

Cystectomy and Surgery to Create an Indiana Pouch

A guide for patients and families

Reading this booklet can help you prepare for your surgery, hospital stay and recovery. 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.
- or
- The ovaries, fallopian tubes, uterus, cervix and part of the vagina may also be removed.

What is a Continent Diversion?

When the bladder is removed, you need another way for the urine to leave the body. An Indiana Pouch is a surgically made pouch made from pieces of your large bowel.

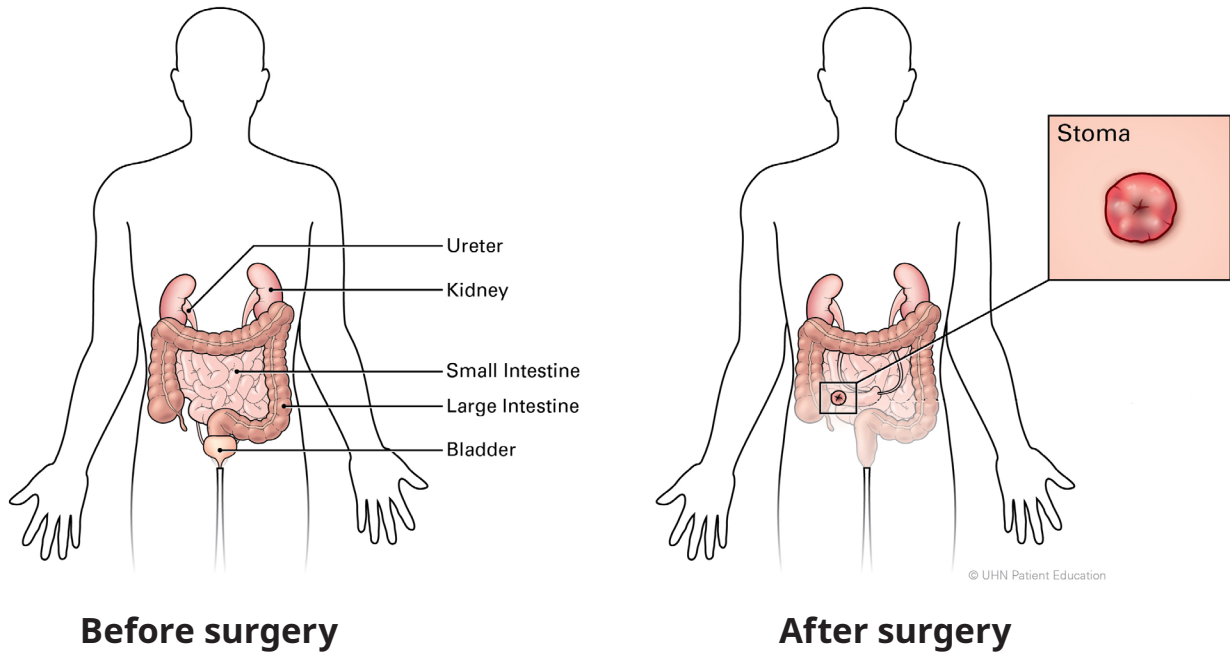
Medical terms

An Indiana Pouch acts like your bladder because a piece of your bowel is made into a pouch that can store urine.

The pouch acts like a bladder, collecting urine that comes down the ureters from the kidneys. The pouch is joined to the outside of your body through a small opening called a **stoma**. The stoma is very small and can be covered with a bandage or small dressing to protect your clothes.

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. An Indiana Pouch is not a muscle, so we will teach you how to use a catheter to empty the urine from your Indiana Pouch.
- When a regular bladder gets full, the nerves around it send messages to your brain, which gives you the urge to pass urine. Your Indiana Pouch does not have the same nerve supply, so you will not feel this urge. You will have to empty your pouch using a thin, soft tube called a catheter at regular times during the day and night.



An Indiana Pouch needs more care than a regular bladder, because it is made from pieces of bowel. As bowels normally make mucus, your pouch will too.

