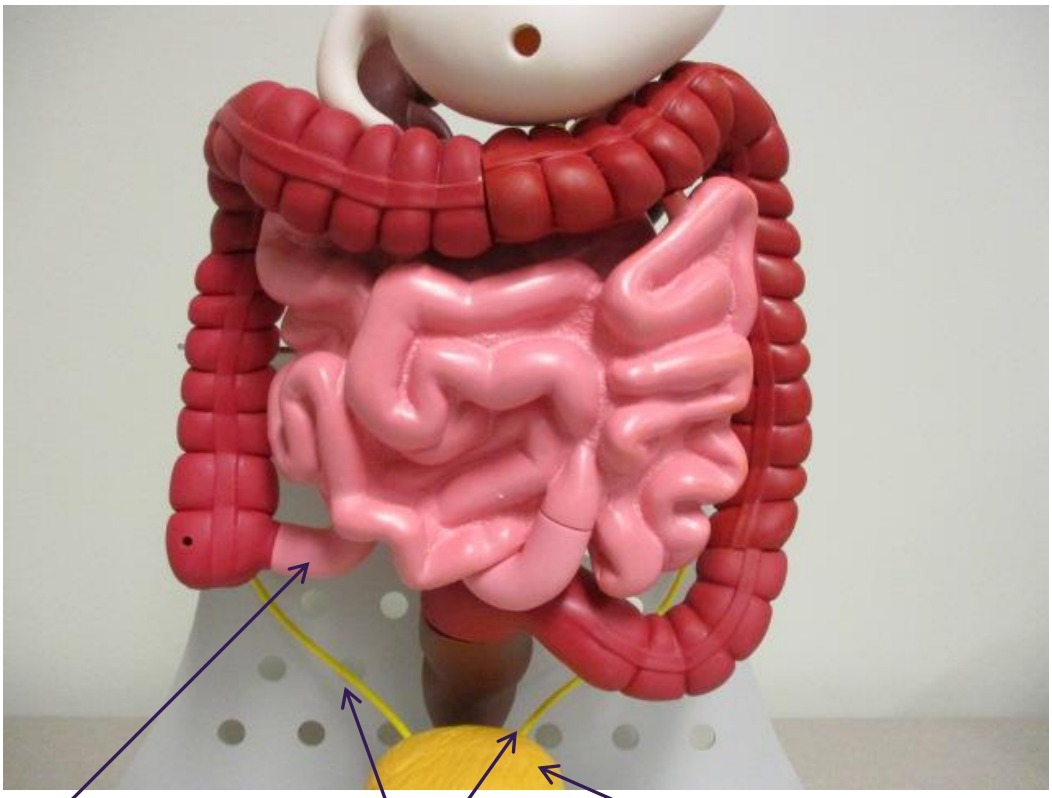
What is a urinary diversion?

When the bladder must be removed or bypassed, a new exit for the urine is needed to divert the flow of urine from its usual pathway. This is called a urinary diversion. The most common type of urinary diversion is an ileal-conduit. With this surgery, a portion of the small bowel is used to capture the urine and a surgical opening is created through the wall of the abdomen (a stoma) to allow the urine to exit the body.

What is an orthotopic neobladder?

Your surgeon may explain that you can consider an orthotopic neobladder as another treatment choice. The main feature of this surgery is the absence of a stoma. An orthotopic neobladder is a surgical alternative to having an ileal-conduit; it is a bladder substitute that is placed in the same location as the old bladder being removed. The reservoir will allow for the storage of urine so that it may exit the body through the urethra.

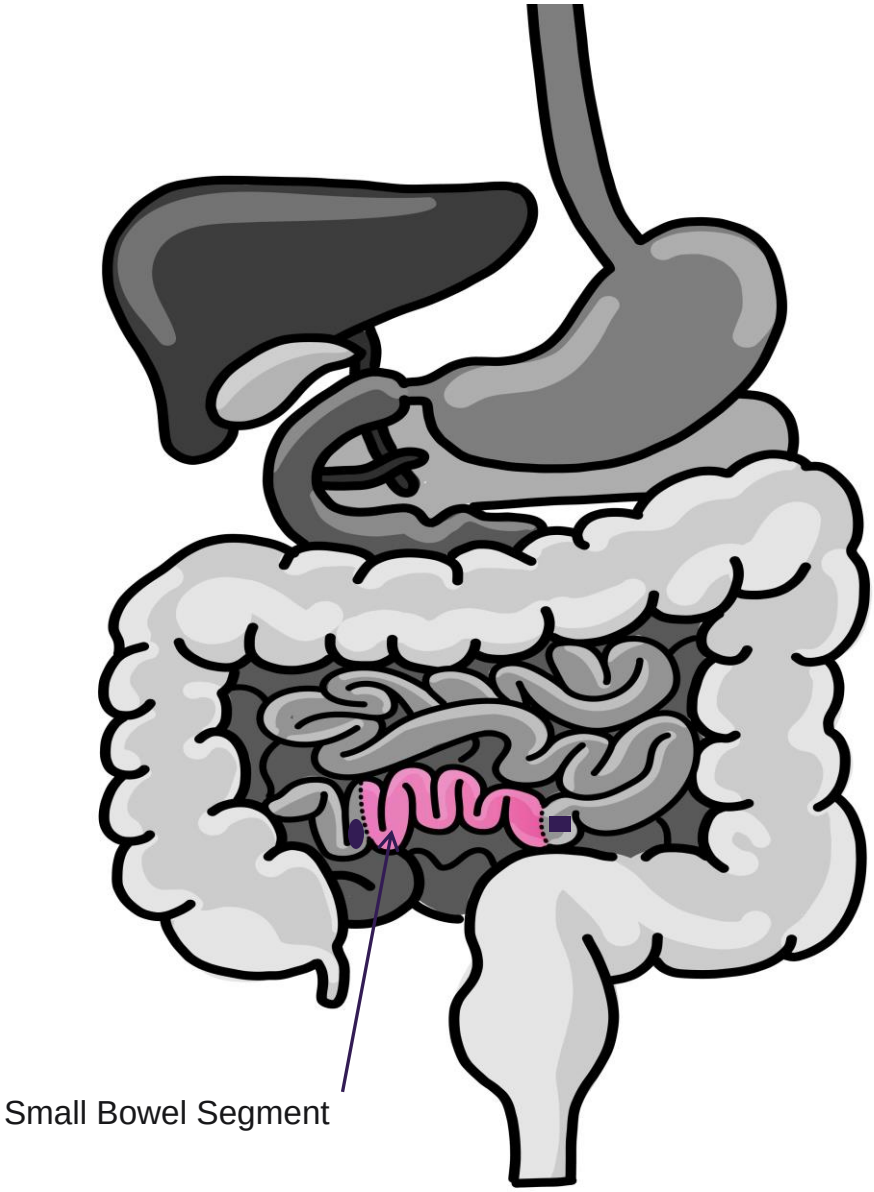
The following diagram illustrates the anatomy of the bladder, ureters and small bowel prior before any surgery.



In the neobladder surgery, the surgeon forms an internal pouch from approximately a 60cm piece of small bowel that is removed from the digestive tract. The bowel is looped together to create the neobladder. The ureters are stitched to the top end of the pouch. The lower end of the pouch is stitched to the urethra. The urine produced by the kidneys flows down the ureters, into the reservoir to be stored. The neobladder is designed to stretch over time and store urine. You then pass urine or "void" from the pouch by relaxing the muscles in your pelvic floor and bearing down with your abdominal muscles. Your neobladder does not have the ability to contract as did the old bladder. Stents are placed either inside the reservoir by attaching them to the urethral catheter using sutures or they may exit the body through a small opening in the abdomen. Stents protect the sutured sites.

