Kingston Health Sciences Centre

Centre des sciences de la santé de Kingston

A New Beginning…
Ileal Conduit Care

Information for patients who are preparing
to receive an ileal conduit (or who have an ileal-conduit).

Hôpital Hotel Dieu Hospital

Hôpital Général de Kingston General Hospital

Contents

Introduction

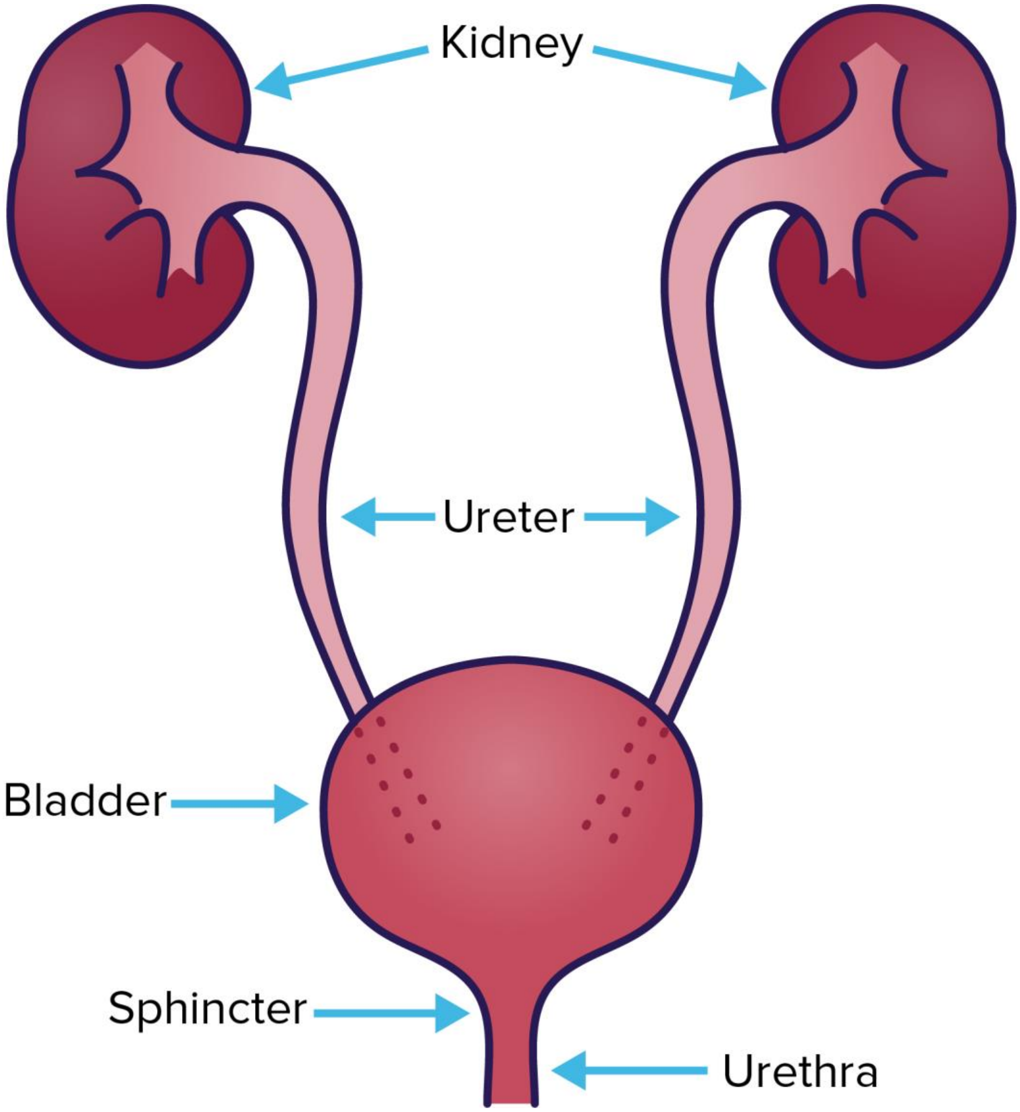
Your surgeon has told you that you need to have your bladder removed (cystectomy) and a urinary diversion created, specifically an ileal-conduit. You may have a lot of questions, but cannot find the words to ask them. Many people feel this way before their ileal-conduit. You are not alone. Many people live long and full lives after their ileal-conduit. For them and for you, an ileal-conduit is a new beginning.

This book is yours to keep. It tells you about your operation and the ileal-conduit. This book also tells you how to care for your ileal-conduit. It also tells you how to return to your usual way of life.

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

The urinary tract

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



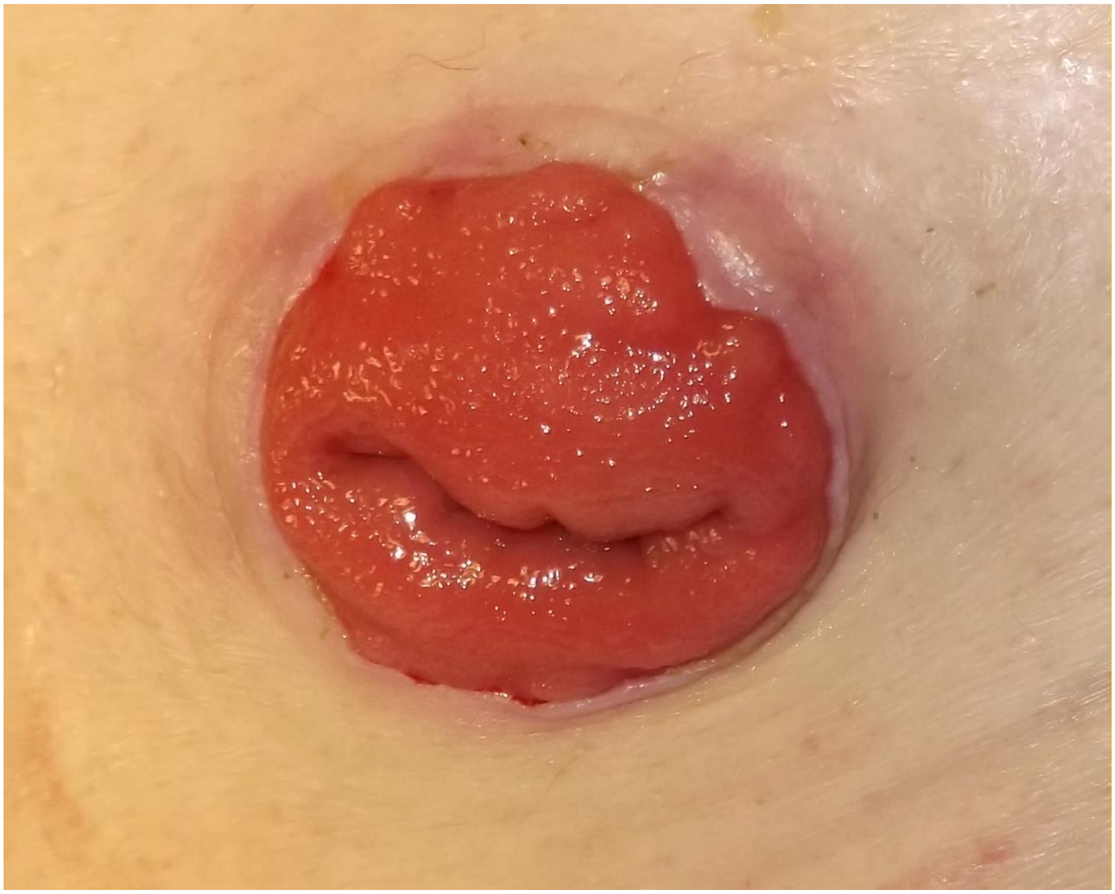
Cornell, B. 2016. *Diagram of the Digestive System* [ONLINE] Available at: http://ib.bioninja.com.au. [Accessed 03 March 2020]

