

Cystectomy and Neo Bladder Surgery

A guide for patients and families

Reading this booklet can help you prepare for your surgery, hospital stay and recovery after surgery. We encourage you to take an active role in your care.

If you have any questions, please ask a member of your health care team.



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Learning about your surgery

What is a Cystectomy?

Cystectomy is surgery to remove your bladder. This is usually done to control bladder cancer. Depending on the extent of the cancer, the bladder and some surrounding organs may need to be removed.

- The prostate gland, seminal vesicles and nerve bundles may also be removed.
- The ovaries, fallopian tubes, uterus, cervix and part of the vagina may also be removed.

What is a Neo Bladder?

A neo bladder is a pouch made from a piece of your bowel that is placed where your bladder was removed.

The pouch acts like a bladder, collecting urine that comes down the ureters from the kidneys. When you pass urine, it leaves the pouch through your urethra.

Words to know

Neo means new.

A neo bladder is a new bladder.

A neo bladder is commonly called a pouch, because a piece of your bowel is made into a pouch that can store urine.

The medical name for this is a continent diversion.

The way you pass urine will be different than with a regular bladder:

- A regular bladder is a muscle that contracts to 'squeeze' urine out. A neo bladder is not a muscle, so we will teach you how to pass urine and empty your neo bladder.
- When a regular bladder gets full, the nerves around it send messages to your brain, which gives you the urge to pass urine. Your neo bladder does not have the same nerve supply, so you will not feel this urge. You will have to pass urine at regular times during the day and night.
- You will be taught how to empty your neo bladder using the Valsalva maneuver.

A few people are not able to pass urine this way. If this happens, we will teach you how to empty your neo bladder using a thin, soft tube called a catheter.

A neo bladder needs more care than a regular bladder, because it is made from a piece of bowel. As bowels normally make mucus, your neo bladder will too. The mucus will collect in your neo bladder along with the urine. We will teach you how to flush out mucus so it will not block the flow of urine.

What happens if a neo bladder isn't possible?

During surgery, your surgeon may decide that it is not possible to form a neo bladder as planned. If this happens, the surgeon will make a different pathway for urine to leave your body.

A piece of your bowel will be used to create a pathway for urine to flow from your ureters to an opening on the outside of your abdomen, called a stoma. A plastic pouch placed over the stoma will collect your urine.

The new pathway is called an ileal conduit.

What are the possible risks?

No surgery is completely without risk. Your surgeon will help you understand the possible risks with cystectomy and neo bladder surgery, which include:

- blood clots (deep vein thrombosis)
- blood loss
- infection
- blockage of the neo bladder
- not being able to achieve or maintain erections (erectile dysfunction)

Preparing for Surgery

When is my Pre-Admission Clinic visit?

You will have an appointment in the Pre-Admission Clinic 1 to 3 weeks before your surgery.

This visit is very important to help you prepare for your surgery and recovery.

If you do not come to this visit, we may have to cancel your surgery.

Pre-Admission Clinic

Ground Floor, Eaton Wing
Toronto General Hospital
200 Elizabeth Street

Depending on your needs, this visit may take 4 to 6 hours. If possible, please bring someone with you to this appointment.

What should I have with me for my Pre-Admission Clinic appointment?

Please have available:

- Your Ontario Health Card (OHIP card)
- Information about any other medical insurance you have, including policy numbers
- All medications you are taking. Bring your prescription medications and the medication, supplements, herbs and natural products that you buy without a prescription
- A list of your questions

What happens at my Pre-Admission Clinic appointment?

You will speak with a **nurse** who will:

- review your health history and assess your health
- help you prepare for surgery and recovery after surgery

The nurse helps you learn:

- ✓ When to stop eating and drinking before surgery.
- ✓ How to do breathing exercises that you will do after surgery to keep your lungs clear and prevent infection. This includes using a device called an incentive spirometer that helps you take slow deep breaths.
- ✓ How to do leg exercises that you will do after surgery to keep your blood flowing and prevent blood clots in your legs.
- ✓ About your choices for pain control after surgery.