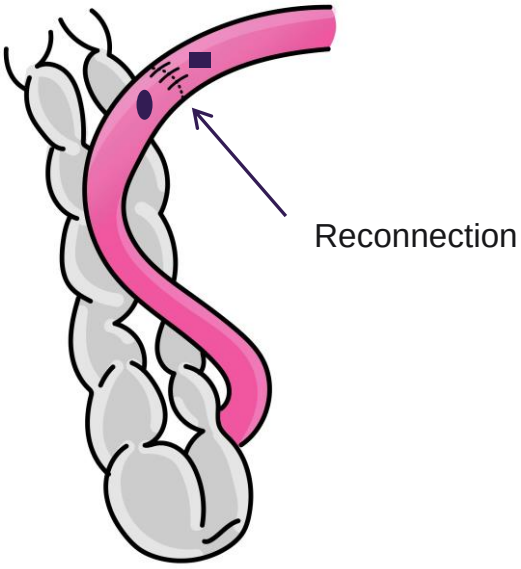
Step One:

The small bowel segment is removed.



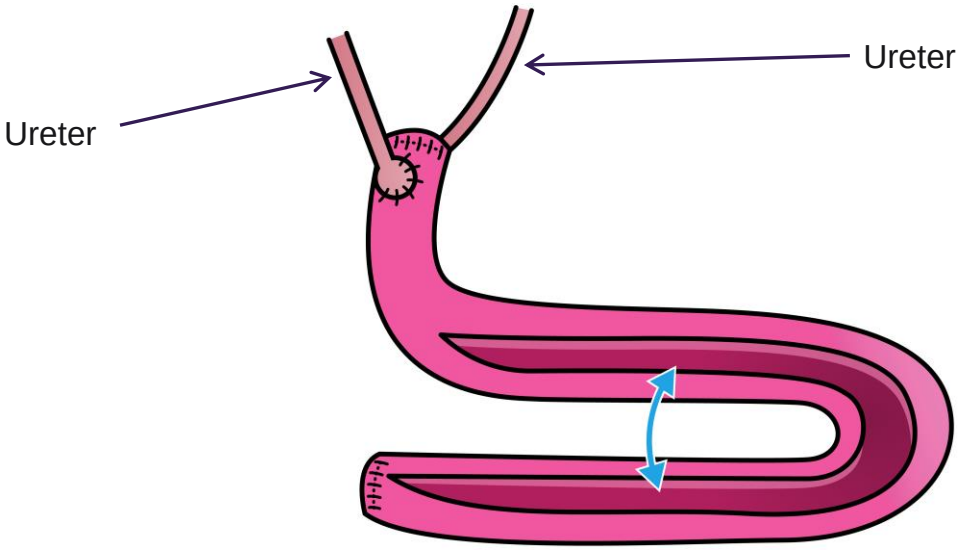
Step Two:

- The remaining small bowel ends are reconnected together after the segment is removed.



Step Three:

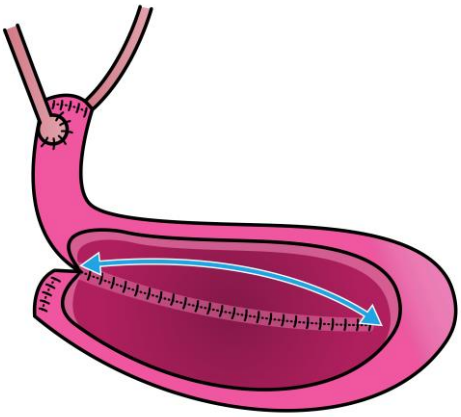
- The top and bottom ends of the bowel segment are closed with sutures.
- Ureters are sewn into the top end of the bowel segment.
- The remaining bowel segment is opened up.



Bowel Segment

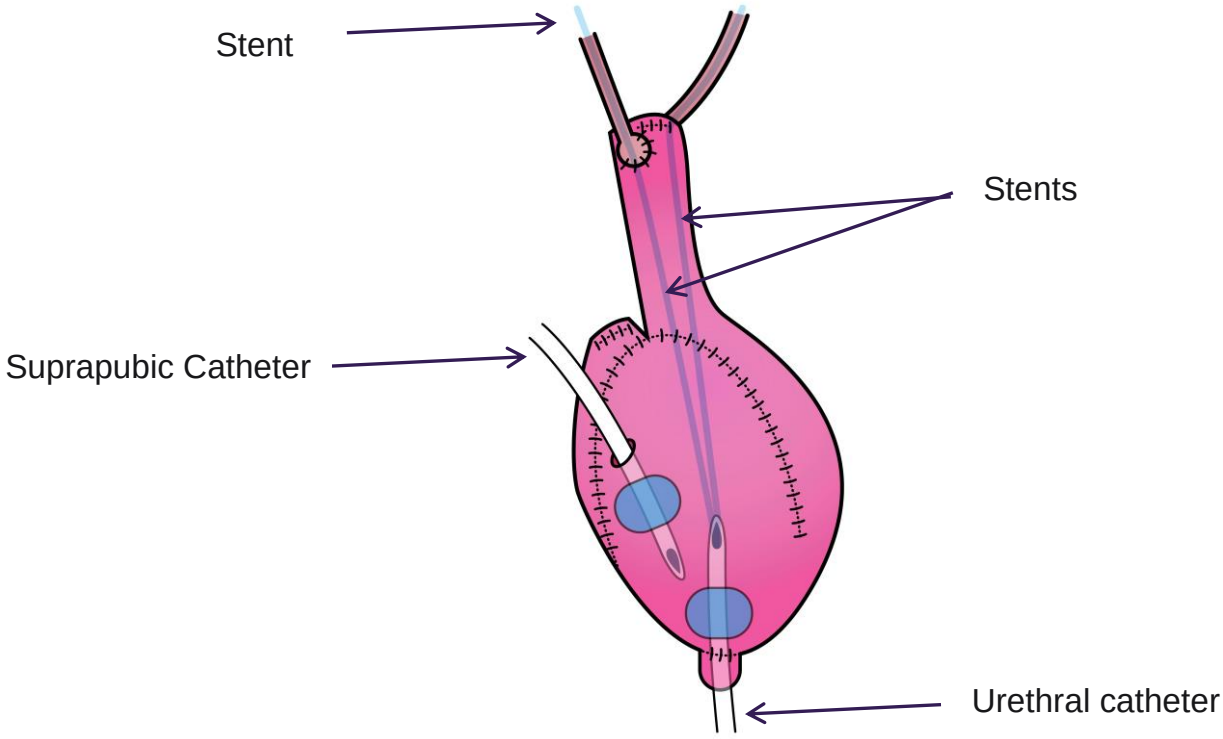
Step Four:

