

# Cystectomy and Ileal Conduit

## A guide for patients and families

Reading this booklet can help you prepare for your surgery, hospital stay and recovery at home. 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

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## 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. Areas that might be removed include:

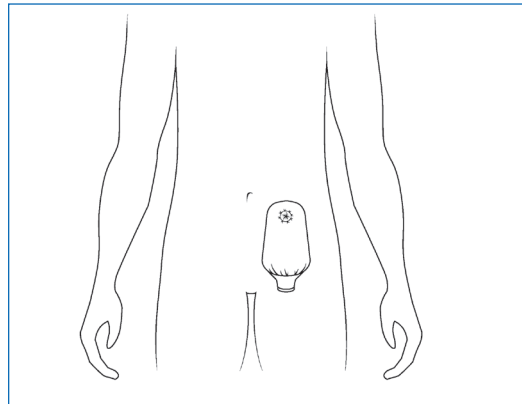
- the prostate gland and seminal vesicles (nerve bundles might also be removed)
- fallopian tubes, uterus, cervix and part of the vagina

## What is an ileal conduit?

When the bladder is removed, you need another way for the urine to leave the body. An ileal conduit is surgically made from a short piece of the small bowel for urine to drain from your ureters to the surface of your skin.

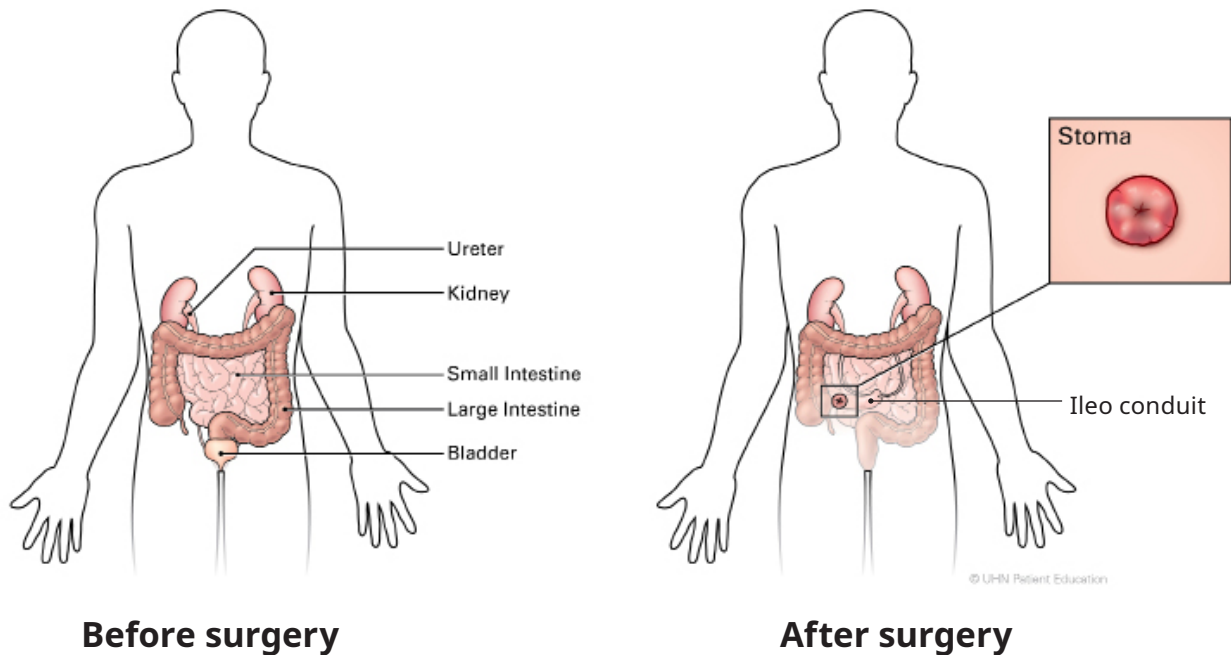
The ileal conduit acts like a passageway, directing urine that comes down the ureters from the kidneys. The conduit is joined to the outside of your body through a small opening called a **stoma**. The urine flows through the new ileal conduit and the stoma into the pouch outside your body.

**Medical terms**  
An ileal conduit acts as a passageway for urine to drain from your ureters into an ostomy appliance (a pouch) outside your body.