What is a urinary diversion?

When the bladder must be removed or bypassed, a new exit for the urine is needed to divert the flow of urine from its usual pathway. This is called a urinary diversion. With this operation, a surgical opening is created through the wall of the abdomen to allow the urine to exit the body.

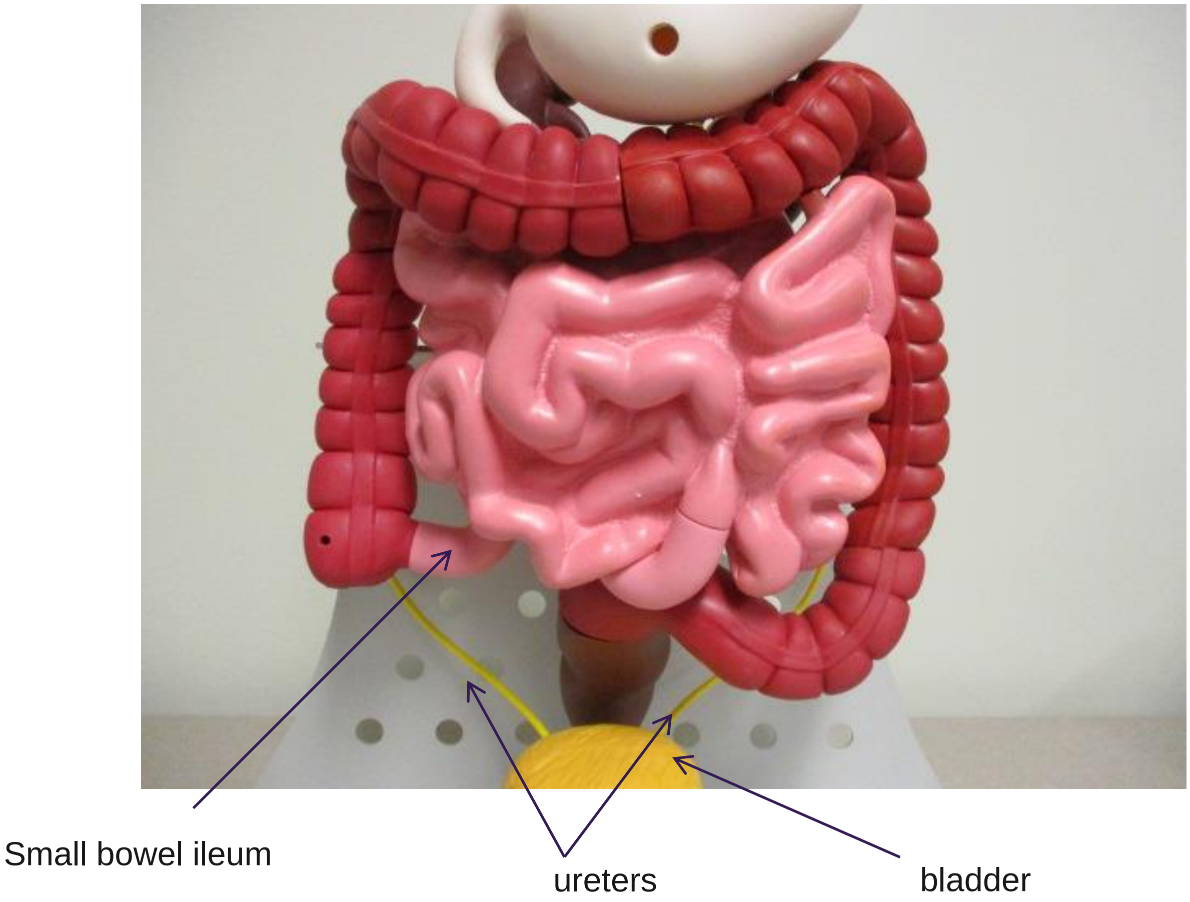
What is an ileal conduit?

An ileal-conduit is a type of urinary diversion. With an ileal-conduit, the surgeon uses a piece of small bowel to create the passageway between the ureters and the outside of the body. This opening is called a stoma. Stoma is the Greek word for mouth or opening. With an ileal-conduit, the urine made in the kidneys will flow down the ureters, through the ileal-conduit (small piece of bowel) and you will pass urine through the stoma instead of storing it in the bladder.



When you have an ileal-conduit, you cannot store or control the flow of urine. You need to wear a pouching system over the stoma to collect the urine. The pouching system consists of a skin barrier and an odour-proof pouch specifically designed for urine. The urinary pouch is also referred to as a urostomy pouch.

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



The most common type of urinary diversion construction is an ileal conduit.

Your surgeon uses the end portion of the small bowel (or small intestine), called the ileum to construct the conduit. The conduit is the channel that allows the urine to exit your body.