You will speak with a **nurse or pharmacist** to review your medications. They will tell you which medications to stop before surgery, and which to take on the morning of your surgery with a sip of water.

You will speak with the **Urology Clinical Nurse Coordinator** who will:

- discuss what to expect before and after surgery
- review possible risks and side effects, and how to manage them
- discuss your feelings about managing a neo bladder

The Urology Clinical Nurse Coordinator helps you learn:

- ✓ How to plan for going home after surgery.
- ✓ How to use PharmaNac to decrease mucus in your neo bladder.
- ✓ How to manage your drainage tubes.
- ✓ How to irrigate your tubes.
- ✓ What warning signs to watch for and when to get medical help.
- ✓ What follow-up appointments you need.

You may speak with other members of the health care team:

- An **anesthetist** may discuss the plans for your anesthetic and pain control after surgery. They will review your medical history

About your appointment before surgery

You will need to come into the hospital before your surgery for pre-admission tests and to fill out the paperwork for your hospital stay. The admitting clerk will register you.

You will have **tests**, which may include:

- blood tests
- an ECG (electrocardiogram) to check your heart beat
- a chest x-ray to check your lungs

You will meet with an **Enterostomal Nurse**. This nurse will mark on your abdomen the best place for a stoma, in case an ileal conduit is needed. If you have questions about alternatives to a neo bladder, please talk with your surgeon or the Urology Clinical Nurse Coordinator.

How do I prepare for surgery at home?

PharmaNac (pure N-acetylcysteine) at any health food store or directly from the company Bio Advantex (<https://bioadvantex.ca>).

If you live alone:

- Make or buy extra meals and freeze them for after your surgery.
- Arrange for someone to drive you home from the hospital after surgery. You can expect to leave the hospital 6 to 8 days after surgery.
- Arrange for help at home during the first few weeks of your recovery. You may need help with groceries, cooking, laundry, cleaning and rides to medical appointments.

What must I do the day before surgery?

The evening before and morning of your surgery:

- Shower or bathe the evening before and on the morning of your surgery

We will give you more information about how to prepare for your surgery.

Your hospital stay

If you were told to take medication on the morning of your surgery, take it with a sip of water.

What should I bring to the hospital?

Please bring:

- Your Ontario Health Card (OHIP card).
- Any other medical insurance information you need for your hospital stay.
- All medications you are taking, in their original bottles. This includes prescription medications, and the medication, supplements, herbs and natural products that you buy without a prescription.
- Your glasses, dentures, hearing aids if needed and cane or assistive device, if needed.
- Non-slip shoes or slippers.
- Personal care items such as toothbrush, toothpaste, soap and deodorant. Please bring unscented products only.

**You are responsible for your belongings.
Please do not bring jewelry or anything valuable.**

When do I come to the hospital?

<p>Come to the Surgical Admission Unit 2 hours before your scheduled surgery time.</p>	<p>Surgical Admission Unit 2nd Floor Peter Munk Building Toronto General Hospital</p>
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What happens before surgery?

After you are admitted, the nurses will help you get ready for surgery.

The nurses will:

- Check your blood pressure, pulse, temperature and breathing.
- Give you a hospital gown to wear.
- Put an intravenous (IV) in a vein in your arm. This will be used to give you fluids and medications during and after surgery.

Important!

For your safety, we will check your hospital identification band and ask the same questions many times, such as your name, date of birth, and the type of surgery you are having.

We will also mark the area of your body where you will have your surgery.

If you are having an epidural for pain management, the anesthetist will put this in before your surgery.

When everything is ready, you will go to the operating room. Your surgery will take about 6 to 8 hours.

Where can my family wait while I am in surgery?

Your surgeon will speak to your family when the surgery is done. Tell the staff or volunteer how a family member can be reached.

Where do I go after surgery?

When your surgery is over, you will go to the **Post Anesthetic Care Unit (PACU)**. It is also called the recovery room. The nurses will care for you until you wake up.