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 ileal conduit is not a muscle and it will constantly drain urine.
- When a regular bladder gets full, the nerves around it send messages to your brain, which gives you the urge to pass urine. Now you will need to monitor the pouch outside your body and empty it when it's one-third to two-thirds full.



An ileal conduit is also different than a regular bladder because it is made from a piece of bowel. As bowels normally make mucus, your ileal conduit will too.

The mucus will collect in your stoma along with the urine. This is normal and is not a sign of infection.

## What are the possible risks?

No surgery is completely without risk. Your surgeon and healthcare team will help you understand the possible risks with cystectomy and ileal conduit surgery, which include:

- **blood clots** (deep vein thrombosis)
- **blood loss**
- **infection**
- **no longer being able to have erections** (erectile dysfunction)

# Preparing for surgery

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## When is my Pre-Admission Clinic visit?

You will have a phone or in-person appointment in the Pre-Admission Clinic 2 or 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  
\*Phone or in-person visit\*

Depending on your needs, this visit may take 4 to 6 hours. Please have someone with you for this appointment.

## What should I have with me during my Pre-Admission Clinic visit?

Please have:

- Your Ontario Health Card (OHIP).
- Information about any other medical insurance you have, including policy numbers.
- All medications you are taking—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 in person Pre-Admission Clinic visit?

The admitting clerk will register you. You will fill out the paperwork for your hospital stay.

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 (ET) who will:

- mark on your abdomen the best place for a stoma
- review the care of your ileal conduit (ostomy) and give you a pouch sample to take home and practice with. You will be expected to take part in your ostomy care after surgery
- answer questions about living with an ileal conduit, including how to prevent a parastomal hernia and what financial resources are available to you

## What happens during my phone Pre-Admission Clinic visit?

You will speak with a nurse who will:

- review your health history and assess your health
- check your weight, height, blood pressure, pulse and breathing
- help you prepare for surgery and recovery at home

### The nurse will review:

- ✓ Your choices for pain control after surgery.
- ✓ Your medical history.

You will speak with a nurse and 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 an ileal conduit

**The Urology Clinical Nurse Coordinator will review:**

- ✓ How to plan for going home after surgery.
- ✓ What warning signs to watch for and when to get medical help.
- ✓ What follow-up appointments you need when you go home.
- ✓ What to expect after surgery, how to care for yourself and what help you may need as you recover.

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

- An **anesthetist** may discuss the plans for your anesthetic and pain control after surgery.

## **How do I prepare for surgery at home?**

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 go home 5 to 7 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?**

We will give you a pamphlet with more information about how to prepare for surgery.

### **The morning of your surgery:**

- Shower or bathe on the morning of your surgery

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



## Your hospital stay

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**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.
- 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 <b>Surgical Admission Unit</b> 2 hours before your scheduled surgery time.</p>	<p><b>Surgical Admission Unit</b> 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.
- Tiny catheters called **stents**, to keep urine flowing from your kidneys to your ureters while you are healing.
- A pouch over the new ileal conduit.

When you are ready, you will go to unit **10 ES**. Your family is welcome to visit you on this unit. You can expect to stay here for 5 to 7 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
- your stoma
- how you are feeling
- your pain and how well it is controlled
- your bowel sounds

The first day of 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.
- Start to walk in the evening.

During the rest of your stay, nurses will assess your condition and provide care, education and support as you recover. The education will include how to empty your ostomy pouch, connect to a night-time drainage bag, and change your ostomy pouching system.

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.

**You will get better faster if your pain is well controlled.  
We will work with you to keep you comfortable.**

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

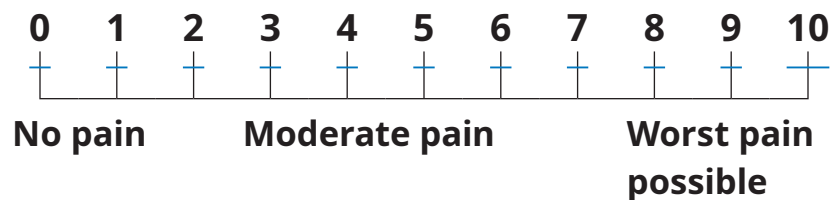
You may have gas pain. Walking is the best way to relieve this type of pain.