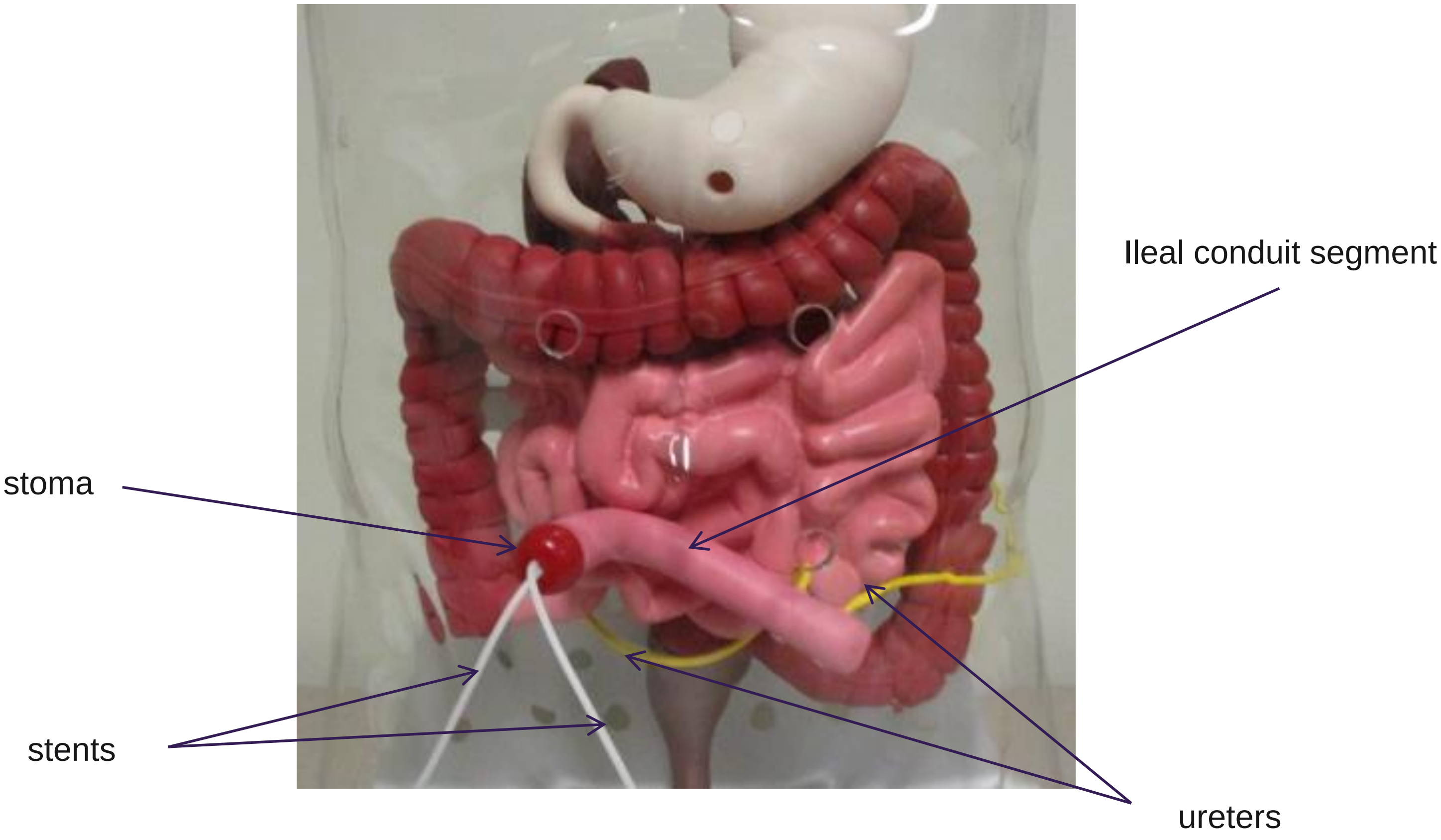
A 10-15cm (4-6 inches) length of bowel is removed from the digestive tract; the open remaining bowel ends are attached to each other to resume the continuity of the digestive tract. The removed segment of bowel is used to create the ileal-conduit.

The segment of ileum is closed at one end and the other end is brought out through the wall of the abdomen to form the stoma. The surgeon stitches the stoma to the abdomen.

The ureters are then attached to the conduit. The urine that is produced by the kidneys flows down the ureters, into the conduit and out of the body through the stoma.

The stoma is usually located on the lower right side of your abdomen.

The following diagram shows the ureters being attached to the new conduit.
Stents are placed within the stoma to protect the sutured areas inside.



Why you need an ileal-conduit

An ileal-conduit is done only if your health is at risk or if you can no longer cope with your condition.

There are many reasons for needing an ileal-conduit. Your surgeon will explain why you need an ileal-conduit.

Bladder cancer is the most common reason for needing a cystectomy (bladder removal) with an ileal-conduit.

Other reasons may include:

- Interstitial cystitis
- Neurogenic bladder
- Chronic urinary tract infection
- Urinary incontinence
- Birth defects
- Trauma

Usually adults have a permanent ileal-conduit.

Before your operation

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

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

In addition, the NSWOC nurse examines your abdomen before surgery and selects the best location for your stoma. Your input is helpful since your lifestyle, clothing and specific needs are considered before choosing the site. Every effort is made to place the stoma in the best possible location. Sites vary depending upon the type of surgery and the anatomy of each person.

Your surgeon tells you how to prepare your bowels for your operation and <u>may</u> arrange for you to take a laxative. This is to make sure your bowels are empty before the operation. You may pass several watery stools after taking the laxative.

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

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

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

During your operation

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

Your surgeon will complete your surgery through an open approach. The surgeon will make one 10 to 20 cm cut (incision) in your abdomen to perform the surgery. The surgeon will remove the diseased bladder and remove a segment of bowel for creating a conduit and a stoma.

You will require the following:

- **Ureteric stents** through the stoma to drain urine from your kidneys
- A **pouching system** is placed over your ileal-conduit.
- A **dressing** is placed over your incision(s).
- An **abdominal binder** placed around your abdomen to support your abdominal incision.

You may require the following:

- **Abdominal or pelvic drains**. These small tubes drain away extra fluid from your abdomen and pelvis.
- **Support stockings or special inflatable stockings**. These help the circulation in your legs and help prevent blood clots.

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

After your operation

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

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

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

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

Day/Evening of surgery:

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

The first day after surgery:

- **Chew 1 piece of gum** 3 times a day for up to 5 minutes
- You **drink/eat liquid food** as tolerated
- You **sit up in a chair 3 times per day** for at least 1 hour
- You may **walk in the hallway** as tolerated
- Empty urine from your pouching system with the help of a nurse

In 2 to 3 days:

- **Chew 1 piece of gum** 3 times a day for up to 5 minutes
- You may **start to introduce soft to solid foods** as tolerated
- **Sit up in a chair for all meals**
- You may **walk in the hallway 4 times per day**, as tolerated
- Empty urine from your pouching system with the help of a nurse
- Connect/disconnect from the night drainage system with the help of a nurse
- Participate in pouching system change

In 4 to 7 days:

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

From the time of your operation, there is urine flowing from your ileal-conduit. A pouching system is placed over your stoma in the operating room. Your pouching system will be attached to a night drainage set.

After your operation, the NSWOC nurse fits you with a new pouching system. As you gradually recover from your surgery, the NSWOC nurse teaches you how to take care of your ileal-conduit and prepares you for going home. It is important that you become as independent and as comfortable as possible with caring for your ileal-conduit. The nurses working on the surgical unit will also reinforce the teaching and support you in your learning. With time, you will develop confidence and the care becomes routine to you. Support from your family and friends are very helpful. If you wish, someone close to you may be included in your teaching sessions. Never hesitate to ask questions.

Prior to your discharge, your urologist wants to ensure you have met three milestones which are:

- Being able to tolerate your food
- Having a return of bowel function
- Having your pain under control

About your stoma

The visible part of the ileal-conduit is the stoma. This is the inner lining of the small bowel and it is soft, moist and red in colour. At first, you may not feel ready to look at your stoma.