- The opened small bowel edges are sewn together to create a reservoir

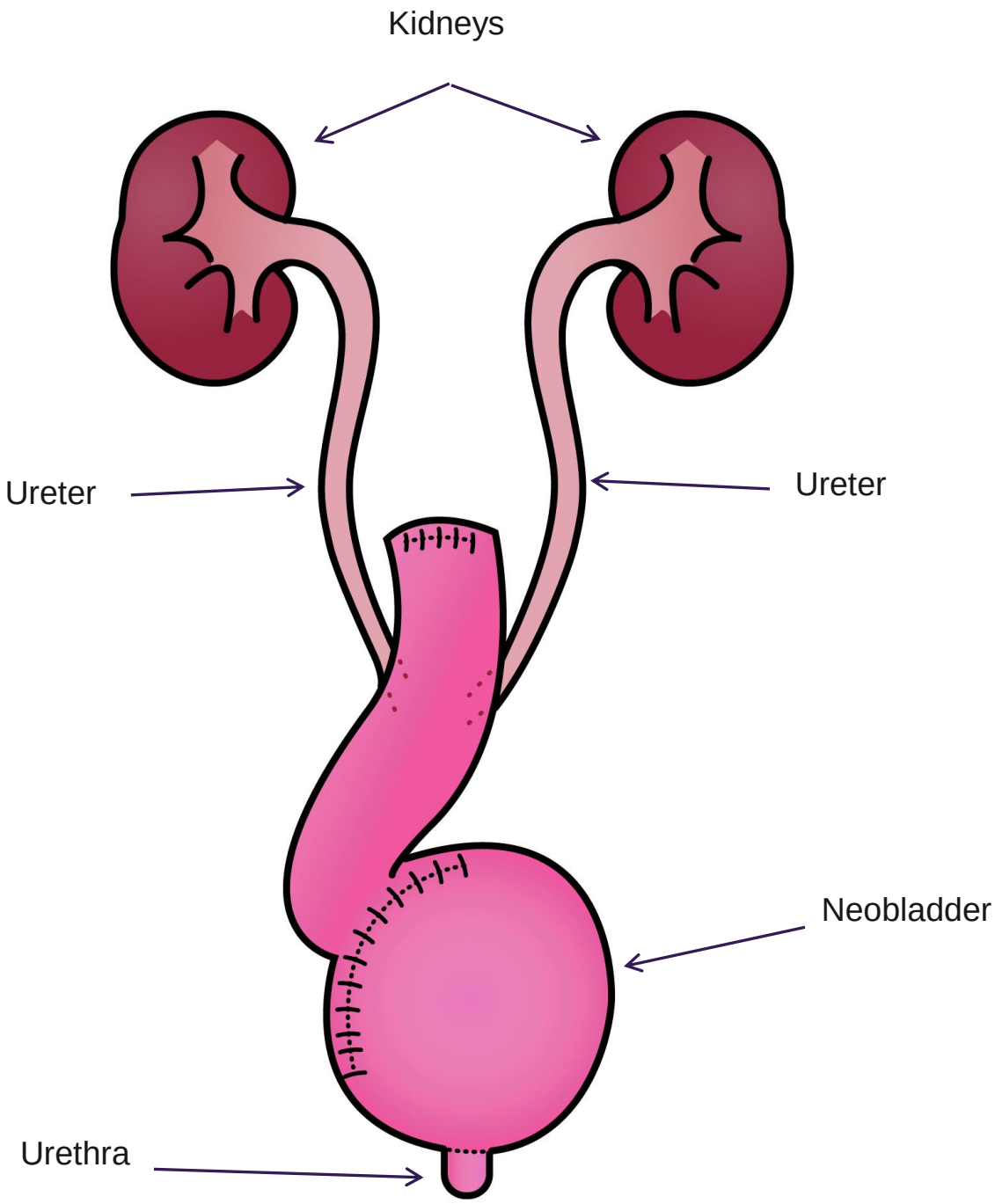


Step Five:

- The neobladder is sutured to the urethra.
- Stents are placed to protect the connected sites.
- Stents are either anchored to the urethral catheter (as shown) or exit the body in a separate small abdominal wound (not shown).
- A urethral catheter is placed to protect the sutured connection.
- A suprapubic catheter may or may not be used.



The following diagram illustrates the anatomy of the urinary system after the neobladder has healed.



Why you need a neobladder

There are several reasons for needing a neobladder. Your surgeon will explain why you need a neobladder.

Bladder cancer is the most common reason for needing a neobladder.

Not all patients are candidates for a neobladder due to the extent of their disease. In addition, in order to be considered for a neobladder, you must:

- Demonstrate the functional ability to self-catheterize
- Demonstrate the willingness to adhere to catheterizations
- Demonstrate the commitment to comply with a voiding re-education plan
- Be willing to accept urine incontinence for at least 4 to 10 weeks after surgery and wear absorptive products
- Recognize the need for long-term urology follow-up.

Before your operation

Your surgeon tells you the date of your operation and arranges for you to come to the Pre-Surgical Screening Centre for tests before your operation. This may include x-rays, a cardiogram, and blood tests.

Kingston Health Sciences Centre has Nurses Specialized in Wound Ostomy Continence, referred to as the NSWOC. They help you learn about your neobladder. The NSWOC from Kingston General Hospital (KGH) site will meet with you to explain what to expect at the time of your operation. In addition, the NSWOC will discuss the impact of having a neobladder on your day-to-day activities and will teach you how to take care of your neobladder. Potential complications and how to manage them will also discussed.

If the neobladder surgery can not be carried out as planned, the alternative would be to create an ileal-conduit. You need to be prepared in the event this happens. The NSWOC examines your abdomen before surgery and selects the best location for a stoma in case it is required. Your input is helpful since your lifestyle, clothing and specific needs are considered before choosing the site. Every effort is made to place the stoma in the best possible location. Sites vary depending upon the anatomy of each person.

You may eat solid foods until 12 midnight the night before your surgery unless you had a bowel prep (laxative). If you had a bowel prep, follow the instructions that were given to you.

You may have up to 3 glasses (800mL) of a high carbohydrate (sugary) drink the night before surgery, and 1.5 glasses (400mL) carbohydrate rich drink 3 hours before surgery. It is important to have sugary drinks before your surgery because it will help you feel stronger after your surgery and recover faster. Examples of high carbohydrate drinks are: apple juice, cranberry cocktail and iced tea. **Do not eat or drink anything within 3 hours of your surgery.**

On the morning of your operation, you will register in the Same Day Admission Centre (SDAC) at KGH located on the second floor of the Connell Wing. After you have registered, you will meet your nurse who will ask you a few questions. Your nurse prepares you for your operation. You put on a hospital gown. An intravenous (IV) is placed in your arm. This gives you fluids and medications that you need during the operation. Once this process is complete, you will be transferred to the operating room. If your family is staying in the hospital while you are in surgery, they will be shown to the waiting room in the Same Day Admission Centre.

During your operation

Your surgeon performs your operation through an incision in your abdomen.

Your surgeon will complete your surgery through an open approach. The surgeon will make one 10 to 20 cm cut (incision) in your abdomen to perform the surgery. The surgeon will remove the bladder and remove a segment of bowel for creating a neobladder. The operation takes 6 to 8 hours.

You will require the following:

- **Urethral catheter** from the urethra to drain urine from your neobladder. It will be also used to irrigate mucus from the new reservoir.
- **Ureteric stents** to drain urine from your kidneys and away from the neobladder. These may be placed in one of two methods based on your urologist's preference:
  - External approach: These will be placed through a small incision on your abdomen and covered with a pouching system. The stents will be removed in approximately 7 days.
  - Internal approach: These will be internalized and sutured to the tip of the urethral catheter. The stents will be removed in approximately 1 month along with the catheter.
- A **dressing** is placed over your incision(s).
- An **abdominal binder** is placed around your abdomen to support your abdominal incision.

You may require the following:

- **Abdominal or pelvic drains**. These small tubes drain away extra fluid from your abdomen and pelvis.
- **Support stockings or special inflatable stockings**. These help the circulation in your legs and help prevent blood clots.
- **Suprapubic catheter**. This tube is placed in the lower abdomen. It drains urine from the internal pouch and is used to irrigate mucus from the internal pouch.
- **Nasogastric (NG) tube.** This tube goes up the nostril; and into your stomach. It drains fluid from your stomach to keep it empty.