## 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 or epidural 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 1 to 3 days.
- The **intravenous** (IV) in your arm will be removed before you go home.
- The **Jackson Pratt** (JP) drain in your abdomen may be removed in 2 to 4 days, when the extra fluid decreases.
- The **stents** at your stoma will be removed at your follow-up appointment. They may stay in longer if you had chemotherapy or radiation.
- Female patients will have their vaginal packing removed the day after surgery.

## Eating and drinking

- 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 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 while in hospital.
- The dressing on your incision will be removed the day after surgery. Leaving it open to the air helps it heal.
- If needed, nurses from the Local Health Integration Network (LHIN) will continue to reinforce teaching and monitoring when you are at home.

#### **Important:**

Health care services needed at home such as nursing care are now provided by the **Local Health Integration Network (LHIN) Home and Community Care**. In this guide, we will call the nurse providing your care at home "home care nurse".

### **VTE Prophylaxis**

- While in hospital, the nurses will give you injections to help lower your chances of developing blood clots.
- Before you leave the hospital, your nurse will teach you how to give yourself these injections at home.

### **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 go home

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## How long will I stay in the hospital?

- You can expect to go home in 5 to 7 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 are going home. This is called your day of discharge. You will usually know a day or two before.

**The usual stay in hospital is 5 to 7 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 go home.

Before you go home, 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 (nurses will give you enough ostomy supplies for the first few days)
- 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 (signs of infection, skin breakdown around your stoma) 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.

The health care team will:

- Make arrangements for the care and services you will need once at home. This includes visits by a nurse from the Local Health Integration Network (LHIN).
- 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
  - ✓ form for provincial ostomy funding the Assistive Devices Program (ADP)
  - ✓ 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 when you leave the hospital

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

A nurse from the Local Health Integration Network (LHIN) will continue your teaching from the hospital. For example, the nurse will continue to teach you about your ostomy care and how to give yourself the injections that help lower the chance of developing blood clots.

You may need help with laundry, cleaning, cooking and grocery shopping and drives to medical appointments. If you live alone, make arrangements for help at home with family or friends if needed.

### 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 meal planning, go to: [www.hc-sc.gc.ca](http://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.
- Ask your stoma nurse about using a **parastomal hernia prevention belt** if you are very active and lift heavy items often.

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 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.



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

## **Tips for using my night urine collector bag:**

- ✓ To prevent the tube from kinking, place the tubing down your leg or towards the end of the bed.
- ✓ To prevent the tubing from moving and twisting, secure it with leg straps or tape.
- ✓ If you have the soft Foley night urine collector bag, replace it 2 times a month. If you have the hard plastic urine jug containers, replace them every 3 months.
- ✓ Some brands of tubing are longer than others. This can help you if you move a lot when you sleep. Check the length of the tubing before you buy it.

## **How do I attach the night urine collector bag?**

**Important:** Before you begin, make sure you are using the right adaptor for the brand of urostomy pouch you have. Each brand has its own special adaptor.

1. Leave a small amount of urine in the pouch before you attach the night time urine collector bag. This stops a vacuum effect from happening.
2. Wash your hands well with soap and water.
3. Attach the adapter to the tubing of the night time urine collector bag if it's not already done.
4. Connect the adaptor to the end of your urostomy pouch. Depending on the brand you are using, you may need to push inwards on the white tabs at either side of the adaptor, and push upwards over the firm drainage spout of your urostomy pouch.
5. Open the closure of the pouch's drainage spout to allow the urine to flow.
6. Place the night time urine drainage collector bag below the level of the urostomy pouch on your abdomen. This helps your urine to drain.

## **How do I detach the urostomy pouch?**

1. Wash your hands well with soap and water.
2. Close the spout of the urostomy pouch to prevent it from leaking.
3. Detach the adaptor and the night time urine collector bag from your urostomy pouch.
  - Depending on which brand you are using, you may need to push inwards on the white tabs at either side of the adaptor, and pull the adaptor downwards over the firm drainage spout of your urostomy pouch.

## **How do I clean the night urine collector bag?**

1. Empty the urine from the night urine collector bag.
2. Using a funnel:
  - Rinse the bag with water.
  - Clean the adapter and night urine collector bag every day with a vinegar and water solution. (Mix 1 part vinegar and 3 parts water).
  - Let solution sit for 1 hour.
  - Empty the bag.
  - Rinse the bag again.
  - Let the urine collector bag air dry with the closure open.