In the PACU, you will have:

- An **intravenous (IV)** in your arm to give you fluids and medications.
- A **central line** in your neck. This tube measures the pressure in the veins near your heart.
- A **Jackson Pratt drain** in the lower part of your abdomen. The drain uses suction to remove any fluid that collects there after your surgery.
- An **oxygen mask** or tubes in your nose to help you breathe.
- A **nasogastric (NG) tube** from your nose to your stomach. The NG tube keeps your stomach empty, so your bowels can heal after surgery.
- A thin, soft tube called a **suprapubic catheter** (Malecot) coming out of your abdomen. You will have another tube called a **foley catheter** in your urethra.
The catheters drain urine and mucus from your neo bladder into drainage bags. They will stay in place for a few weeks to keep your neo bladder empty while it heals.
- Tiny catheters called **stents**, to keep urine flowing from your kidneys to your ureters while you are healing.

When you are ready, you will go to **Unit 10 ES (Eaton South)**. Your family is welcome to visit you on this unit. You can expect to stay here for 6 to 8 days.

What can I expect on Unit 10 ES?

Your care

Nurses will regularly check:

- your temperature, pulse, breathing and blood pressure
- your incision
- all your tubes and drains
- the flow and amount of urine
- how you are feeling
- your pain and how well it is controlled
- your bowel sounds to see when you can start drinking and eating

The first day after your surgery, your nurse will encourage you to do these activities every hour while you are awake:

- Deep breathing and coughing to keep your lungs clear and prevent infection.
- Incentive spirometry to help you take slow deep breaths. Expanding your lungs helps them to work better.
- Exercises for your legs and feet, to keep blood flowing and prevent blood clots.

Your suprapubic/Malecot and foley catheters need to be flushed (irrigated) with saline to remove any mucus that could block them. At first, a nurse will irrigate them every 2 hours. After a while, they only need to be irrigated every 4 hours. The nurses will teach you how to do this before you leave the hospital. See page 21 for more information.

During the rest of your stay, nurses will assess your condition and provide care, education and support as you recover.

You will have blood tests each day for 2 to 3 days after your surgery, then as needed.

Your Surgeon and the surgical team will follow your progress every day while you are in the hospital.

How you will feel

You will have some pain and discomfort after surgery. The nurses will assess your pain and provide pain medication to relieve it.

**You will get better faster if your pain is well controlled.
We will do all we can to keep you comfortable.**

You may have an upset stomach (nausea) at first. Your nurse can give you a medication to relieve nausea.

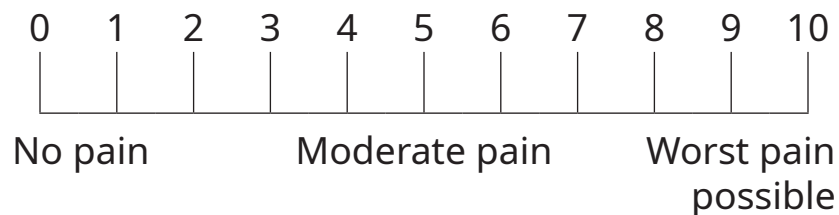
A few days after surgery, you may have gas pain. Walking is the best way to relieve this type of pain.

Assessing your pain

We will ask you to rate your pain on a scale of 0 to 10 (0 means you have no pain and 10 means that you have the worst pain possible). This number helps us understand how much pain you are having and how well the pain medication is working.

How to use the pain scale:

Pick a number that tells how much pain you are having.



Managing your pain

Right after surgery, you will be given pain medication with a pump. There are 3 types of pain control pumps:

- **Patient Controlled Anesthesia (PCA)** is a pump that delivers pain medication through your IV when you press a button. The pump is set to give you a certain amount of medication every few hours. It has a safety lock to make sure you cannot give yourself too much medication.
- An **Epidural** uses a pump to deliver a small, steady amount of pain medication into your lower back, near the spine. Your epidural is managed by the health care team.
- A **regional TAP block** delivers pain medicine through tiny tubes that were placed in your abdomen muscles during surgery. After your surgery, someone from the Acute Pain Service team will visit you and give you pain medicine in your TAP blocks.