The mucus will collect in your Indiana Pouch along with the urine. We will teach you how to flush out mucus so it will not block the flow of urine.

What are the possible risks?

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

- **blood clots (deep vein thrombosis)**
- **blood loss**
- **infection**
- **blockage of the pouch**
- **losing the ability to have 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.

Please have someone with you to this appointment.

What should I have available for my Pre-Admission Clinic visit?

Please have with you:

- 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.
- any past test results or reports from your specialists (for example, past scans, blood test or reports from a cardiologist)
- someone to support you and help remember important information
- 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 your abdomen for the best place to put a stoma, in case an ileal conduit is needed. If you have questions about other options besides an Indiana pouch, 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>).

Pharmacy Department
1st floor,
Norman Urquart Wing
Peter Munk Building
Toronto General Hospital

If you live alone:

- Make or buy extra meals and freeze them for after your surgery.
- Arrange for someone to drive you surgery 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?

Your stomach has to be empty before the surgery. You need to have a clean bowel with no stool inside. On the day before your surgery:

- Drink only clear fluids such as apple juice, cranberry juice, ginger ale, Jell-O, clear broth or tea.
- After lunch on the day before your surgery start taking the laxative prescribed for you. Drink all of it. It helps to clean your bowel.
- After midnight the night before your surgery, do not eat or drink anything. Do not chew gum or eat candy.

The evening and morning of your surgery:

- Shower or bathe on the evening before and 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
- Enough comfortable clothes for several days and 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 4 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 **possible 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 or Malecot catheter** coming out of your abdomen. You will have another tube called a **catheter** in your new pouch.
- The catheters drain urine and mucus from your Indiana pouch into drainage bags. They will stay in place for a few weeks to keep your pouch 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 Eaton South Nursing Unit (10ES)**. 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 and Malecot 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, usually by the time you leave the hospital, they only need to be irrigated every 4 hours. But this really depends on the amount of mucus that is made. 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 will I 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.

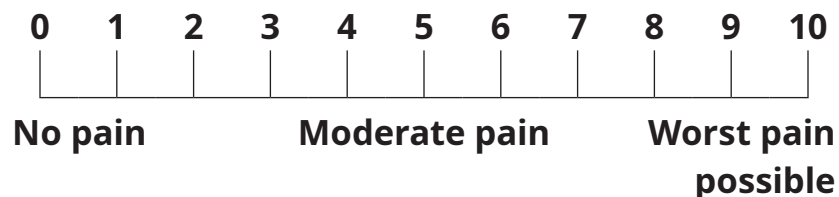
A few days after surgery, you may have gas pain. Walking is the best way to relieve this type of pain.

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 will 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 stopped 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 assist you to 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 stay in hospital for 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 or 2 days before.

The usual stay in hospital is 6 to 8 days.

What happens before I leave the hospital?

Planning for your safe recovery after your hospital stay 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 leave, we will review:

- 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 or Malecot and Foley catheters
- How to gradually increase your activity level
- When and how to resume your usual 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 (signs of infection, skin breakdown or a blocked Indiana pouch) 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 pouch.

Take 2 pills a day, one in the morning and one in the evening.

Pharmacy Department

1st floor

Normal Urquart Wing

Peter Munk Building

Toronto General Hospital

The health care team will:

- Make arrangements for the care and services you will need once at home. This includes home 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

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

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

Plan to have someone help you 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.
- Avoid long car rides. When riding in any vehicle, stop often to walk and stretch your legs.

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:

- 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 4 weeks at your follow-up appointment.
- 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 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 catheters with 75 to 100 ml of saline. (Read how to make saline on page 25.)
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. If there is no urine return after 3 syringes of saline, stop and call the 10ES Nursing unit.
5. If urine does return, 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 tip 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 catheterize my Indiana pouch?

At your first follow-up appointment, your stents in your stoma are removed. At your second appointment, you will have a pouchagram to make sure the pouch has healed and your Foley catheter is removed from the pouch.

