



# Getting ready for and recovering from Cystectomy Surgery



Island Health Surgery Resources



# About these materials

This booklet was developed with input from doctors and health care providers. It provides specific information to help you prepare for your surgery and recovery.

**Please read this booklet as soon as you get it!**

**If your surgeon or nurse gives you information that is different than what is in this booklet, please follow their directions.**

This booklet is meant to be read with the *Getting ready for and recovering from Surgery* booklet; it provides general information to help you prepare for your surgery and recovery. It is important that you read both booklets. You can find copies by:

- Asking your surgeon's office, or
- Going to Island Health's Getting Ready for Surgery website:

[www.islandhealth.ca/learn-about-health/surgery/getting-ready-surgery](http://www.islandhealth.ca/learn-about-health/surgery/getting-ready-surgery)

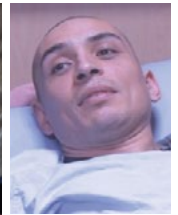
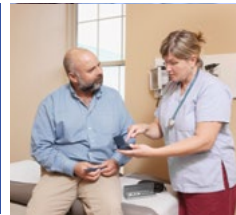


## Help your care team help you!

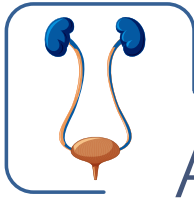
Share this booklet with your care team so they know about your plans to recover and get home as soon as possible.

**Please note that the information in this booklet is current as of the date printed on it.**

Surgical Services, Island Health



# Preparing for Surgery



# About your cystectomy surgery



Your likely length of hospital stay is **7 days**. You may go home earlier or later, depending on your recovery.

## How is the surgery done?

### What is a Radical Cystectomy?

Radical cystectomy surgery involves removing your bladder.

- In men, the prostate, and seminal vesicles (glands that help make up semen) are also removed.
- In women, often the ovaries, fallopian tubes, uterus, and part of the vagina are removed.

In both men and women, removal of surrounding lymph nodes in the pelvis is an important part of the operation.

When the bladder is removed, a new path must be made for urine to leave your body.

There are 3 options for doing this; your Surgeon will discuss which option is best for you:

#### 1 Ileal Conduit

**Ileal Conduit** (also known as an *Ileal Loop*). For this option, your urine will drain into a pouch on your abdomen.

#### 2 Neobladder

**Neobladder** (also known as a *Studer neobladder*). For this option, your original bladder is recreated, using a section of your small bowel. The neobladder is sewn to your urethra so urine is passed in the usual way.

#### 3 Indiana Pouch

**Indiana Pouch.** For this option, a pouch is created from your small and large bowel. Urine is stored in the pouch until you empty it.

**Each option has benefits, drawbacks and risks, and each requires a different level of commitment. Some options are only available to you for certain reasons.**

# 1 ILEAL CONDUIT

## What is an Ileal Conduit?

An ileal conduit is an opening on your abdomen that is made during surgery to pass urine. The hole is called a stoma.

Urine passes out of your body through the stoma and into a pouch. The pouch is on the outside of your body.



**This operation is 3-5 hours long.**

## How is an Ileal Conduit done?

To make a permanent ileal conduit, a 10 cm (4") piece of small bowel is taken from your digestive tract.

The rest of the small bowel is reconnected and will return to normal function.