This will happen while you are still asleep during the surgery.

From the time of your operation, there is urine flowing from your neobladder therefore, your catheter(s) will be attached to a urinary drainage set or a leg bag.

After your operation

After your operation, you are taken to the recovery room until you are awake. From there, you go to a surgical unit. Your nurse:

- Makes sure that you are comfortable
- Checks your tubes, drains and vital signs
- Looks at your incision
- Helps you with your breathing, splinted coughing, and leg exercises

Recovery takes time and patience. **Gentle activities, movement, and nutrition** are extremely beneficial to getting back on your feet and a successful road to recovery after surgery.

It is important to remember everybody's experience may be different, but this is what you might expect:

Day/Evening of surgery:

- You may **start drinking clear fluids** 2 hours after your surgery
- You **sit up at the side of the bed** and dangle your legs

The first day after surgery:

- **Chew 1 piece of gum** 3 times a day for up to 5 minutes
- You **drink/eat liquid food** as tolerated
- You **sit up in a chair 3 times per day** for at least 1 hour
- You may **walk in the hallway** as tolerated
- **Observe** your urethral/suprapubic catheter irrigations completed by the nurse

In 2 to 3 days:

- **Chew 1 piece of gum** 3 times a day for up to 5 minutes
- You may **start to introduce soft to solid foods** as tolerated
- **Sit up in a chair for all meals**
- You may **walk in the hallway 4 times per day**, as tolerated
- **Participate** in flushing your urethral/suprapubic catheters with assistance

In 4 to 7 days:

- **Chew 1 piece of gum 3 times a day** for up to 5 minutes
- **Eat solid food** as tolerated or as ordered by your doctor
- **Sit up in a chair for all meals**
- You should aim to **walk in the hallway a minimum of 4 times per day**, as tolerated
- **Fully participate** in your urethral/suprapubic flushes
- Discuss and understand any dietary changes
- Review information about potential complications, products and financial supports
- Be discharged from the hospital

As you gradually recover from your surgery, the NSWOC teaches you how to take care of your neobladder and prepares you for going home. It is important that you become as independent and comfortable as possible with caring for your neobladder and irrigations. The hospital nurses will also reinforce the teaching and support you in your learning. With time, you will develop confidence and the care becomes routine. Support from your family and friends is very helpful. If you wish, someone close to you may be included in your teaching sessions. Never hesitate to ask questions.

Before your discharge, your surgeon wants to ensure you have met four milestones which are:

- Being able to tolerate your food
- Having a return of bowel function (passing gas and having a bowel movement)
- Having your pain under control
- Being able to perform your irrigations independently

About your urine

After your operation, the urine will be reddish in colour because it contains some blood. This will take 2 to 3 days to clear, and the urine will then be yellow in colour.

The lining of the bowel secretes a jelly-like substance called mucus. As the urine flows through the neobladder, some of the mucus mixes with the urine and is expelled. A large amount of mucus will be present after your surgery. Although the amount of mucus decreases over time, the urine will always contain some shreds of mucus.

How to irrigate your catheter

The inside of the bowel makes a clear jelly-like fluid called mucus. Because the orthotopic neobladder is made from part of your bowel, there will be mucus inside of it. This mucus may block your catheter(s). Irrigating your neobladder through the suprapubic and/or urethral catheters removes the mucus. The NSWOC shows you how to irrigate your neobladder. You practice irrigating your catheter before you leave the hospital.

Follow these steps:

1. Wash your hands with soap and water and dry them with a clean towel.
2. Draw 50mL of normal saline into a clean catheter-tip syringe. Make sure the saline is at room temperature.
3. Remove the plug from the end of the catheter. Connect the syringe to the end of the catheter.
4. Push the normal saline gently into the catheter.
5. Remove the syringe and let the normal saline drain out through the catheter.
6. Watch how much urine, saline and mucus returns from the catheter.
7. Repeat as necessary until the return is clear. A small amount of mucus is normal.
8. If there is no urine from the catheter, there may be mucus blocking the catheter. Gently draw back on the catheter using the empty syringe.
9. If there is no return, connect to the drainage bag.
10. Wash your hands with soap and water and dry them with a clean towel.
11. Walking around may help move the mucus and allow the urine to start draining.
12. If there is no return after 2 to 3 hours or you feel cramping and pain, call your NSWOC or urologist.
13. If you have a urethral catheter and a suprapubic catheter, you will need to irrigate both catheters, one at a time while clamping off the other one. The NSWOC will show you how to do this.

Irrigate your catheter(s) every 4 hours, and whenever you suspect that there may be mucus blocking your catheter. The catheter will not drain any urine if there is mucus blocking it. You will need to continue to do this until the urethral catheter is removed.

Making your own saline

You can make your own saline for catheter irrigation by following these simple steps:

1. Put 10 mL (2 level tsp) of salt in 1 Liter (4 cups) of boiled water.
2. Let it cool.
3. Store in the refrigerator.
4. Bring approximately 125mL (1/2 cup) of the normal saline to room temperature before using it to irrigate your catheter.

An alternative method to making your own saline involves the following steps:

1. Buy a 4-Liter jug of distilled water.
2. Add 40 mL (8 tsp) of salt and shake until dissolved.
3. Store in the refrigerator.
4. Bring approximately 125mL (1/2 cup) of the normal saline to room temperature before using it to irrigate your catheter.

Urethral tube care

It is important to keep the tissue around the urethral catheter healthy. Make sure that the area is washed with soap and water once a day. Dry well. You can tape the tube against your leg to secure it in place.

Suprapubic tube care (if applicable)

It is also important to keep the skin around the suprapubic catheter healthy. To do this, wash the skin surrounding the tube once a day with soap and water. Dry well. You can tape the tube against your body to secure it in place. Report any redness, soreness and drainage to your nurse.

Stent pouching (if applicable)