## **Supplies I will need**

The hospital will provide your supplies at first. Then your nurse providing you care at home will tell you what products to buy. Please ask us for pamphlets and more information about where you can buy your stoma supplies.

## What follow-up appointments do I need?

### Removing your staples

- The staples in your incision will be removed at your follow-up appointment back in the Cystoscopy Department.

### Cystoscopy Department

You will have a follow-up appointment at the Cystoscopy Department.

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

### Enterostomal therapy (ET) or Stoma (ostomy) nurse

After your cystoscopy appointment, you will also see the ET or Stoma nurse. The nurse will make sure you are wearing the correct pouching system, give you information and answer your questions about living with an ostomy.

**Enterostomal  
therapy nurses  
10th floor,  
Peter Munk Building  
Toronto General Hospital**

During this appointment, you will be given a follow-up appointment with the ET or Stoma nurse. The reason for this appointment is to give you the correct size for a pouching system.

## 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 a sexually active male and would like to start penile rehabilitation, we will give you a prescription for erectile dysfunction (ED) medication. You will also receive an appointment in the mail for the Prostate Cancer Rehabilitation Clinic located at 123 Edward Street.

## 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 ileal conduit. It is normal to have many emotions.

Talk about your feelings with someone close to you. Ask your family doctor or your homecare 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 [www.uhnpatienteducation.ca](http://www.uhnpatienteducation.ca).



## How do I get a urine sample?

**Important:** Give this information to a health care professional if you need to get a urine sample. Taking the sample incorrectly will always give you a positive result.



**Never take urine samples directly from your urostomy pouch or night urine collector bag.** This can spread germs and cause infection. Sometimes you may need to explain to people on your health care team how to get a urine sample from your urostomy.

**Step 1.** Gather these supplies:

- Cleaning solution such as betadine
- Sterile 4x4 gauze
- Sterile specimen container with lid, label and laboratory specimen bag
- Sterile and clean gloves
- Soft cloths for cleaning before replacing the pouch
- New pouching system

**Step 2.** Follow these steps:

1. Wash your hands well with soap and water.
2. Put on clean gloves.
3. Open the supplies, and maintain sterility.
4. Remove the pouch and throw it away in a yellow biohazard waste container.
5. Wash your hands well again.
6. Put on clean gloves.
7. Use sterile technique.
8. Clean the stoma with the cleansing solution using a circular motion from the stoma opening outward.
9. Dry the stoma with sterile gauze.
10. Throw away the first few drops of urine by allowing the urine to drip onto sterile gauze.
11. Hold the sterile specimen cup under the stoma. Collect about 5-10 millilitres of urine. This may take 5 to 15 minutes.
12. Clean and dry stoma and peristomal skin.
13. Throw away the supplies according to the institutional policy.
14. Place a lid on the specimen container. Write on the label that the sample has been taken from an ileal conduit. Place in a laboratory transport bag.
15. Apply new ostomy pouching system.
- 16. Send specimen to the lab within 1 hour.** If you are not able to deliver specimen to lab within 1 hour, refrigerate the specimen and deliver it within 24 hours.

Adapted from Mahoney, Baxter, Burgess et al; 2013

## **Do I need to wear medical identification?**

Yes, you do. In an emergency, it is important that health care providers know that you have an ileal conduit. 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 [www.medicalert.ca](http://www.medicalert.ca).

## Who to call if you have questions

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If you have questions after surgery, please call your health care team.  
Do not call the Princess Margaret Hospital Triage number.  
The only 24-hour phone number is the 10 ES Nursing Unit.

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

<b>Doctors' offices</b>	
Dr. Finelli	416 946 2851
Dr. Fleshner	416 946 2989
Dr. Hamilton	416 946 2909
Dr. Kulkarni	416 946 2246
Dr. Perlis	416 946 2957
Dr. Zlotta	416 586 4800 ext. 3910

# When to get medical help

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**Call your doctor, Unit 6A Munk or your home care nurse or if you notice ANY of these problems:**

- your stoma seems to be shrinking below skin level, or breaking away from your skin
- your stoma is changing from pink or red to a dark blue, purple or black/brown colour
- 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



**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 Ileal conduit using bowel. This means any urine sample you give will always contain Ecoli.



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