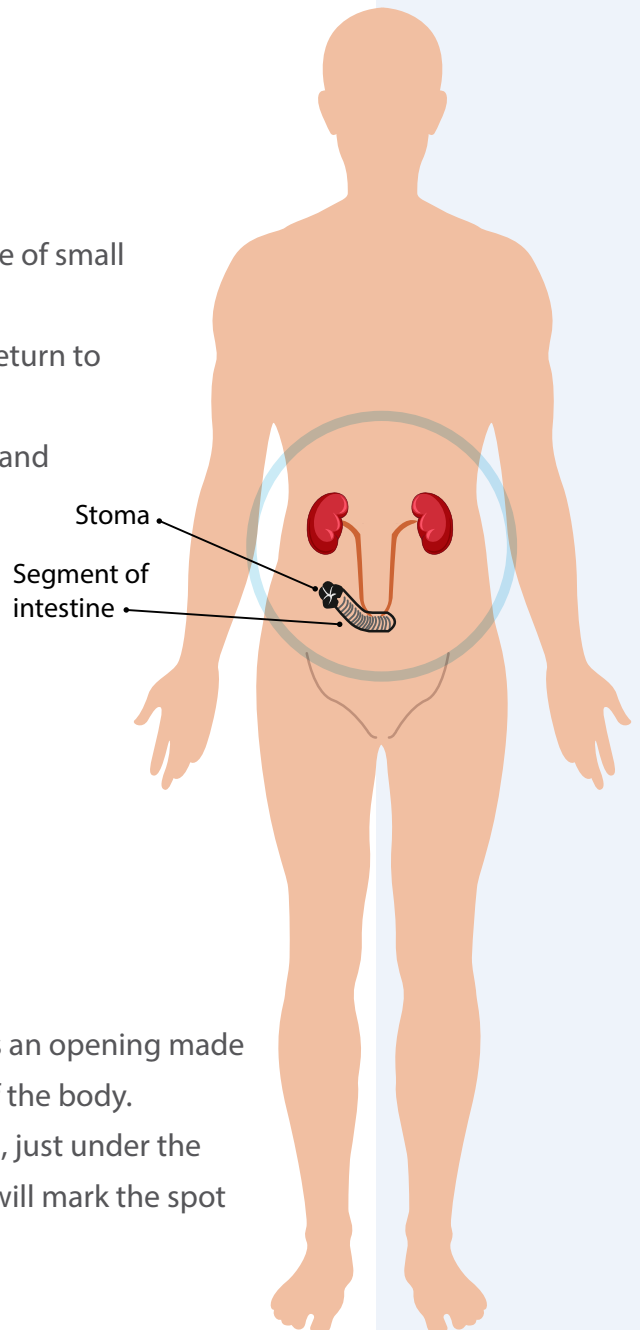
The 10 cm piece of small bowel is closed at one end and the ureters (the tubes that drain the urine from the kidney to the bladder) are sewn into it.

The Surgeon will make a hole in your abdominal muscle and skin. Then they will bring the open piece of borrowed small bowel to the outside of the skin and sew it in place.

- The part of the small bowel that can be seen on your stomach is called a stoma. The stoma is where urine will come out of your body. The urine will then drain into a pouch.

In patients who have a radical cystectomy, a stoma is an opening made on the outside of the body that lets urine pass out of the body.

The stoma is usually on the right side of the stomach, just under the belly button. Before your surgery, an Ostomy Nurse will mark the spot for the stoma.

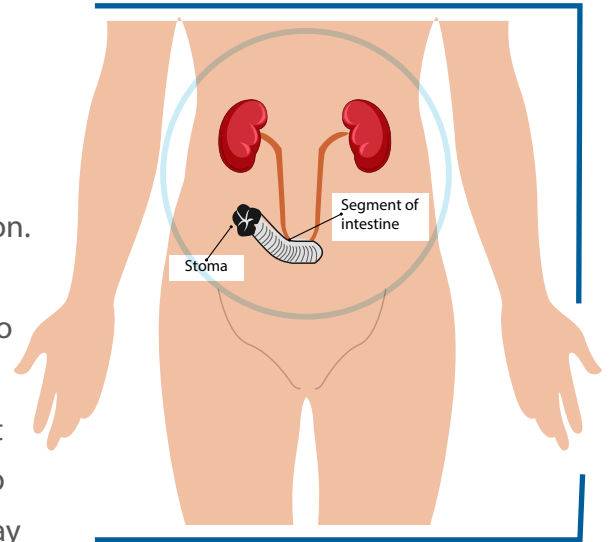


### The stoma:

- Is soft, moist and red, like the inside your mouth.
- Will be about 1"-1 ½" in size right after surgery, but may get smaller than 1" as it heals.
- Does not hurt; there is no feeling in the stoma.
- Urine passes out of the stoma without any sensation.

During the operation, several tubes may be put in place to help healing:

- **Two stents** are placed into the ureters; they go out through the stoma. Stents are tubes that help keep the ureters open and help healing. These stents may be removed before you go home.
- **A drain tube** that goes out through an incision in your abdomen. This tube drains fluid from around your incision.