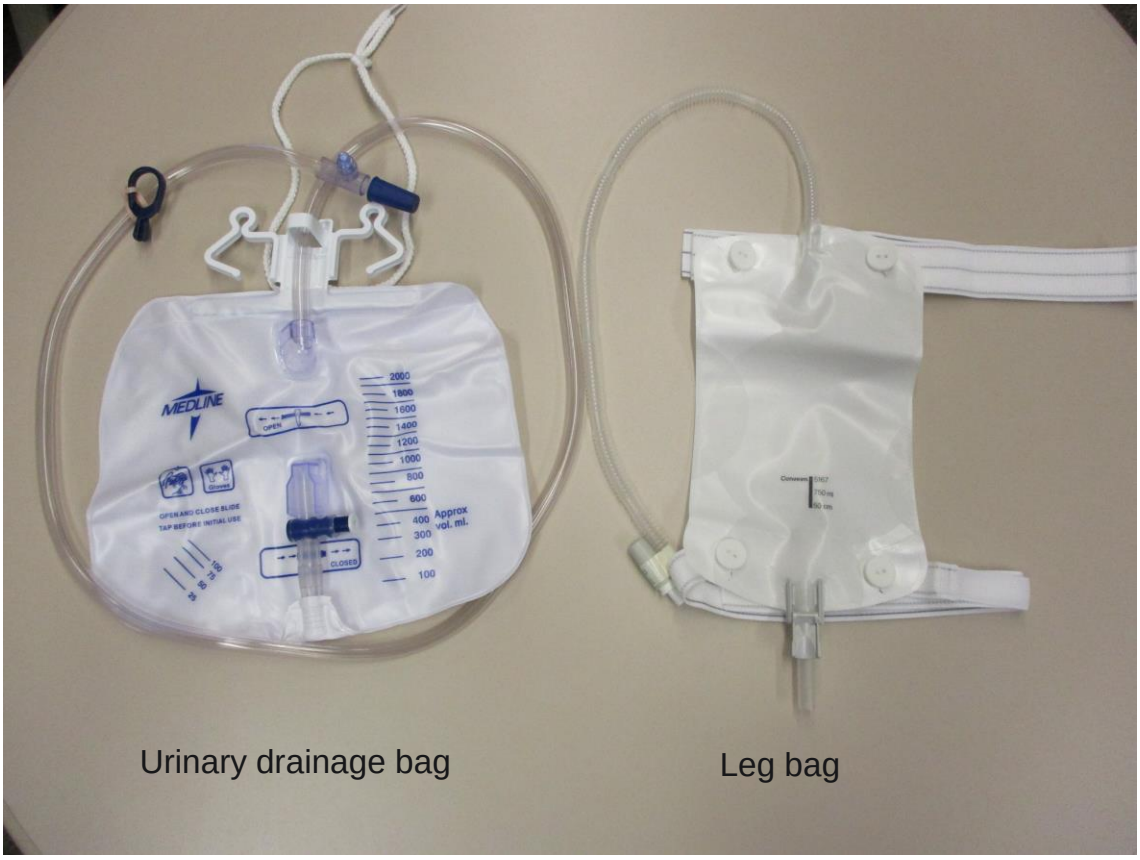
It is important to keep the skin around the stents healthy. To do this, a temporary plastic pouching system is placed around the tubes to collect the urine drainage. If the stents are not removed in the hospital, continue to empty the pouch when it is approximately 1/3 full while at home. Pouches can stay in place for up to 7 days. Your nurse will be able to assist you with pouching changes until they are no longer required. Report any redness, soreness to your nurse.

About your urinary drainage bag or leg bag

A urinary drainage bag collects urine from the urethral catheter. The urinary drainage bag can be hung on the edge of your bed at night. To prevent kinking and pulling of the drainage tubing, you may wish to tape it to the inside of your leg or run the tubing inside your underwear or pyjama bottom.

You may wish to use a leg bag for ease of mobility during the day. The leg bag is secured to your leg with two straps.

Regardless of the type of bag you are using, you will need to empty it into the toilet throughout the day as it fills with urine. There is an outlet at the bottom of each bag for ease of emptying. You will be shown how to empty your bag(s) while you are in the hospital.



Urinary drainage bag

Leg bag

How to clean your urinary drainage or leg bag

It is important to keep your equipment clean and free from odour. The urinary and leg bag(s) need to be cleaned daily.

1. Wash your hands with soap and water and dry them with a clean towel.
2. Empty the bag into the toilet.
3. Remove the bag from the end of the catheter. Place a plug into the open end of the catheter.
4. Rinse the bag by running warm tap water into it to partially fill the bag.
5. With a plastic squeeze bottle or a large catheter tipped syringe, put 15 mL (1 tablespoon) of liquid laundry detergent into the bag through the tubing.
   - Use a low sudsing laundry detergent or any detergent with the “HE” (high efficiency) symbol.
6. Shake the bag and empty it into the toilet.
7. With a second squeeze bottle or catheter tipped syringe, put 250ml (1cup) of vinegar solution (¼ cup white vinegar and ¾ cup water) into the bag through the tubing.
8. Shake and leave the solution to soak in the leg bag for 30 minutes.
9. Empty the bag into the toilet.
10. Rinse the bag again with running warm tap water through the tubing.
11. Shake the bag and empty it into the toilet.
12. Remove the plug from the catheter and connect the bag to the catheter.
13. Plastic water bottles and syringes can be re-used but should be washed in soapy warm water and dried before using them again
14. Wash your hands with soap and water and dry them with a clean towel.

How to void though the urethra

Three to four weeks after your surgery you will have an X-ray called a cystogram. The neobladder is filled with a dye. An X-ray shows if the neobladder has any leaks. If there are no leaks, the neobladder is considered to be “healed”. This means that the urethral catheter can be removed. If the neobladder is not healed, the urethral catheter may stay in place a little longer until it heals. After the urethral catheter is removed, you will need to re-learn to void through your urethra.

At first, you will void frequently. This is because the neobladder can only hold small amounts of urine until it learns to stretch. When your neobladder can hold more urine, you void less often. **You must follow a voiding schedule.** Set an alarm clock at night in order to keep to this schedule.

Initially, the neobladder may only hold 100mL of urine. By following the schedule the NSWOC nurse gives you, the capacity should increase to approximately 350 mL at 6 months and 500 mL at 12 months. Your voiding volume should never exceed 500 mL of urine. You must not allow the neobladder to overfill. It is ideal to void every 4 to 6 hours. You need to void more often if your volume exceeds 500 mL

Always void first thing in the morning and before you go to bed at night. Never skip a voiding or irrigation. If your activities conflict with your voiding schedule, void and/or irrigate before the event. Then, return to your regular schedule.

As the neobladder fills, you will feel fullness as mild cramping. If you are used to standing to void, it might be easier to sit on the toilet to void. You empty your neobladder by bearing down with your abdominal muscles and relaxing your pelvic muscles. This is called the Valsalva maneuver. The abdominal muscles squeeze the neobladder to empty it. The pelvic muscles control the urine flow from the neobladder. You may have to press on your abdomen just above the pubic bone in order to start the stream of urine.

Double voiding is encouraged to ensure the neobladder is empty. This means voiding twice, immediately one after the other.

It is important to measure and record the amount of urine. Report the urine amounts to your surgeon so that your progress can be measured. As the voided amounts increase, you can decrease the frequency of the voiding schedule. If you have no urine leakage between your scheduled voids, you are ready to increase your voiding interval by 30 to 60 minutes.

See the sample voiding schedule on the next page.

At first, you have to catheterize and irrigate the neobladder often. This is to clear the mucus from your neobladder. When there is less mucus in the neobladder, you do not need to irrigate as often. You must follow the schedule for catheterization and irrigation.

Once the urethral catheter is removed, there may be some urine leakage in between voids for the next 4 to 10 weeks. You should wear a pad inside your underwear to manage the leakage. Change the pad often to keep your skin clean and dry.

As the capacity of the neobladder increases, there is less urine leakage in the daytime. Leakage at night is common as the muscles relax during sleep. To reduce nighttime leakage, you can try the following:

- Get up to void through the night
- Restrict your fluid intake in the evening
- Restrict your caffeine and alcohol intake

Sample voiding schedule

Date	Daytime	Nightime	Irrigation
Week #1	every 2 hours	Every 3 hours **OR** connect suprapubic catheter to leg bag	twice a day, evenly spaced
Week #2	every 3 hours	every 4 hours **OR** connect supra-pubic catheter to leg bag	twice a day evenly spaced
Week #3	every 4 hours	every 5 hours	twice a day, evenly spaced
Week #4	every 5 hours	every 6 hours	once a day
Week #5 This is the ideal goal	every 6 hours	every 8 hours	as needed only

About catheterization

When the urethral (and suprapubic catheter) is removed, you empty your neobladder by voiding. Your surgeon tells you to catheterize your neobladder through your urethra when:

- You are unable to void
- The mucus is thick and you want to thin it
- To make sure the neobladder is empty

Post void residual is the amount of urine left in the neobladder after voiding. Measure your post-void residual (PVR) 1 to 2 times per day for 3 to 4 weeks once the catheter is removed. To do this, you void, and then you catheterize the neobladder and measure the amount of urine that is left inside the neobladder. This tells you if you have completely emptied the neobladder with voiding. If the amounts are less than 50mls, you move to the next week's schedule. If the amount is greater than 50mls, you are not ready to move to the next week's schedule. Once the catheter is already inserted in your neobladder, you may irrigate with normal saline to clear away mucus. Use a clean, dry catheter every time.