When your pain gets better, the PCA, epidural or TAP block can be removed. We will give you pain medication by mouth.

- Tell the nurse when you have pain. We want to keep your pain at a level you can manage (at a rating of 3 or lower on the pain scale). Do not wait until your pain gets worse to ask for pain medication.
- You can expect to need pain medication every 3 to 4 hours for the first few days after surgery.
- Take your pain medication regularly. This is the best way to control pain. You need to feel comfortable enough to walk, do your exercises and other activities that help you recover.
- As you heal, you will feel less pain and will not need the medication as often.

Removing your tubes

- Your **pain control pump** (PCA or Epidural) may be removed when you are drinking well and passing gas after surgery.
- The **central line** in your neck may be removed in 2 or 3 days.
- The **intravenous (IV)** in your arm may be removed in 3 to 4 days, when you are drinking well.
- The **Jackson Pratt (JP)** drain in your abdomen may be removed in 2 to 4 days, when the extra fluid decreases.
- The **stents** may be removed at your follow-up appointment. They may stay in longer if you had chemotherapy or radiation.
- Your **suprapubic/Malecot** and **foley catheters** will stay in for a few weeks. They will be removed at your follow-up appointments at the Cystoscopy Department.

Eating and drinking

- The first day after surgery you may only have sips of water. The nurse will check for sounds that show your bowels are returning to normal.
- When you pass gas, you can drink clear fluids.
- When you are drinking well, your intravenous can be taken out and you can start to eat solid food. This happens a few days after surgery.

Activity and exercise

- Continue to do your deep breathing, coughing, incentive spirometry and leg exercises anytime you are in bed.
- It is important to get moving soon after surgery. The nurse will help you get up, walk and sit in a chair on the morning after surgery. This will get easier each day. Slowly you will be able to get up and walk by yourself.
- Each day, we will assess your activity level and help you become more independent.

Walking is very important as it helps to:

- ✓ keep your lungs clear and prevent infection
- ✓ keep your blood flowing and prevent blood clots
- ✓ speed recovery of your bowels, relieve gas pain and prevent constipation
- ✓ relieve pressure on your skin

Caring for your incision

- Your incision was closed with staples.
- Your nurse will check your incision each day.
- The dressing on your incision will be removed the second day after surgery. Leaving it open to the air helps it heal.

Showering

- The first day after surgery, your nurse will help you wash in bed. As your tubes are removed, you will be able to do more of your personal care.
- Your nurse will tell you when you can shower. Wash your incision with mild soap and water. Rinse well and pat dry with a clean towel.
- You can have a tub bath after 6 weeks or when your incision is completely healed.

Getting ready to leave the hospital

How long will I stay in the hospital?

- You can expect to leave the hospital in 6 to 8 days.
- The goal is for you to continue your recovery at home, as quickly and as safely as possible.
- Your health care team will tell you what day you leave the hospital. This is called your day of discharge. You will usually know 1-2 days before.

**The usual stay
in hospital is
6 to 8 days.**

What happens before I leave the hospital?

Planning for your return home is called discharge planning. We start discharge planning soon after your surgery, so you will know how to care for yourself by the time you leave the hospital.

Before you go leave the hospital, we will help you learn:

- How to manage your pain
- What to eat and drink to help your recovery
- How to take care of your incision
- What supplies you need at home
- How to flush (irrigate) your suprapubic/Malecot and foley catheters
- How to gradually increase your activity level
- When and how to resume your normal activities, such as housework, gardening and sex
- When you can drive and return to work
- How to take your blood thinner medicine
- What the warning signs of blood clots are and when to go to the Emergency Department
- What warning signs to watch for (how to spot infection, skin breakdown or a blocked neo bladder) and when to call the doctor
- What follow-up appointments you need

A nurse or pharmacist will review your medications. Some may have changed during your hospital stay. You will get a prescription for any new medications.