- There are no nerve endings in the stoma, so you have no feeling in it. It does not hurt, and you cannot tell when urine is passing through it.
- The stoma may be oval or round. At first, it is a little swollen. The swelling goes away in 6-8 weeks.
- The ureteric stents are stitched to the stoma. These stitches will dissolve in 2 to 3 weeks. The ureteric stents will slowly slip out of the stoma as the swelling goes away. These stents can be discarded if you find them loose (no longer attached) in your pouch. If the stents do not slip out on their own, your surgeon or the NSWOC nurse will remove them at the time of your follow-up appointment in the clinic within 4 to 6 weeks.
- A clear gel covers your stoma. This is mucus that coats the inside of the bowel. It is normal to see small bits of mucus in your urine.
- The stoma bleeds easily since there are many small blood vessels close to the surface. The pouching system protects it well in case it is bumped.
- The stitches around the stoma dissolve in 2 to 3 weeks.
- The skin around your stoma may be bruised from the operation. The bruising lasts 1 to 2 weeks. It may last longer if you take drugs that thin your blood.

About your urine

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

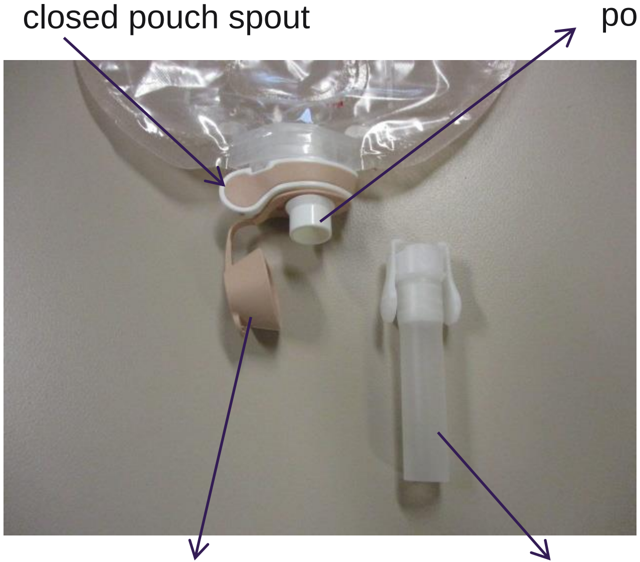
The lining of the bowel secretes a jelly-like substance called mucus. As the urine flows through the stoma, some of the mucus mixes with the urine and is expelled. A large amount of mucus will be present initially after your surgery. Although the amount of mucus decreases over time, the urine will always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

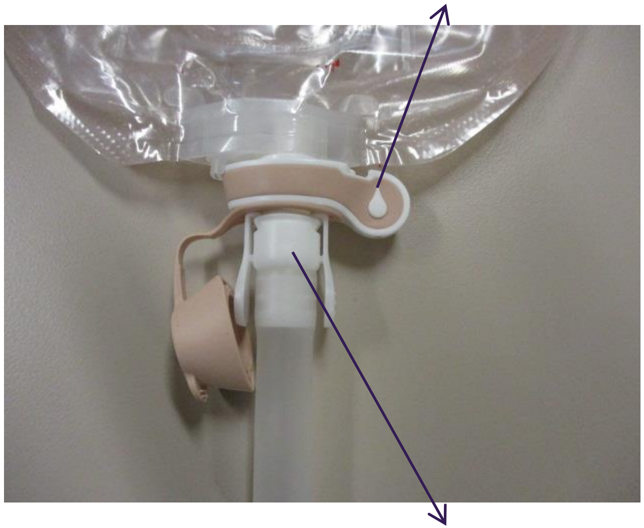
About your pouching system

The pouching system is made to contain the urine that flows from your ileal-conduit. It is made up of a skin barrier to protect the skin around your stoma and an odour-proof pouch. Pouches designed for the collection of urine are also called a urostomy pouch.

The urostomy pouch has an anti-reflux mechanism. This is a special mechanism that prevents urine from flowing from the pouch back into the stoma.

There is a spout at the bottom of the pouch that allows for easy emptying.





You can connect your urostomy pouch to a night drainage set using an adapter to collect the urine overnight. It drains your urostomy pouch while you sleep.

You may choose not to use a night drainage set. Depending on how much urine you pass, you will have to empty your pouch at least once or twice through the night.

Pouching systems are also lightweight, waterproof, odour-proof, and low profile (not noticeable under clothing).

The pouches are available in clear or opaque. You will have a clear pouch while you are in hospital to allow viewing of your stoma by your surgeon and your nurses. You can change to an opaque pouch after you are discharged if you prefer.

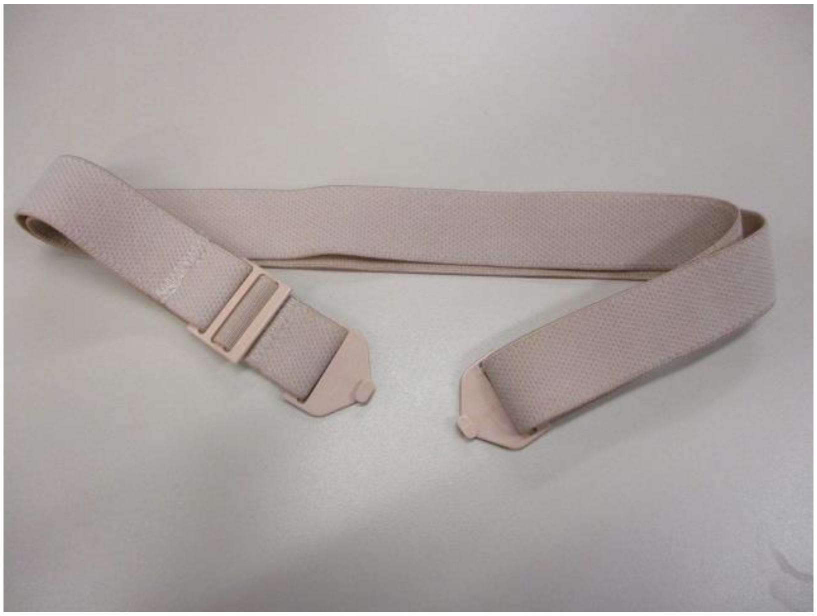
There are a wide variety of pouching systems available. Your choice depends on your body type, personal preference and your lifestyle. The NSWOC nurse shows you pouch samples and helps you with your selection.

There are generally two kinds of pouching systems: one and two-piece systems.

The **1-piece pouching system:** The skin barrier and the pouch are pre-attached.

The **2-piece pouching system:** The pouch can be removed from the skin barrier. The skin barrier has a plastic ring. The pouch snaps onto or sticks to the plastic ring depending on the manufacturer.