Your NSWOC nurse shows you how to do your catheterization.

Supplies needed for catheterization:

- #14 or #16 Fr catheter
- Water soluble lubricant (Do not use petroleum jelly)
- Wash cloth
- Soap and water
- Measuring container
- Mirror, if needed
- Equipment for irrigation, if needed

How to catheterize your neobladder for people with male genitalia:

1. Wash your hands with soap and water and dry them with a clean towel.
2. Wash the end of your penis with soap and warm water.
   - If you are not circumcised, push back your foreskin over the glans before washing.
3. Sit on the toilet or in another comfortable position.
4. Put water soluble lubricant on the last 5 cm (2 inches) of the tip of the catheter.
   - Take care not to plug the holes in the tip of the catheter.
5. Hold your penis straight up with one hand.
6. With the other hand, slowly push the lubricated tip of the catheter into your penis until urine flows out of it. When urine starts to flow, push in the catheter another 2.5 cm (1 inch).
   - Keep the open end of the catheter over the toilet or measuring container.
7. Make sure your neobladder is empty. To do this, push down with your abdominal muscles as if you are voiding or gently push in your lower abdomen with your hands.
8. When the urine stops flowing, you may irrigate the catheter, if necessary, otherwise, remove the catheter.
   - Stop removing the catheter if your urine starts flowing again. When the flow stops, remove the catheter
9. Wipe the end of your penis and return the foreskin over the glans if you are not circumcised.
10. Discard the catheter and wash your hands
11. Measure the urine and record the amount.

How to catheterize your neobladder for people with female genitalia:

1. Wash your hands with soap and water and dry them with a clean towel.
2. Get in a comfortable and natural position. For example, you can sit on the side of a toilet or chair, or stand with one foot on a stool or lie in bed.
3. Separate your labia with your fingers.
4. Wash your labia from front to back using soap and water.
5. Keep the labia separate with your non-dominant hand. If you use a mirror, place it so that you can see where the catheter enters.
6. With your other hand, put water soluble lubricant on the last 5 cm (2 inches) of the tip of the catheter.
   - Take care not to plug the holes in the tip of the catheter.
7. Slowly push the lubricated tip of the catheter about 7.5 cm (3 inches) into your urethral opening.
8. When urine starts flowing out of the end of the catheter, push in the catheter another 2.5 cm (1 inch).
   - Keep the open end of the catheter over the toilet or measuring container.
9. Make sure your neobladder is empty. To do this, push down with your abdominal muscles as if you are voiding or gently push in your lower abdomen with your hands.
10. When the urine stops flowing, you may irrigate the catheter, if necessary, otherwise, remove the catheter.
    - Stop removing the catheter if your urine starts flowing again. When the flow stops, remove the catheter
11. Wipe the labia.
12. Discard the catheter and wash your hands.
13. Measure the urine and record the amount.

Common catheterization challenges

If urine does not flow....

Make sure that the catheter tip is not plugged with lubricant

For female genitalia: Make sure that the catheter is in your urethra and not your vagina. Use a mirror to visualize the urethral opening.

Put a tampon in your vagina to make sure you do not put the catheter in there.

Then, direct the catheter tip up and forward to the urinary opening. Spread your labia with your second and fourth fingers. Use your third finger to feel for the urinary opening.

If you can not push the catheter into the neobladder....

Ensure you are using enough lubricant

Relax and hold the catheter in place.

Push gently and firmly until the catheter goes in and urine flows out of the catheter.

It is sometimes hard to pass the catheter into the entry of the neobladder. Relax. Use gentle pressure until the catheter goes in and urine starts to flow. Do not keep trying to push in the catheter. This will make you sore. Try relaxing in a warm bath. Call your NSWOC nurse or doctor if you cannot insert the catheter within 6 hours.

If you see blood in your urine...

You may see a pink colour in your urine or blood on the tip of the catheter. If so, lubricate the catheter well. If the blood does not go away in 1 to 2 days, call your doctor.

Call your doctor if your urine is red. This means that it may have more blood in it.

If you cannot remove the catheter when urine stops flowing...

Wait 5 to 10 minutes. Try to relax

Try to remove the catheter again.

Try twisting the catheter between your fingers to roll it out,

Call your doctor if the catheter does not come out.

How to care for your catheters

A single use, pre-lubricated sterile catheter is highly recommended to reduce complications. These are thrown away after every use. If you choose to use a catheter, you will need to clean it immediately after each use or place in a plastic bag until it can be cleaned as soon as possible. Keeping your catheters clean helps prevent infection. After every time you catheterize, wash the used catheter and store it in a clean plastic bag when it is dry.

Supplies for cleaning your catheter:

- Clear liquid soap such as dish soap
- Vinegar
- A clean, 60ml catheter-tip syringe
- A clean towel or paper towels for a clean workspace
- A clean towel or paper towels for drying the catheter
- A clean container and a clean measuring cup
- A clean sealable plastic bag or container with a lid

Follow these steps to clean your catheter:

1. Wash your hands with soap and water.
2. Add a few drops of soap to 1 cup of hot water in a clean container.
3. Soak and wash used catheters in hot, soapy water.
4. Push water through each catheter tubing using a syringe.
5. Rinse the inside and outside in clean water.
6. Soak catheters in 250ml (1cup) of a vinegar solution (¼ cup white vinegar and ¾ cup water) for 30 minutes.
7. Put clean catheter on a clean towel to dry. Fold the towel over and hang it on a rack or towel bar. Never put a clean catheter on a toilet or sink in a public washroom.
8. When dry, keep clean catheters in a clean plastic bag.
9. Wash the syringe and container in hot soapy water after every time you use it, rinse it, and let it dry.

Things to remember when cleaning your catheter:

- Throw away your catheters after 24 hours of use or sooner if the one you are using gets discoloured, stops draining, or feels different than usual (harder, brittle, or softer).
- Discard any used plastic bags. Use a new plastic bag each time.
- Never put used and clean catheters in the same bag.
- Throw away your syringe if it looks damaged or broken, changes colour, or feels different than usual (harder, brittle, softer).

Your voiding and irrigation diary

You may wish to use a chart such as the one below to record your voiding progress. Bring your diary to your next clinic visit to review with your surgeon.

Date	Time	Urine amount voided (mL)	Post void residual (PVR) urine amount by catheter (mL)	Irrigation (yes or no)	Comments: (eg. Leakage, large mucus, clots..)

Pelvic floor exercises…

Pelvic floor exercises strengthen the sphincter muscles allowing you to control leakage. Your abdominal muscles empty the pouch however sphincter and pelvic floor muscles prevent incontinence. To perform pelvic floor exercises, complete the following steps:

1. Relax your abdominal muscles
2. Squeeze and hold for 10 seconds
3. Relax for 10 seconds
4. Repeat 15 times in the morning, afternoon and 20 at night

You may have to work up to this amount and frequency. Do as many as you can three times per day and eventually you will be able to complete the recommended number of repetitions.

What is a urinary tract infection?

Urine is normally free of bacteria. A urinary tract infection occurs when bacteria enter the urinary tract and cause an infection.