You will need to have PharmaNac ready at home, to help decrease mucus in your neo bladder.

You can buy PharmaNac at any health food store or directly from the company. Take 2 pills a day, one in the morning and one in the evening.

The health care team will:

- Make arrangements for the care and services you will need once at home or wherever you may be staying after your surgery. This includes visits by a nurse from Home and Community Care Support Services.
- Give you a discharge letter to take home. This letter is for you and your family doctor. It contains important information, including:
 - ✓ details of your surgery and hospital stay
 - ✓ changes to your medication
 - ✓ follow-up instructions

Plan to leave the hospital before 11:00 am on your day of discharge. Please arrange for someone to pick you up by this time.

Your recovery at home

You will continue to recover at home over the next few weeks to months.

A nurse from Home and Community Care Support Services (HCCSS) will visit you at home. The home care nurse will continue your teaching from the hospital and make sure you are managing well at home with your neo bladder.

We do recommend if possible to plan to have someone help you at home for at least 1 to 2 weeks after your surgery. You may need help with laundry, cleaning, cooking and grocery shopping and drives to medical appointments.

What can I eat and drink?

- Drink lots of fluids. We recommend that you drink at least 2 to 3 litres (8 to 12 cups) of fluid a day.
- You can eat as usual. Start with frequent, small meals as they are easier to digest.
- Eating a variety of healthy foods can help you heal and recover from surgery. For more information about nutritious eating, go to: www.hc-sc.gc.ca and click on **Eating Well with Canada's Food Guide**.

How can I prevent constipation?

Constipation is common after surgery because of the effects of the pain medicine. To keep bowel movements soft and regular:

- Drink lots of fluids.
- Eat foods that are high in fibre such as fruits, vegetables, legumes (beans, peas and lentils), and whole grain breads and cereals.
- Take a stool softener each day, as soon as you begin eating and drinking.
- If you have not had a bowel movement in 2 days, take a laxative. You can buy a laxative (such as Senocot or Lax-A-Day) at your pharmacy without a prescription.
- Keep active by walking each day.

What activities can I do?

- Exercise, such as walking, can help with your recovery. Start slowly with short, easy walks. Plan rest periods during the day.
- Try to walk a little more each day. You can walk outside or use a treadmill.
- As you become more active, you will have more energy and feel less tired.

For 6 weeks after surgery:



- Do not lift anything heavier than 10 lbs (5 kg). This is the same weight as a small bag of groceries.
- Do not do strenuous activities such as shovelling snow, gardening, jogging, golfing or skiing.

After 6 weeks, you can do most of your usual activities with some cautions:

- Avoid long car rides. When riding in any vehicle, stop often to walk and stretch your legs.
- Follow your surgeon's instructions about when to drive and return to work.

How do I care for my incision?

- Your incision is closed with clips (staples). You may shower while the clips are in place. They will be removed at your follow-up appointment 4 weeks after surgery.
- Check your incision each day.
- Keep your incision clean and dry. Wash around the incision with mild soap. Rinse and gently pat dry with a clean towel.
- Do not put creams, lotions or powder on your incision.

How do I care for my suprapubic/Malecot and foley catheters?

Flushing the catheters

It's important to flush (irrigate) the catheters 4 times a day. Flush more often if there is a lot of mucus in your urine. Flushing the catheters keeps urine flowing well and prevents infections and blockage.

To flush the catheters, follow these steps:

1. Wash your hands well with soap and warm water.
2. Remove the bag or connection.
3. Flush the tube or catheter with 75 to 100 cc of saline. (Read how to make saline on page 26.)
4. Draw the fluid in the syringe back gently. It can be hard to withdraw the fluid from this tube, but do not use force.
5. Repeat these steps until the liquid returns clear.



Do NOT flush the stents if they are still in place.