The NSWOC nurse will tell you if you need to use an ostomy belt to secure your pouching system. The belt fastens onto tabs of the pouching system and must be worn at the level of the stoma. The NSWOC nurse will show you how to adjust the belt.



Pouch care

After your surgery, you will have a 2-piece pouching system with a drainable spout.
The pouching system will be connected to a drainage system with an adapter.

Learning how to care for your ileal-conduit will be new for you. If you wish, you can have a family member or friend learn with you. It is important that you become as independent and comfortable as possible with the care and management of your ileal-conduit.

When to empty your urostomy pouch

- When the pouch is about one third full
- Before going out
- Before going to bed
- Before physical activity or exercise
- Before sexual activity
- Whenever it is convenient for you

How to empty your urostomy pouch

1. Stand facing the toilet, or sit well back on the toilet.
2. You may choose to put a few sheets of toilet paper on top of the water in the toilet. This can help to prevent splashing.
3. Direct the end of the pouch into the toilet.
4. Remove the cap and open the spout.
5. Empty the urine from the pouch.
6. Hold the end of the pouch up and wipe it dry with toilet paper.
7. Shut the pouch closure and replace the cap.

Changing your pouching system

The wear time of your pouching system depends on the amount and character of your urine. It is also dependent on the climate in which you live, your daily activities and the type of skin barrier you use. There are two types of skin barriers: standard and long-wear. The NSWOC nurse helps you choose the type that best suits your needs.

When to change your pouching system

- At least every 5 to 7 days
- When it is leaking
- When your skin under the skin barrier burns or feels itchy

It is best to change your pouching system before or at least 2 hours after drinking liquids when your ileal-conduit is less active. A good time may be before breakfast or bedtime. When your incision is completely healed, you may take a shower or bath with the pouching system off.

How to change your pouching system

1. Pull off the pouching system gently with one hand. At the same time, hold your skin back with the other hand. Discard the used pouching system in the garbage. **Do not flush it down the toilet.**
2. Wash the stoma and skin with warm water and a soft wash cloth. If you use soap, choose a soap that does not contain oil. Oil prevents the pouching system from sticking to your skin. **Many commercial skin wipes such as baby wipes contain lanolin and are not appropriate for stoma care as they prevent the skin barrier from sticking well to the skin.**

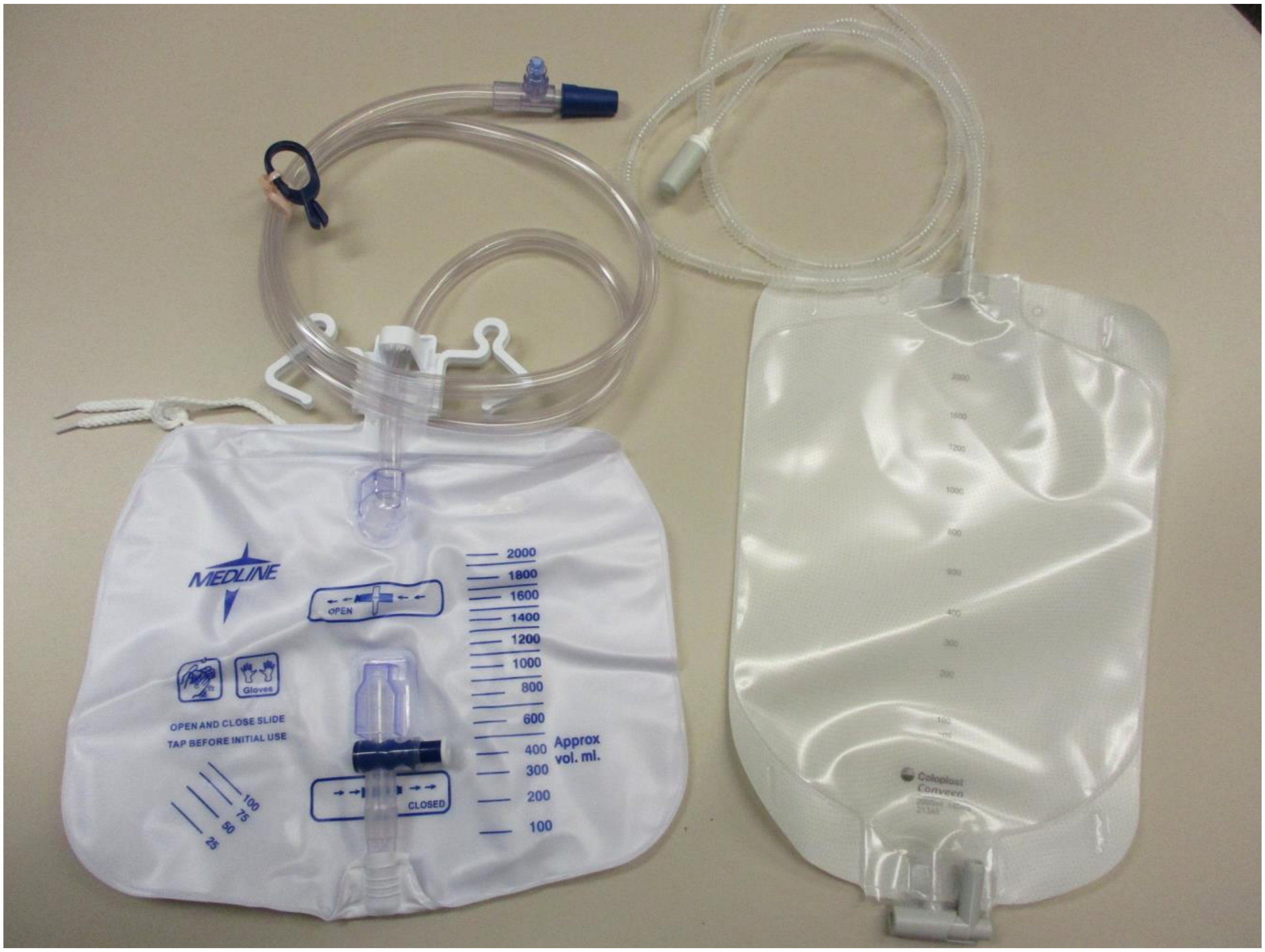
3. Rinse the area well and pat it dry with a soft towel
4. Any adhesive residue can be removed with an ostomy adhesive remover. Make sure that you cleanse the area well with warm water afterwards as the remover may interfere with the adherence of your new pouching system.
5. Shave around the stoma if needed. You can use a light dusting of ostomy powder as a dry lubricant for shaving. Make sure that you shave away from the stoma to avoid accidentally cutting the stoma. Gently brush the skin clean. **Do not use a commercial hair removal product.**
6. Check the condition of your skin to make sure that it is not sore. Skin irritation can be caused by:
   - Traumatic removal of the pouching system
   - Incorrect pouching system fit from weight gain or loss
   - Leakage of urine onto skin
   - Sensitivity to products
   - Trapped moisture
7. If your skin is clear, wipe skin protector around your stoma and keep it dry. This step is optional. **If you have skin sensitivities or if your skin is red and sore, do not use skin protector.**
8. If your skin is red and sore, dust it lightly with ostomy powder. Brush away excess powder. Do not use creams or lotions because these products can interfere with the adherence of the new pouching system. **If you have persistent skin irritation, contact the NSWOC nurse.**
9. For the first 6 to 8 weeks, measure your stoma size each time you change the pouching system. Use a stoma measuring guide provided in the product packaging. After the stoma stops shrinking, measure it when your weight changes. Weight gain or loss changes the size of the stoma.