## 2 STUDER NEOBLADDER

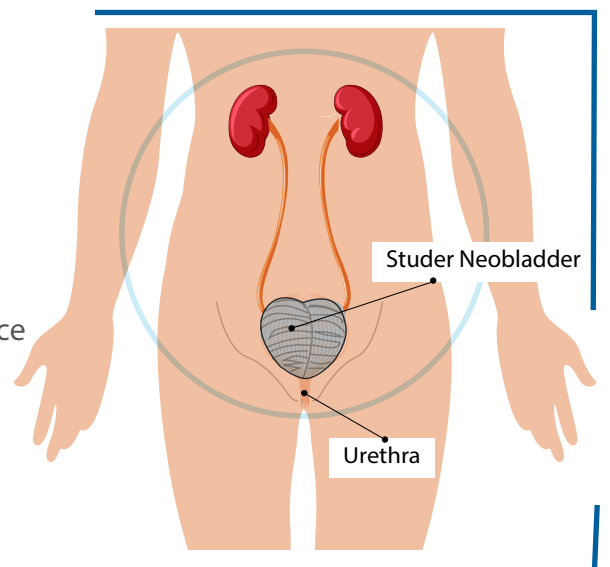
### What is a neobladder?

A neobladder is a new bladder made from part of your small bowel. The neobladder is sewn to your urethra so urine leaves your body in the usual way.

However, you may have either incontinence (when you can't control when you pee), or hyper continence (when you can't pee). If you have incontinence or hyper continence after surgery, it may need to be managed.



**This operation is about 5 hours long.**





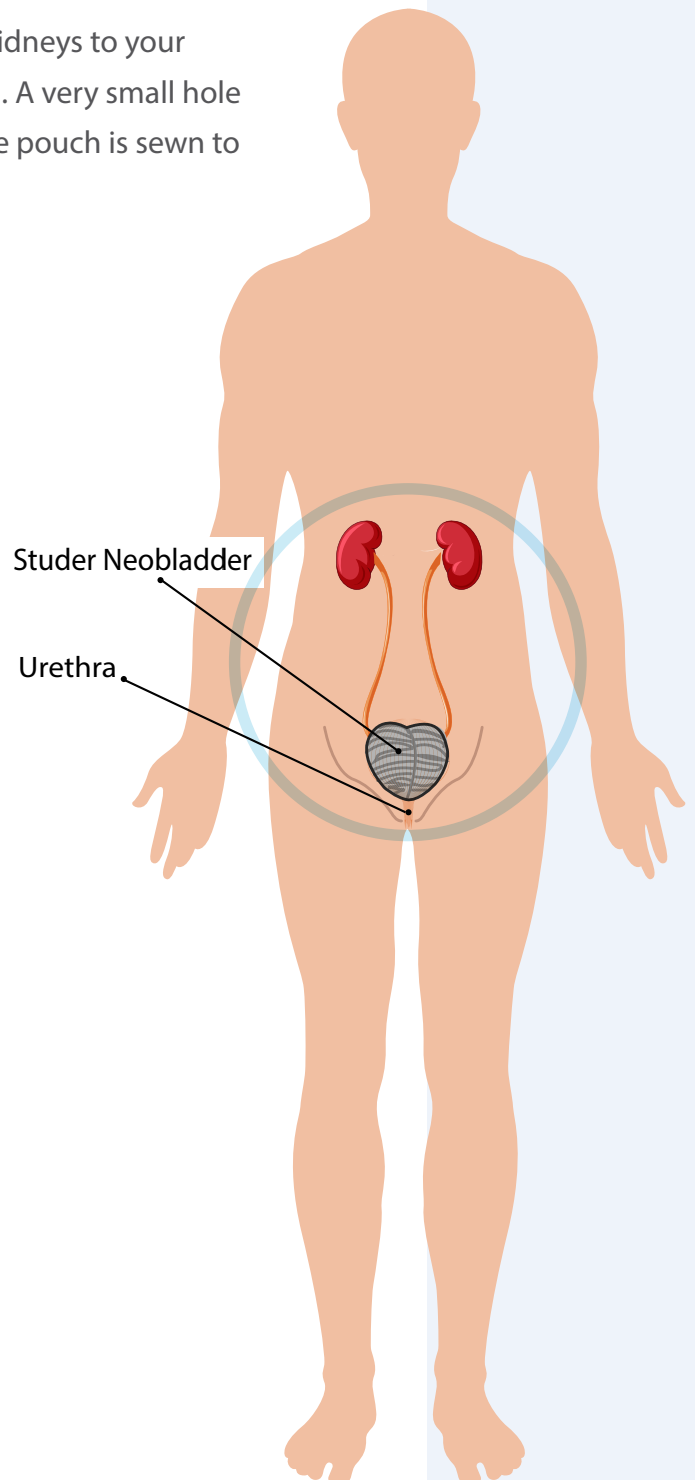
## How is a Studer Neobladder done?

The Neobladder is made using 50-60 cm (20-24") of small bowel. The remaining small bowel is sewn back together and will return to normal function. The 'borrowed' piece of small bowel is reshaped into a pouch.