Changing the urine drainage bags

To change the drainage bags, follow these steps:

1. Wash your hands well with soap and warm water for 15 seconds.
2. Empty the bag into the toilet. Do not touch the tip.
3. Pinch the tubing and disconnect used bag using a twisting motion.
4. Clean the end of the catheter with an alcohol pad.
5. Use a new alcohol pad to clean the end of the new bag.
6. Insert the tip of the clean bag to the catheter and release the pinch.
7. Check that there are no kinks or loops in the tubing. Leave some slack so you will pull the catheter when you move your leg.
8. Wash your hands again.

Cleaning the urine drainage bags

When you change drainage bags, clean and rinse the used bag, then let it drip dry.

You can clean drainage bags using:

- mild liquid soap and warm water, or
- a mixture of equal parts white vinegar and warm water to prevent odour

When do I start to pass urine on my own?

At your first follow-up appointment, 1 month after surgery, your foley catheter is removed and your suprapubic/Malecot catheter is clamped. Your neo bladder will start to fill with urine. As it can only hold a small amount, you will need to pass urine often, day and night.

We will teach you how to do this. See the schedule on page 23.

Passing urine empties your neo bladder of urine and mucus.

A list of your follow-up appointments is on page 27

How to pass urine:

1. Relax your pelvic floor muscles.
2. Contract the muscles of your abdomen and push down on your lower abdomen with your hands.
3. Take time to make sure your neo bladder is emptied well.

How often should I pass urine?

Start by passing urine every 2 hours during the day. At night, set an alarm so that you can pass urine every 3 hours. You must be careful that your neo bladder does not get too full.

Over time, you can go a little longer between trips to the bathroom. This allows your neo bladder to gradually stretch, hold more urine and work better.

Use the schedule below as your guide. Adjust the schedule to meet your needs. For example, if you are drinking lots of fluids, you may not be able to hold your urine for 4 hours during the day. Eventually, this will become routine.

	Day	Night
Week 1	every 2 hours	every 3 – 4 hours
Week 4	every 2 to 3 hours	every 4 hours
Week 8 (and ongoing)	every 3 to 4 hours	every 6 hours

Important: These times are suggestions and may not be the same for you. Your times may be shorter.

At first, to get a good night's sleep as you recover after surgery, we recommend that you connect the suprapubic catheter (Malecot) to the night drainage bag. In the morning, re-clamp it shut and follow the voiding schedule.

Will I gain control of my neo bladder?

Some leakage of urine is normal in the first few weeks, especially at night. We will teach you how to do Kegel exercises. Over time, these exercises strengthen your pelvic floor muscles, which can help reduce or prevent leakage.

How to do Kegel exercises

4. Stand, lie down or sit to do the exercises.
5. Tighten your pelvic floor muscles for 2 – 5 seconds. Then increase to 7 – 10 seconds.
6. Hold the muscles as tightly as you can.
7. Slowly release the muscles.

Repeat your Kegel exercises 10 to 20 times, 3 times a day (morning, afternoon and night).

Over time, try repeating 40 to 50 times, 3 times a day (morning, afternoon and night).

Remember!

Most people leak urine at night. As this may not go away, we recommend wearing an incontinence pad or underwear overnight.

To reduce leakage of urine:

**Helpful
Tips!**

1. **Drink less** in the evening before you go to bed. Drink 3 litres of fluid during the day.
2. **Set an alarm** to wake you up during the night to pass urine.
3. **Catheterize yourself before bedtime** to empty your neo bladder. Wear an incontinence pad during the night.

How do I catheterize myself?

Begin by buying the supplies you will need to irrigate your catheter. Catheters come in different shapes, sizes and flexibility. We recommend sizes 14 – 16. Please ask us for pamphlets and more information we have about where you can buy your catheter supplies.

At your second follow-up appointment, your suprapubic catheter will be removed. The nurses will teach you how to use a different type of catheter to clear your neo bladder of mucus.