10. Cut a hole in the centre of the skin barrier. The hole should be 3mm (1/8th inch) bigger than your stoma. It should also be the same shape as your stoma. **Note:** Some skin barriers are available with pre-cut stomal openings. The centre opening has already been created for your stoma size. They are simpler to use since there is no cutting involved. These skin barriers are not appropriate while your stoma is still swollen or if you have an oval or irregular-shaped stoma.
11. Remove the paper backing from the skin barrier.
12. If you choose to use ostomy paste, put a thin layer around the hole on the skin barrier for the stoma.
13. If your skin has wrinkles, pull your skin slightly to make sure it is smooth before applying the skin barrier. Place the skin barrier against your abdomen, fitting it around your stoma. Gently press it into your skin.
14. Smooth the skin barrier with your fingertips to make sure it sticks to your skin.
15. Attach the pouch to the skin barrier. Give the pouch a firm tug to make sure it is secure.
16. Close off the spout on the pouch.
17. Place your hand over the pouching system for 2 or 3 minutes. The warmth from your hand will help the skin barrier to stick.
18. Secure your ostomy belt if you use one.

You may want to try a pouching system that is different from the one introduced to you by the NSWOC nurse. Ask the NSWOC nurse to show you samples or you can contact the manufacturers directly (see **Helpful resources**). They all have websites and toll-free numbers you can access for free samples. You are encouraged to try different brands and types of pouching systems. You can also attend open houses sponsored by various pharmacies to talk directly with ostomy sales representatives.

About your night drainage set

A night drainage set lets you enjoy a full night's sleep. It drains your urostomy pouch while you sleep.



How to connect the night drainage set

1. Empty the pouch.
   - Leave a small amount of urine in the pouch before attaching it to the drainage set. This prevents a vacuum in the pouch.
2. Close the spout.
3. Attach the adapter to the spout.
4. Fit the tubing securely to the open end of the adapter.
5. Place the night drainage set beside your bed.
6. Open the pouch spout.
7. Make sure the urine is flowing from the pouch into the drainage set before you go to sleep.
8. Prevent kinking and pulling of the drainage tubing by taping it to the inside of your leg or running the tubing inside your underwear or pajama bottom.

How to clean the night drainage set

1. Shut the pouch closure and remove the adaptor from the pouch closure.
2. Empty the night drainage set into the toilet.
3. Run warm tap water into the adapter and tubing to partially fill the night drainage set.
4. With a plastic squeeze bottle or a large catheter tipped syringe, put 15 mL (1 tablespoon) of liquid laundry detergent into the adapter and tubing.
   - Use a low sudsing laundry detergent or any detergent with the "he" (high efficiency) symbol.
5. Shake the night drainage set and empty it into the toilet.
6. With a second squeeze bottle, put 250ml (1cup) of vinegar solution (¼ cup white vinegar and ¾ cup water) into the adapter and tubing.
7. Shake and leave the solution to soak in the night drainage set for 30 minutes.
8. Empty the night drainage set into the toilet.
9. Rinse the night drainage set again with running warm tap water into the adaptor and tubing.
10. Shake the night drainage set and empty it into the toilet.
11. Store the night drainage set in a clean, dry area, away from direct sunlight.

When to replace the night drainage set

- Every 2 to 3 months

OR

- When it has an odour
- When it looks worn

What is a urinary tract infection?

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

Preventing urinary tract infections

Most urinary tract infections can be prevented by:

- Proper hand hygiene when performing your ileal-conduit care
- Cleaning and replacing your night drainage set as directed
- Drinking 8 to 10 cups of fluid each day
- Drinking a glass (1 cup/ 250 mL) of cranberry juice each day

Signs of a urinary tract infection

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

- Cloudy, foul-smelling urine
- Blood in the urine
- Excessive mucus in the urine
- Low back pain
- Fever
- Chills
- Malaise

You will not experience the traditional signs of burning that occur when urine is passing through the urethra as the urine is now passing through the stoma which has no nerve endings.

If you have symptoms of a urinary tract infection, call your doctor or your NSWOC nurse to have a urine sample taken. A urine sample is obtained by inserting a small catheter gently into the stoma. The urine is collected into a sterile container and sent to the laboratory for testing. **A urine sample should not be taken from your pouch.** Urine from the pouch already contains bacteria and this may give a false reading.

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

What about food?

As you recover from your operation, you will progress from clear fluids to a regular diet. There is very little to no change in your diet when you have an ileal-conduit. Typically, you do not need to be on a special diet unless you have another medical condition or as advised by your doctor. Canada's Food Guide (see **Helpful resources)** recommends that you include a variety of healthy foods each day. The food guide includes the following recommendations:

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

To keep your kidneys healthy and your ileal-conduit flush, you must drink extra fluids. This helps to reduce the risk of infection. Drink 2 to 2.5 liters (8 to 10 cups) of fluid each day. Your surgeon may suggest that you drink a glass of cranberry juice daily to avoid infection.

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

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

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

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

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

Maintain a healthy weight. It is unwise to gain weight unless your doctor tells you too. Extra weight changes how your pouching system fits.

What to wear?

Choose comfortable clothes to wear home from the hospital. Your pouching system is not visible when worn beneath your clothes and when emptied frequently.

You can wear the pouch over or under your underwear. Wearing pantyhose or a light girdle over your pouching system will not harm the stoma. Wearing snug underclothing over your stoma will help to conceal your pouching system and may help you feel more secure.

You can wear a belt or clothing with a waistband. Avoid a tight belt directly over the stoma. Make sure you can pass your fingers easily under your belt or waistband to make sure it is not too tight.

Pants that are worn tightly over the stoma won’t allow the urine to enter the pouch and could cause harm to the stoma. Remember the stoma has no nerve endings so you can’t feel it and won’t know if you are injuring it.

If your ileal-conduit is located above your beltline, you may wear an undershirt or camisole to keep the pouch secure and smooth. Wear loose outer clothing such as vests, sweaters, scarves and jackets to help conceal your pouching system.

When choosing swimwear, select a dark coloured suit with pattern to disguise your pouching system.

- For women, choose a suit with a small ruffle, skirt or panel.
- For men, choose boxer trunks with a high cut waist or longer leg.