The ureters (the tubes that move urine from your kidneys to your bladder) are sewn into the upper end of this pouch. A very small hole is cut into the lowest part of the pouch wall and the pouch is sewn to connect to the urethra.

During the operation, several tubes may be put in place to help healing:

- **A large drainage tube** (suprapubic catheter) is put into the pouch and goes out through the abdominal wall. This catheter will be removed before you go home.
- **Two stents** are placed into the ureters; they go out through an incision in your abdomen. Stents are tubes that help keep the ureters open and help healing. These stents are removed before you go home.
- **A catheter** is put inside the pouch and goes out through your urethra. The catheter will be left in for about 3 weeks after surgery.
- **A drain tube** goes out through an incision on your abdomen. This tube drains fluid from around your incision.



### 3 **INDIANA POUCH**

#### **What is an Indiana Pouch?**

An Indiana Pouch is a pouch made from your small and large bowel. It stores urine until you drain it by self-catheterization.

The catheter is brought in through a small channel located on the abdominal wall that is often hidden in the belly button.

- Self-catheterization is when you put a long, bendable tube (called a *catheter*) into your bladder to empty urine.



**This operation is about 5 hours long.**

#### **How is an Indiana Pouch made?**

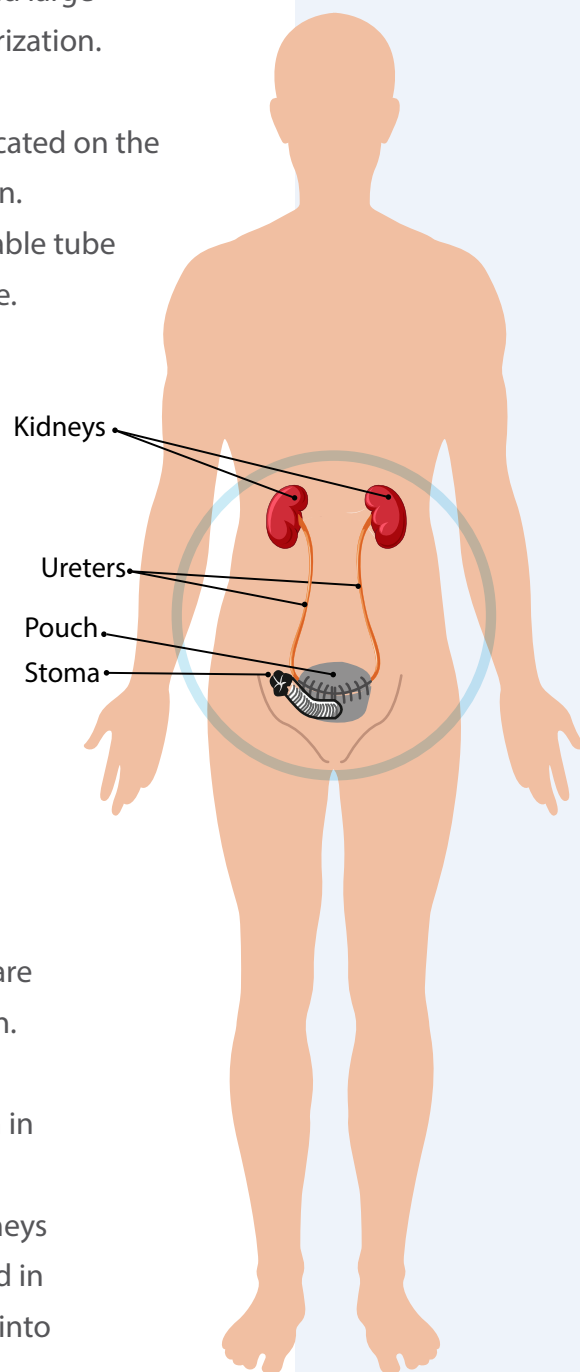
The Indiana Pouch is made from 20 cm (8") of the first part of the large bowel, the ileocecal valve, and the last 10 cm (4") of the small bowel.

- The ileocecal valve is used to keep urine from leaking out of the pouch.

The end of the small bowel is narrowed and then brought to the outside of your abdomen through an incision. The remaining small bowel and large bowel are sewn back together and will return to normal function.

The part of the small bowel that can be seen on your abdomen is called a stoma. The stoma is often hidden in the belly button or right side of the abdomen.