Preventing urinary tract infections

Most urinary tract infections can be prevented by:

- Always washing your hands before performing your catheterization care
- Using a new or clean catheter for each catheterization
- Cleaning and replacing your drainage bag(s) and tubes as directed
- Drinking 8 to 10 cups of fluid each day
- Drinking a glass (1 cup/ 250 mL) of cranberry juice daily

Signs of a urinary tract infection

If a urinary tract infection develops, you may notice the following signs and symptoms:

- Cloudy, foul-smelling urine
- Pain or burning when you urinate
- Blood in the urine
- Excessive mucus in the urine
- Low back pain
- Fever
- Chills
- Malaise (feeling generally unwell)

If you have symptoms of a urinary tract infection, call your doctor or your NSWOC nurse to have a urine sample taken.

Your doctor will advise you on how to treat your urinary tract infection. Many cases will resolve without medication. See your doctor if you have frequent infections (more than 3 in a year) and persistent symptoms. Sometimes, a short course of antibiotics is prescribed.

What about food?

As you recover from your operation, you will progress from clear fluids to a regular diet. There is very little to no change in your diet when you have a neobladder. Canada's Food Guide (see **Helpful resources**) recommends that you include a variety of healthy foods each day. The food guide includes the following recommendations:

- Have plenty of vegetables and fruits
- Eat protein-rich foods
- Choose whole grain foods
- Make water your drink of choice

To keep your kidneys healthy and your neobladder draining well, you should drink extra fluids. This helps to reduce the risk of infection. Drink 2 to 2.5 liters (8 to 10 cups) of fluid each day. In addition, your surgeon may suggest that you drink a glass of cranberry juice daily to avoid infection.

Do not try to control your neobladder output by withholding fluids throughout the day. This will result in concentrated urine which is more irritating to the urinary tract and puts you at a greater risk of urinary tract infection.

You can enjoy alcoholic beverages in moderation. Keep in mind that drinking alcohol may not be advisable when taking prescribed medications. Seek the advice of your pharmacist.

Some foods give your urine an odour. Such foods include asparagus, garlic, fish and poultry. You do not have to stop eating these foods. However, drinking extra fluids helps reduce the odour. Eating parsley also helps.

Eating beets or rhubarb may cause your urine to turn a reddish colour. This is temporary and is no cause for alarm.

Your bowel movements may change temporarily after your operation. Call your surgeon if you have difficulty having bowel movements or have frequent bowel movements.

Maintain a healthy weight. It is unwise to gain weight unless your doctor tells you to.

What to wear?

Choose comfortable clothes to wear home from the hospital. When your incision heals, wear your usual clothes.

The abdominal binder can be removed when you are discharged from the hospital.

It is a good idea to wear a medical alert bracelet. This lets others know that you have had your bladder surgically removed and have a new bladder if you have a medical emergency (see **Helpful resources**).

What about work?

You need time to recover and learn to care for your neobladder after your operation. It can take several weeks to regain your former strength. As your recovery progresses, you will have many questions about your work. After a time of healing (approximately 4-6 weeks), you can usually slowly return to work.

Depending on the kind of work, you may need to make a few changes. For example, jobs that demand a lot of physical activity may have to be limited. You may find a gradual schedule will work best for you. Your surgeon and NSWOC will help you with this decision.

Keep extra catheterization supplies at your workplace in case you need them.

What about travel?

You can travel anywhere you like. Having a neobladder should not have a negative impact on your ability to travel. With proper preparation, you should be able to live your life the same as you did before surgery. You may start to drive when you are no longer taking opioid pain medications that affect your driving. Of course, you need to feel comfortable with your neobladder care before you travel to far-away places.

Here are a few tips to make your travels a success:

- Carry clean supplies wherever you go. You can carry supplies in a small cosmetic purse, waist pouch or briefcase.
- Be sure to take extra supplies. Take at least twice the supplies you normally use.
- When flying, bring supplies in your carry-on baggage so that you always have them with you in case your luggage is lost.
- Keep your catheters out of the sun. Do not keep them in a hot place such as the trunk or glove compartment of a car.

What about physical activity?

The day after your surgery, you may be visited by a physiotherapist who will begin working with you on your physical activity. They will work with you to help you return to your pre-operative mobility. Typically, the goal will be to walk to the bathroom and in the hallway with little to no assistance in order to be ready to go home. If your home is equipped with stairs, the physiotherapist will also ensure you are able to safely walk up and down the stairs before being discharged.

During surgery, your abdominal muscles were cut. It is important to avoid any stress on this incision while it is healing. Additional stress on the abdominal muscles during the healing phases can cause a hernia to develop.

How to get out of bed after surgery

- Step one: bend both knees with feet on the bed, reach both arms towards the bedrail and in the direction of exit.
- Step two: push with your feet and roll onto your side.
- Step three: push yourself up using both arms on the bed.

It is normal to tire easily after your operation. Your body is using a great deal of energy to heal itself. Listen to your body and rest when you feel tired. Activity can help with the healing. Don't be afraid to be active when you feel up to it. You can resume most normal activities once your pain is manageable, including sexual intercourse. Slowly increase your activity to your usual level. Follow a regular exercise program with activities like walking and bicycling. Exercise is good for you. Be as active as you like.

Temporary physical limitations

During the first 4-6 weeks after surgery while your body is still recovering, practice the following limitations:

- **Do not lift more than 10 to 15 pounds** (one laundry bin or 2 small bags of groceries) for the first 4-6 weeks after surgery. This also includes pushing and pulling activities.
- Do not do abdominal exercises, high intensity aerobic activities or weight training for 4 to 6 weeks after surgery.
- Avoid playing golf or any sport where there are twisting movements during this time.
- Avoid any sport where there is body contact during this time.

Ask your friends and family to help you with getting meals ready, grocery shopping, house cleaning and laundry.

Returning/starting a new sport

When your return to a sport, or try a new sport, remember the following:

- Ask your doctor about any limitations.
- Choose sports that are relaxing, comfortable and fun.
- Take it easy at first until you build up your strength. If you want to work out in a gym, avoid abdominal exercises for a while. Only introduce these gently, in gradual amounts after your surgeon says it is okay.
- Void before the activity
- Talk to your NSWOC about products to meet your needs.

Swimming and other water activities

Swimming, hot tubbing and saunas may be resumed once your incision heals completely.

Hernia prevention

The abdominal muscles need time to heal and become stronger after surgery. In addition to avoiding heavy lifting, intensive abdominal exercises should begin no sooner than 3 months after your surgery. Always wait until your surgeon says it is okay to resume abdominal exercises. Maintaining a good posture will help to develop your muscles. Supporting your abdomen while coughing in the first few months after surgery will also assist in reducing the chance of developing a hernia. Gentle abdominal exercises you can try after surgery once your wound has completely healed include:

- **Pelvic tilting**: Lie on your back on a firm surface with knees bent and feet flat. Pull your tummy in, tilt your bottom upwards while pressing the middle of your back into the surface (floor/bed) and hold for 2 seconds, let go slowly. Repeat 10 times daily.
- **Knee rolling:** Lie on your back on a firm surface with knees bent and feet flat on the surface (floor/bed). Pull your tummy in and keeping your knees together, slowly roll them from side to side. Repeat 10 times daily.
- **Partial abdominal sit ups:** Lie on your back on a firm surface with knees bent and feet flat on the surface (floor/bed). Place your hands on the front of your thighs and pull your tummy in. Lift your head off the pillow. Do not roll your back up off of the surface. Hold for 3 seconds, then slowly return to starting position. Repeat 10 times daily.

What about intimacy?

Your neobladder does not need to limit your sexual activity. It takes time for both partners to understand and get used to each other's feelings. Open discussion with your spouse or partner helps in your adjustment to changes in your body. Your surgeon will talk to you about any sexual problems you might have when you resume sexual activity.