**A list of your
follow-up
appointments is on
page 27.**

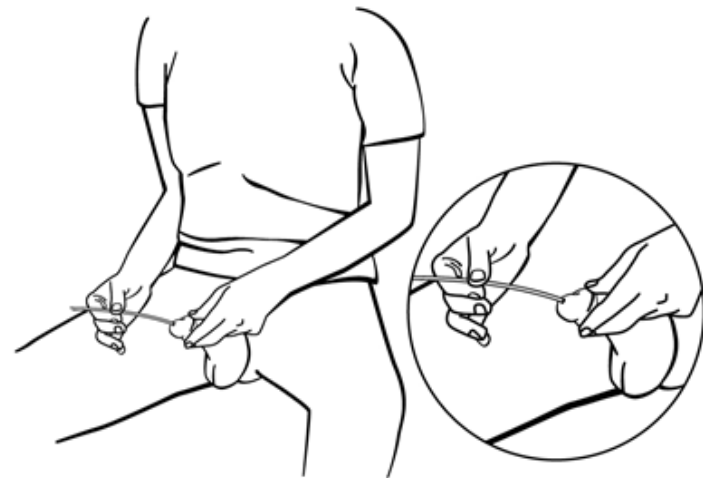
You will insert and remove the catheter at least once a day or more often, depending on the amount of mucus you have. This is called intermittent self-catheterization.

Keep to your schedule for irrigating your catheter. It's important that you continue to irrigate.

How to catheterize yourself:

Try and pass your urine normally before you start.

1. Wash your hands well.
2. Wash the opening of your urethra well with a mild, unscented soap and water. If you are an uncircumcised male, pull back the foreskin of your penis and wash.
3. Wash your hands again, for at least 15 seconds.
4. Lubricate the tip of the catheter with a water-soluble gel.
5. Sit down in a comfortable position.
6. Hold your penis up towards the ceiling. This creates a straighter passage down the urethra.



7. Slide the catheter in.
 - Slide the catheter in about 6 to 8 inches (15 to 20 cm)
 - Continue to insert the catheter until you start to see urine draining from it. When urine is coming out, slide the catheter in 1 more inch (2.5 cm). Then stop.
8. Wait for all the urine to drain from your neo bladder.
 - Insert 75 ml to 100 ml of saline and flush the neo bladder.
 - Repeat the process until you see little or no mucus.

If you have trouble inserting the catheter:

- Try taking a couple for deep breaths and exhale slowly. This helps to relax your muscles.
- You can also try and turn the catheter as you are inserting it into the urethra.
- Never force the catheter. If you are not able not able to insert the catheter, call your doctor.
- It's normal to see some pink urine when you insert or remove the catheter.

Your catheter may be reused for about 1 month, or before the catheter becomes brittle and discoloured. To clean your catheter, follow these steps:

1. Wash your catheter with warm, soapy water.
2. Rinse well.
3. Air dry.
4. Throw away after 1 month or when the catheter is brittle and discoloured.

How do I make saline?

You need saline to flush your suprapubic and foley catheters. You can buy saline at your pharmacy or make it yourself.

Method One	Method Two
Making 1 cup of saline	Making 3 litres of saline
<ul style="list-style-type: none">• Mix ½ teaspoon of table salt in 1 cup (250 ml) of boiled water.• Store opened containers of saline in the fridge for up to 3 days.• Take the container out of the fridge ½ hour (30 minutes) before you use it.	<ul style="list-style-type: none">• Mix 8 teaspoons of table salt in 3 litres of distilled water. You can buy distilled water at your pharmacy.• Pour the saline into sterilized containers.• Keep the containers in the fridge for up to 4 weeks. If you cannot refrigerate them, you can keep saline for 2 weeks at room temperature.

What follow-up appointments do I need?

Removing your stents

- The stents may fall out by themselves or may be removed at your appointment or by your home care nurse.

Removing your staples

- The staples in your incision should be removed in 4 weeks.
- This will be done at your follow-up appointment.

Cystoscopy Department

You will have 3 follow-up appointments at the Cystoscopy Department.

Your stents will be removed 2 weeks after surgery.