If you are concerned that your pouching system is noticeable or that your pouch may shift when your suit is wet, wear a support garment or bike shorts under your suit. Customized swimwear with inside pockets is also available for additional pouch support (see **Helpful resources**).

How to bathe and shower

You can bathe or shower without taking your pouching system off. After showering or bathing, dry both sides of the pouch to avoid skin irritation from trapped moisture.

Once your incision has healed completely, you can bathe or shower when your pouching system is off. This is the best way to clean your stoma and skin.

- Water does not harm or get into your stoma.
- Direct the forceful water stream away from the stoma.
- Do not use bath oils or soaps that leave an oily film on your skin. These can prevent your pouching system from sticking properly to your skin.
- After your bath or shower, dry well and place the new pouching system over your stoma.

What about work?

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

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

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

What about travel?

You can travel anywhere you like. You may start to drive when you are no longer taking opioid pain medications that can affect your driving. Of course, you need to feel comfortable with the care of your ileal-conduit before you go to far-away places.

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

- Carry clean supplies wherever you go. You can carry supplies in a small cosmetic purse, waist pouch or briefcase.
- Be sure to take extra supplies. Take at least twice the supplies you normally use.
- When flying, bring supplies in your carry-on baggage so that you always have them with you in case your luggage is lost.
- If you are planning air travel, purchase pre-cut skin barriers so you will not need to carry scissors in your carry-on bag. Air pressure in airplanes will not affect your pouch.
- Keep your supplies out of the sun. Do not keep them in a hot place such as the trunk or glove compartment of a car. The skin barrier can melt in the heat.
- Wear your seatbelt when travelling in a car. Make sure that the belt goes across your lower abdomen. A soft pad can be placed under the seatbelt to protect the stoma.
- Drink bottled water if there is any doubt as to the safety of the water.
- If you are camping, sleep on a cot (if possible) raised off the ground to allow the urine to flow down by gravity into the night drainage set.
- Ask the NSWOC nurse or contact the Ostomy Canada Society about available resources in the area you plan to visit (see **Helpful resources**).

What about physical activity?

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

How to get out of bed after surgery

- Step one: bend both knees with feet on the bed, reach both arms towards the bedrail and in the direction of exit.
- Step two: push with your feet and roll onto your side.
- Step three: push yourself up using both your arms on the bed. This reduces strain on the abdominal muscles, and protects the incision and reduces the risk of developing a hernia.

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

Temporary physical limitations

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

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

Returning/starting a new sport

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

- Ask your doctor about any limitations.
- Choose sports that are relaxing, comfortable and fun.
- Take it easy at first until you build up your strength. If you want to work out in a gym, avoid abdominal exercises for 4 to 6 weeks. Only introduce these gently, in gradual amounts after your surgeon says it is ok.
- Wear an ostomy belt, stoma shield, panty girdle or close-fitting briefs, if necessary.
- Talk to your NSWOC about products to meet your needs.

Swimming and other water activities

Swimming, hot tubbing and saunas may be resumed once your incision heals completely. This includes personal and public-use areas. If you enjoy water sports, try these tips:

- Don’t go swimming right after putting on a new pouching system.
- Make sure your pouch is empty or wear a stoma cap or mini-pouch instead of a standard sized pouch.
- You may choose to cover the edges of your pouching system with waterproof tape or seal.
- You may choose to change and towel off in a bathroom stall for more privacy.
- You may choose to put on a dry, oversized T-shirt as a cover-up while you change.
- You may choose to wear your bathing suit under your clothing to avoid having to change.
- Arrange to go swimming when your urinary diversion is less likely to be active (for example: not immediately after drinking large quantities of fluids).
- A dry suit is easier to take off than a wet one.

Hernia prevention

The abdominal muscles need time to heal and become stronger after surgery. Supporting and splinting your stoma and abdomen while coughing in the first few months after surgery will also assist in reducing the chance of developing a hernia. Your weight should be kept within the appropriate Body Mass Index (BMI) range for your height. Maintaining a good posture will help to develop your muscles.

Gentle abdominal exercises you can try after surgery once your wound has completely healed include:

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

In addition to avoiding heavy lifting, intensive abdominal exercises should begin no sooner than 3 months after your surgery. Always wait until your surgeon says it is okay to resume abdominal exercises.

What about intimacy?

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

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

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

Sometimes, the problem is emotional. It helps to make sure your pouching system is clean and secure. Stoma caps or mini-pouches can be used as these are much smaller than a standard pouch and are discreet. Also, try making your pouching system less noticeable by wearing customized underwear or lingerie (see **Helpful resources**). Only through time and experience will you know how it will be for you. If you do have problems, talk with your surgeon or NSWOC nurse. They can help you find solutions or direct you to other services.

Medications

Most medications can be taken safely when you have an ileal-conduit. Most medications are absorbed in the stomach and small bowel. Keep in mind that certain medications such as vitamins and antibiotics can affect the odour and colour of the urine. Discuss any concerns with your pharmacist or doctor.

Questions/concerns about your medications:

Adjusting to your ileal-conduit

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

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

Besides your medical team, not everyone needs to know that you have an ileal-conduit. You can decide whom to talk to about your ileal-conduit. It may help to talk to your family, close friends or others who have an ileal-conduit. Discussion with a volunteer from a local chapter of the Ostomy Canada Society who has experienced similar surgery is helpful (see **Helpful resources**).

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

Before you go home

You will be required to demonstrate your independence with pouch care before going home.

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

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

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

Post-surgical follow-up

Within one week after discharge, you will be encouraged to participate with your pouching system change. Your visiting nurse will support you and encourage you to become independent with pouching system changes.

You will receive an appointment for follow-up with your surgeon 4 to 6 weeks after your hospital discharge. The NSWOC from Hotel Dieu Hospital (HDH) site will be able to assist you with any ostomy or skin related difficulties that may arise after you have gone home.

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

How to pay for supplies

If you are an Ontario resident and have a urinary diversion for longer than 6 months, you can apply for a grant from the **Assistive Devices Program (ADP)**. Your surgeon or family doctor must certify that you have an ileal-conduit and sign the application form. Through this program, you are eligible for $975.00 per year. If you receive social assistance benefits, you are eligible to receive $1,300.00 per year. If you are a resident of a Long-Term Care facility, you are eligible for $1,300.00 per year. You receive two cheques from ADP, in equal amounts, six months apart.

You can also set up for direct deposit into your bank account.

You must keep your receipts or copies of your receipts for two years. The Ministry of Health may ask you to produce these receipts to confirm your claim.

It is important to note that these benefits may not fully cover the annual costs of your ileal-conduit supplies.

For income tax purposes, you can claim receipts for costs that exceed the amount of your ADP grant. For more information, talk to your NSWOC nurse or contact ADP:

Ministry of Health and Long-Term Care
Assistive Devices Program
5700 Yonge Street, 7th Floor
Toronto, ON
M2M 4K5
Toll free 1-800-268-6021
TDD (for the hearing impaired) 1-800-387-5559
www.health.gov.on.ca

If you have a **private medical insurance** plan, contact your insurance compnay. Many private insurance plans will reimburse you for some of the costs of your ostomy supplies. If you have ADP funding, your private insurance may cover some of the costs that exceed the ADP funding.