A list of your follow-up appointments is on page 26

Your suprapubic/Malecot catheter is clamped to allow the urine to build up in the Indiana pouch. You will be taught how to catheterize the new pouch. Your Indiana pouch will start to fill with urine. As it can only hold a small amount, you will need to catheterize your pouch often, day and night. We will teach you how to do this. See the schedule on page 23.

Catheterizing urine empties your Indiana pouch of urine and mucus.

How often should I catheterize my Indiana pouch?

Start by catheterizing 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 Indiana pouch does not get too full.

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

- **Important:** the time between trips to the bathroom varies between people.


Use the schedule below as your guide. Adjust the schedule to meet your needs. For example, if you are drinking lots of fluids, you need to catheterize more often. Eventually, this will become routine.

Approximate schedule for catheterizing your Indiana pouch

	Day	Night
Week 1	every 2 hours	every 3 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 to the night drainage bag. In the morning, re-clamp it shut and follow the catheterizing schedule.

To reduce leakage of urine:	
	<ol style="list-style-type: none"> 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 catheterize to empty the urine. 3. Catheterize yourself before bedtime to empty your Indiana Pouch.

How to catheterize yourself:

1. Wash your hands well.
2. Wash the opening of your stoma well with a mild, unscented soap and water.
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. Slide the catheter in.
 - Slide the catheter in about 10 to 12 inches (25 to 30 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.
7. Wait for all the urine to drain from your Indiana Pouch.
 - Insert 75 ml to 100 ml of saline and flush the Indiana Pouch.
 - 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 or tip your body from side to side or front to back.
- **Never force the catheter.** If you are not able to insert the catheter, call the 10 ES nursing unit or your doctor.
- It's normal to see some pink urine when you insert or remove the catheter.

Supplies I will need

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.

Your catheter may be reused for about 1 month, 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. Store in an open Ziploc bag.

How do I make saline?

You need saline to flush your suprapubic and Malecot 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 first appointment.

Cystoscopy Department

You will have 2 follow-up appointments at the Cystoscopy Department.

Cystoscopy Department
2nd floor,
Peter Munk Building
Toronto General Hospital

1

Your first appointment will be about 2 weeks after surgery.

During this appointment your stents will be removed.

2

Your second appointment will be about 4 weeks after surgery.

During this appointment:

- You will have a pouchagram. 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 Indiana Pouch by catheterizing through the stoma and review the schedule for emptying your new bladder. (See pages 22-24.)
- The suprapubic/Malecot catheter will be clamped. You will continue to unclamp the tube and irrigate as usual.

3

Your third appointment will be 1 – 2 weeks after your suprapubic catheter is removed. During this appointment:

- Your suprapubic catheter will be removed.
- We will reinforce teaching about how to catheterize and review how to care for your Indiana Pouch. (See pages 24–25.)

Genitourinary (GU) Clinic

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

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

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

If you are sexually active and would like to start penile rehabilitation, we will give you a prescription for erectile dysfunction medication.

4

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

- 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.trueth.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 Indiana pouch. 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](https://bladdercancer canada.org/en/facing-bladder-cancer/support-groups) (<https://bladdercancer canada.org/en/facing-bladder-cancer/support-groups>). You can talk to your health care team about more information on how to cope after this surgery. Or, visit UHN Patient Education (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 Indiana pouch and need catheterization. Keep emergency contact information and medical notes on a card in your wallet and on your smartphone. You will need to wear a medical alert bracelet.

Medical alert products (such as bracelets, necklaces or watches) can be ordered from MedicAlert Foundation Canada at 1 800 668 1507 or visit the website 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 or your home care nurse or if you notice ANY of these problems:

- your stoma seems to be shrinking, sticking out or breaking away from your skin
- 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
- you have blood in your urine
- your urine is cloudy or smells bad
- you are unable to catheterize or flush your pouch 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 Indiana pouch 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 Indiana pouch, not an ileo conduit.



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