Cystoscopy Department

2nd floor,
Peter Munk Building
Toronto General Hospital

1

Your first appointment will be about 4 weeks after surgery. During this appointment:

- You will have a cystogram. This is an x-ray that tells us how your new pouch is healing.
- Your foley catheter will be removed, if everything is healing well.
- We will teach you how to empty your neo bladder and review the schedule for emptying your new bladder. (See pages 21-23.)
- The suprapubic catheter will be clamped. You will continue to unclamp the tube and irrigate as usual.

2

Your second appointment will be 2 weeks after your foley catheter is removed. During this appointment:

- Your suprapubic catheter will be removed.
- We will teach you how to catheterize your neo bladder and review how to care for your new bladder. (See pages 23-25.)

3

Genitourinary (GU) Clinic

You will have a follow-up appointment at the GU Clinic to:

**GU Clinic, 4th floor
Princess Margaret Cancer Centre**

- check that you are recovering well, and
- review the results of tests on the bladder that was removed.

If you are a sexually active male and would like to start penile rehabilitation, we will give you a prescription for erectile dysfunction medication. See <https://sharec.truenth.ca>.

4

If you are sexually active, your fourth appointment may be at the SHAReClinic, a sexual health and rehabilitation e-clinic:

- Your SHAReClinic is a free, online health care clinic that helps people cope with the sexual side effects of prostate cancer.
- Ask a member of your health care team or the Urology Clinical Coordinator for more information about how to register.
- To learn more about the SHAReClinic, go to <https://sharec.truenth.ca>.

What if I have trouble adjusting after surgery?

It takes time to recover physically and emotionally after major surgery. It may be many months before you have the strength and energy you had before surgery. You also have to adjust to living with your new bladder. It is normal to have many emotions.

Talk about your feelings with someone close to you. Ask your family doctor or your home care nurse to refer you to a health professional for help, if needed. You may also benefit from talking with other people who have gone through this experience. One option for connecting with others is [Bladder Cancer Canada](#). You can talk to your health care team about more information on how to cope after this surgery. Or, visit www.uhnpatienteducation.ca

Do I need to wear medical identification?

Yes, you do. In an emergency, it is important that health care providers know that you have a neo bladder and may need catheterization. Keep emergency contact information and medical notes on a card in your wallet, on your smartphone, and consider wearing medical identification.

Medical alert products (such as bracelets, necklaces or watches) can be ordered from MedicAlert Foundation Canada at 1-800-668-1507 or www.medicalert.ca.

Who to call if you have questions

If you have questions after surgery, please call your health care team.

Do not call the Princess Margaret Hospital Triage number.

Unit 10 ES (Eaton South)	416 340 3521
Enterostomal Nurse, Debra Johnston	416 340 4800 ext. 7209
Urology Clinical Coordinator, Leah Jamnicky	416 340 4666
Cystoscopy Department	416 340 3882

Doctors' offices	
Dr. Fleshner	416 946 2989
Dr. Kulkarni	416 946 2246
Dr. Zlotta	416 586 4800 ext. 3910

When to get medical help

Call your doctor, Unit 10ES Eaton South or your home care nurse or if you notice ANY of these problems:

- pain, redness, swelling or drainage at your incision
- pain in your stomach or side (the kidney area)
- fever, a temperature above 38 °C (100.4 °F) or chills
- feeling very tired
- your urine is cloudy or smells bad
- you are unable to pass urine or flush your neo bladder and may have a blockage



Go to the nearest hospital Emergency Department if you have pain, redness or swelling in your calf or inner thigh area. These are signs of a blood clot in your leg.



When you visit your health care provider or the and Emergency Department:

- Remember that we have created your bladder using bowel. This means any urine sample you give will always contain Ecoli, which should not be treated with antibiotics, unless you have symptoms of an infection.
- Be sure to tell your health care provider you have a neo bladder, not a 'new' bladder.

Visit www.uhnpatienteducation.ca for more health information. Contact us to provide feedback or request this brochure in a different format, such as large print or electronic formats: pfep@uhn.ca

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