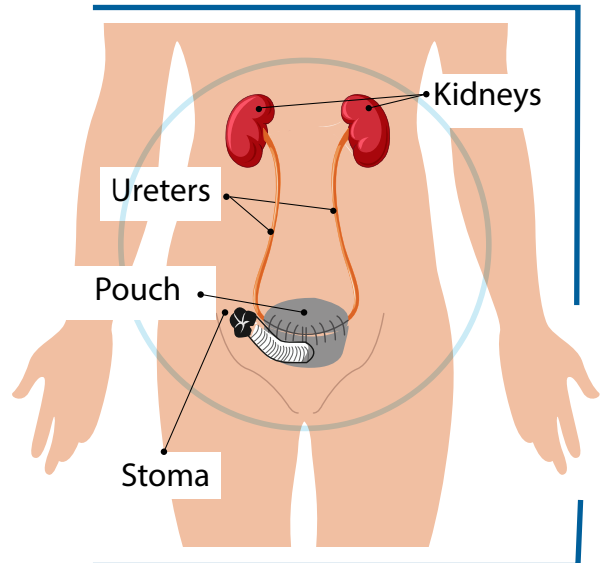
The ureters (the tubes that move urine from your kidneys to your bladder) are sewn into the pouch. Urine is held in the pouch without any leakage until a catheter is put into the stoma and drained.





During the operation, several tubes may be put in place to help healing:

- **A large drainage tube** (suprapubic catheter) is put into the pouch and goes out through the abdominal wall.
- **Two stents** are placed into the ureters; they go out through the stoma or abdomen. Stents are tubes that help keep the ureters open and help healing. These stents are removed before you go home.
- **A catheter** is put inside the pouch and goes out through your belly button. This is called a stoma. The stoma will need to be catheterized 4-5 times a day to empty the pouch. Most catheters are left in for about 3 weeks after surgery.
- **A drain tube** that goes out through an incision in your abdomen. This tube drains fluid from around your incision.



## Surgery Information



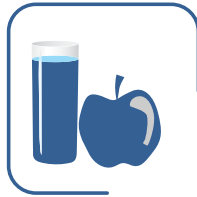
**By knowing what to expect after surgery, you can plan now to help your recovery.**



## Stay active

You need a lot of energy to recover from this major surgery – about as much as you would need to run a marathon every day. It is very stressful on your body. The better shape you are in before surgery, the better you will recover.

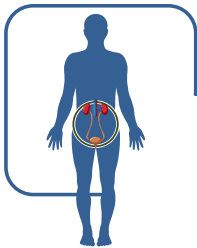
Before your surgery, think about how much activity you do, and if there is anything extra you can do to help get yourself ready. For example – if you already walk 30 minutes a day, 3 days a week that’s great! But consider walking 45 minutes a day, 6 days a week!



## Eat right

Canada’s *Food Guide* is your best source for eating right! It is based on years of research and evidence. Stick to it!

You don’t need to make big changes, take a lot of health supplements or follow a fad diet; just eat healthy, don’t eat too much, and stay away from “empty” calories and fats.



## Do kegel exercises

Kegel exercises make your pelvic muscles stronger. This is important for stude neobladder surgery because these muscles help keep your bladder from leaking urine.

Kegel exercises can be done when you are sitting, lying down, or standing up.

To do these exercises, “squeeze” your pelvic muscles as if you are trying to hold in urine or gas. Hold the squeeze for 5-10 seconds, then relax the muscle for about 10 seconds. Do this about 10 times, 3-4 times a day.

You can also do these exercises when you are urinating. When you are urinating, stop and start as many times as you can. When you do this, you will feel the pelvic muscles. This will help you quickly learn what the pelvic muscles feel like.





## Planning now for when you go home

You are admitted to hospital on the morning of your surgery.

You can expect to go home 7 days after your surgery but this might be different, depending on the type of surgery you are having and your health. Most people are ready to go home at 11:00 in the morning. Please arrange for a ride home.

Before you come to the hospital, think about what you will need when you go home (or wherever you will be staying). Get things ready before you come for your surgery so they are ready when you leave the hospital. You will need help with meals, laundry, bathing, etc., for the first week or so. Try and arrange for family and friends to help you.

If you need help with wound care or other care related to your surgery, we will arrange this before you leave the hospital. If you need more support, ask your Surgeon's Assistant about talking to a Social Worker.



# What to expect after your surgery



## Eating and drinking

Eating and drinking as soon as you can after surgery helps your bowels return to working normally. You will start drinking fluids the day of your surgery. You will be given nutrition supplements (like Boost® or Ensure®) to drink. When your body is ready, you will start eating food.