When the bladder is removed, people often have nerve damage in their lower abdomen that makes it difficult to have an erection. If you do experience difficulties, talk to your doctor. Treatments are available.

Bladder removal does not usually have any effect of female sexual function unless more extensive surgery is carried out. Some people find the size and/or position of their vagina changes. This can make it difficult to have a climax. Try different positions to find what works best for you. If you do experience difficulties, talk to your doctor. Treatments are available.

Voiding before sexual activity helps prevent leaks.

Only through time and experience will you know how it will be for you. If you do have problems, talk with your surgeon or NSWOC nurse. They can help you find solutions or direct you to other services.

Medications

Most medications can be taken safely when you have a neobladder. Keep in mind that certain medications such as vitamins and antibiotics can affect the odour and colour of the urine. Discuss any concerns with your pharmacist or doctor.

Adjusting to your neobladder

Your feelings about your neobladder may change from day to day. Sometimes you may feel confused, angry, or sad. Other times you may feel happy that the operation is over. It is natural to feel this way after your body has had such a major change. It helps to talk about your feelings.

As you get used to having a neobladder and feel more confident in your ability to care for it, you will find it easier. This change begins in the hospital and continues when you are at home. Each new experience you master helps you feel more comfortable and confident. This takes time, so be patient with yourself.

Not everyone needs to know that you have a neobladder. You can decide whom to talk to about your neobladder. It helps to talk to your family, close friends or others who have a neobladder. Discussion with a volunteer from a local chapter of the Ostomy Canada Society or Bladder Cancer Canada who has experienced similar surgery is helpful (see **Helpful resources**).

Your family and close friends also need time to understand and accept your neobladder. You can help them feel more relaxed about your neobladder if you feel at ease, and treat it as a part of you. In time, they will see that you are still the same person that they have always known. They will see that you can return to your previous family and social roles.

Before you go home

You will be required to demonstrate your independence with neobladder irrigations before going home.

A Home and Community Care Case manager (or Local Health Integration Network –LHIN-manager) calls you in the hospital to:

- Talk to you about your community care needs
- Arrange for a nurse to help you with care
- Arrange for other health care that you may need
- Determine if you qualify for supplies

The Ontario government pays for Home and Community Care. It is a service for Ontario residents who have a valid Ontario Health Insurance Plan (OHIP).

How to pay for supplies

If you have a **private medical insurance** plan, contact your agent. Many private insurance plans will reimburse you for some of the costs of your neobladder supplies.

Post-surgical follow-up

Your visiting nurse will support you and encourage you to continue to be independent with neobladder irrigations and assist with any challenges you may have.

You will receive an appointment for a cystogram of the neobladder to ensure there are no leaks. You will then receive a follow-up appointment with your surgeon 4 to 6 weeks after your hospital discharge. If there are no leaks, the urethral catheter will be removed at the clinic appointment. The NSWOC from Hotel Dieu Hospital site (HDH) will be able to assist you with learning to self-catheterize once the urethral catheter is removed.

The HDH site NSWOC nurse will also be available to see you in the clinic for reassessment of your neobladder concerns at any point in your neobladder journey. Bring along your supplies for catheterization. Pre-booked visits are arranged between the NSWOC and the patient by calling the ostomy clinic (refer to page 36).

What to do if…

Warning signs	Possible cause	Response/Contact
• Inability to void • Decrease in urine drainage • Lower back pain	Urinary blockage	Catheterize your neobladder Irrigate the neobladder Call the surgeon
• Abdominal full ness • Bloating • Nausea and vomiting	Bowel blockage	Call the surgeon
• Suprapubic catheter or urethral catheter falls out	Breakdown of the catheter balloon	Call the surgeon
• Increase in urine leakage • Strong smell to urine • Cloudy appearance to urine • Lower back pain • Fever • Chills • Body aches • Flank pain • Increase in mucus • Presence of blood in urine	Urinary tract infection	Drink extra fluids Call the surgeon

Information to remember

Name of operation: _____

_____

Date of operation: _____

Discharge date: _____

Surgeon: _____

telephone: ext:

NSWOC nurse: KGH site:

KGH site:

HDH site:

Ostomy clinic location: Hotel Dieu Hospital (HDH), Jeanne Mance Level 5

Telephone: 613-544-3400 ext. 3720

Hours: Monday and Friday mornings from 0800 until 1200 (Noon)

Supplies list

Brand Name	Order Number	Description

Helpful resources

Bladder Cancer Canada

4936 Yonge St., Suite 1000

Toronto, ON M2N 6S3

Toll Free: 1-866-674-8889

info@bladdercancercanada.org

Canadian Cancer Society

National Office

55 St. Clair Avenue West Suite 500

Toronto, ON M4V 2Y7

Toll Free: 1-888-939-3333

www.cancer.ca

Canadian MedicAlert® Foundation Inc.

Morneau Shepell Centre II

895 Don Mills Road, Suite 600

Toronto, ON M3L 1W3

Toll Free: 1-800-668-1507

www.medicalert.ca

Cancer Care Ontario

620 University Avenue, 15th floor

Toronto, ON M5G 2L7

Toll Free: 1-888-939-3333

www.cancercareontario.ca

Coloplast Canada Corporation

2401 Bristol Circle, Suite A205

Oakville, ON L6H 5S9

Toll Free: 1-866-293-6349

www.coloplast.ca

ConvaTec

Suite 250, 1425 Trans-Canada Hwy.

Dorval, QC H9P 2V3

Toll Free: 1-800-465-6302

www.convatec.ca/CA/en (English)

www. convatec.ca/CA/fr (French)

Hollister Limited

95 Mary Street

Aurora, ON L4G 1G3

Toll Free: 1-800-263-7400

www.hollister.ca

Nurses Specialized in Wound, Ostomy, Continence Canada

66 Leopolds Drive

Ottawa, ON K1V 7E3

Toll Free: 1-888-739-5072

Fax: 1-514-739-3035

www.nswoc.ca

Canada's Food Guide

www.food-guide.canada.ca

Additional resources

Glossary

Bowel	the part of the digestive system between the stomach and the anus where food is broken down and stool is stored. This is also known as the intestines.
Cancer	a disease involving abnormal cell growth with the potential to invade or spread to other parts of the body and to destroy normal tissue
Catheter	a thin, soft tube used to drain fluids such as urine
Conduit	a channel or passageway
Cystectomy	removal of the bladder
Drain	a thin, flexible tube used to drain fluids out of the body
Enema	fluid to put into the rectum to clean out stool
Incision	the cut, or wound, made by the doctor during the operation
Laxative	medication that cause bowel movements
Malaise	generally feeling unwell
Mucus	a clear jelly-like substance made by the lining of the digestive tract to keep it moist
Nurse Specialized in Wound, Ostomy, Continence	a nurse with special training in caring for persons with ostomies; also known as an NSWOC nurse
Orthotopic neobladder	an internal urinary diversion created from a segment of small bowel to form a new reservoir for urine, also called a neobladder
Ostomy	a surgical opening into the bowel segment or conduit, a short form for ileal-conduit diversion
Pouching System	the pouch worn over your stents to collect urine from the kidneys

Small bowel	the part of the digestive system between the stomach and large bowel, that breaks down the food and absorbs nutrients (also called the small intestine)
Stoma	an opening through the abdomen to allow the bowel segment to pass urine, also the Greek word for “mouth”

Notes

Transforming care, together™

Kingston Health Sciences Centre
Centre des sciences de la santé de Kingston

Hôpital Hotel Dieu Hospital

KGH Hôpital Général de Kingston General Hospital

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Aussi disponible en francais

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