Once you have an ostomy for a continuous period for at least 12 months, you may be eligible for the **Disability Tax Credit.** This is a non-refundable tax credit used to reduce the amount of tax payable on your income. Your physician must certify the tax credit certificate and it must also be approved by Canada Revenue Agency (CRA). A T2201 Form is required and can be downloaded from the CRA website or picked up from your local Service Canada Centre office.

For more information, talk to your NSWOC nurse or contact CRA: http://www.cra-arc.gc.ca/

What to do if…

Stoma

Stoma turns dark purple or black	*Go to the emergency room/urgent care centre*
Stoma bulges out from your abdomen	Call your surgeon or go to the emergency room/urgent care centre
Stoma becomes smaller and more narrow	*Call the NSWOC nurse*. *Remember that it takes 6 to 8 weeks for your stoma to shrink to its final size.*
Excessive bleeding	A small amount of bleeding is normal. If a lot of blood comes from the stoma, call your surgeon or go to the Emergency Department
Stoma becomes hidden in abdomen	*Call the NSWOC nurse*

Skin

Bruising	Call the NSWOC nurse if the bruising does not go away after 4 weeks. Remember that it may take longer if you take blood thinners.
Rash	*Do not use skin protector .* *Stop using a skin protector if you are already using one. Remove the pouching system and wash your skin in the shower or bath. Pat your skin dry. Apply a light dusting of ostomy powder. Place a new pouching system.* *If the rash does not get better, call the NSWOC nurse*.

What to do if…

Pouching system

Leaks	Use soap without oil to wash the skin around your stoma before placing a new pouching system. Make sure that your skin is dry before placing a new pouching system Use a hair dryer on a low setting to blow the skin dry. Spread a thin layer of ostomy paste around the opening on the back of the skin barrier to help create a good seal. Place the pouching system on a smooth skin surface. Pull gently on your skin to remove wrinkles and creases. Weight gain or loss changes the fit of your pouching system. Call the NSWOC nurse for re-fitting.
Painful to remove	*Add adhesive removers to your routine.* *Shave the hair from the skin around your stoma before placing a new pouching system.*

Call the NSWOC nurse if any problems with your stoma, skin or pouching system persist. Refer to Page 36 for contact numbers.

Note your stoma/skin/pouching system concerns

Information to remember

Name of operation:

Reason for operation:

Date of operation:

Discharge date:

Surgeon:

telephone: ext:

NSWOC nurse: KGH site:

KGH site:

HDH site:

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

Telephone: 613-544-3400 ext. 3720

Type of urinary diversion: ☐ ileal-conduit

Stoma size:

Stoma shape:

Date of last pouching system change:

Pouching system type: ☐ 1-piece system ☐ 2 piece system

Ostomy supplies list

Brand Name	Order Number	Description

Helpful resources

Bladder Cancer Canada
4936 Yonge Street Suite 1000
Toronto, ON M2N 6S3
Toll Free: 1-866-674-8889
www.bladdercancercanada.org

Canada's Food Guide
www.food-guide.canada.ca

Canada Revenue Agency
Disability tax Credit
www.cra-arc.gc.ca

Canadian Cancer Society
National Office
55 St. Clair Avenue West Suite 500
Toronto, ON M4V 2Y7
Toll Free: 1-888-939-3333
www.cancer.ca

Canadian MedicAlert® Foundation Inc.
Morneau Shepell Centre II
895 Don Mills Road, Suite 600
Toronto, ON M3L 1W3
Toll Free: 1-800-668-1507
www.medicalert.ca

Canadian Urological Association
185 Dorval Avenue Suite 401
Dorval, Quebec H9S 5J9
1-514-395-0376
www.cua.org

Coloplast Canada Corporation
2401 Bristol Circle, Suite A205
Oakville, ON L6H 5S9
Toll Free: 1-866-293-6349
www.coloplast.ca

ConvaTec
Suite 250, 1425 Trans-Canada Hwy.
Dorval, QC H9P 2V3
Toll Free: 1-800-465-6302
www.convatec.ca/CA/en (English)
www. convatec.ca/CA/fr (French)

Friends of Ostomates Worldwide (F.O.W Canada)
301 Benlock Road
Grafton, ON K0K 2G0
Phone: 647-951-3940
www.fowc.ca

Hollister Limited

95 Mary Street

Aurora, ON L4G 1G3

Toll Free: 1-800-263-7400

www.hollister.ca

Nurses Specialized in Wound, Ostomy, Continence Canada

66 Leopolds Drive

Ottawa, ON K1V 7E3

Toll Free: 1-888-739-5072

Fax: 1-514-739-3035

www.nswoc.ca

Ostomy Canada Society

Suite 210, 5800 Ambler Drive

Mississauga, ON L4W 4J4

Phone: 905-212-7111

Toll Free: 1-888-969-9698

www.ostomycanada.ca

Stealth Belt

210 West Oakland Avenue Suite B

Johnson City, TN 37604

Toll Free: 1-800-237-4491

www.stealthbelt.com

Weir Comfees

P.O Box 255 Alliston, ON L9R 1V5

Toll Free 1-866-856-5088

www.weirdcomfees.com

Additional resources

Glossary

Bowel	the part of the digestive system between the stomach and the anus where food is broken down and stool is stored. This is also known as the intestines.
Cancer	a disease involving abnormal cell growth with the potential to invade or spread to other parts of the body and to destroy normal tissue
Catheter	a thin, soft tube used to drain fluids such as urine
Conduit	a tubular channel or passageway
Cystectomy	removal of the bladder
Drain	a thin, flexible tube used to drain fluids out of the body
Enema	fluid to put into the rectum to clean out stool
Incision	the cut, or wound, made by the doctor during the operation
Laxative	medication that cause bowel movements
Malaise	generally feeling unwell
Mucus	a clear jelly-like substance made by the lining of the digestive tract to keep it moist
Nurse Specialized in Wound, Ostomy, Continence	a nurse with special training in caring for persons with ostomies; also known as an NSWOC nurse
Ostomy	a surgical opening through the abdomen that allows urine to exit the body, a short form for ileal-conduit
Skin barrier	the part of the pouching system that adheres to the abdomen and protect the skin around the stoma

Small bowel	the part of the digestive system between the stomach and large bowel, that breaks down the food and absorbs nutrients (also called the small intestine)
Stoma	an opening through the abdomen to allow the bowel pass urine, also the Greek word for “mouth”
Urinary diversion	is one of several surgical procedures to reroute the flow of urine from its usual pathway
Urostomy pouch	a pouch with an integrated valve, spout, or tap to allow urine to be emptied.

Notes

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April 2021

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