After surgery, we will ask you often if you are passing any gas out of your backside. This is a sign your bowels are starting to 'wake up' after the surgery.

Chewing sugar-free gum helps wake up your bowel faster. It can also help keep your mouth moist. We ask that you chew gum for at least of 15 minutes, several times a day. Do not swallow the gum.



## Activity

The sooner you can get up and move around, the better it is for your recovery. Lying in bed leads to muscle weakness and can cause blood clots and pneumonia. Activity increases strength, helps prevent complications, and helps get your bowels moving. On the day of your surgery, your Nurse or Physiotherapist will help you sit up at the edge of the bed. When you start to eat, you will sit in a chair for all of your meals.

As you heal each day, you will be able to do more for yourself. Keep your activities short, but do them often. Do not try to do everything at once. We don't want you to get too tired.

We will encourage you to get up and walk around the unit as soon as you can. Most people are up and walking the day after surgery.





# Going home after Surgery

## Caring for yourself at home

It can take 8 to 12 weeks to recover from a radical cystectomy. Even when you are 'healed' it can still be several months before you feel completely recovered. There are some things you can do to help your recovery.

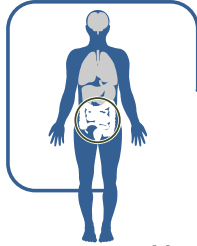


## Diet

It might take some time for your hunger to return to normal. To heal, your body will need extra calories, nutrients and, especially, protein.

- Drink at least 6 to 8 glasses (1.5 to 2 L) of water everyday (1 glass equals 250 mL), unless you have been told differently because of a medical condition.
- Eat foods high in protein, such as chicken, beef, fish, eggs, tofu, lentils, dried peas, and beans. Dairy products such as milk, yogurt and cheese are also good sources of protein.
- Try to eat 5 or 6 small meals throughout the day, rather than 3 big meals.
- If you are not able to eat enough food each day, you can continue drink 1 or 2 oral nutrition supplement drinks (e.g., Boost® or Ensure®) every day.

If you have questions about your diet, you can call 8-1-1 (HealthLink BC) any time; ask to speak to a dietitian.



## Caring for your bowels

You might find your bowels do not work the same way they did before your surgery. It can take a few weeks for your bowels to work normally.

### Constipation

Constipation (hard bowel movements) can be from your pain medicine, especially if you are taking opioids.

There are some things you can do to prevent constipation:

- Drink at least 6 to 8 glasses (1.5 to 2 L) of water each day, unless you have been told differently because of a medical condition.
- Include fruits, vegetables, dried peas, beans, lentils and whole grains in your diet each day. These foods are high in fiber.
- Keep active. Go for a walk every day.

To treat constipation, talk to your Pharmacist about a mild laxative or stool softener. Do not use an enema or suppository without checking with your Surgeon first.

### Diarrhea

If you have persistent, severe diarrhea, tell your Surgeon right away.

So you do not become dehydrated, drink 8 to 12 glasses (2 to 2.5 L) of water each day unless your doctor or dietitian has told you to limit how much you drink.



## Care of your incision

Your incision(s) will be closed with staples; you will need to make an appointment with your family doctor to have them removed 10-14 days after surgery.



You may change your dressing every 1-2 days following these instructions:

- Wash your hands well before and after changing or removing dressings, or touching your incision.
- Keep the surgical area clean and dry at all times.
- Do not apply oils, creams or lotions on your incision unless your surgeon tells you to.
- Expect some swelling and bruising around the incision. It can last a few weeks.
- It's not unusual for your incision to be uncomfortable for 2 to 3 weeks after surgery. To help with this, you can put an ice pack over the dressing. Do this up to 4 times a day. Do not leave on for more than 10 minutes at a time.



## Activity

Support your incision with a small pillow or towel when you cough or sneeze.

Gradually increase activities over the next few weeks. If your pain gets worse when you increase activity, you may be doing too much.

Walk as much as you can, but rest often. Short walks will strengthen your abdominal muscles. You may find that during the first 4 to 6 weeks that you will need to rest or sleep 2 to 3 times a day.

Do not lift, push, or pull anything over 4 to 5kg (10 pounds) for 8 to 12 weeks after surgery. This includes carrying children and groceries.

Do not do any activities that pull on your incision and abdominal muscles, such as vacuuming, raking, painting walls, or reaching for things in high places, for 4 to 6 weeks after surgery.

After 6 weeks you can begin to build up your level of activity and exercise. Check with your Surgeon before doing any sports-type activities.



## Sexual Activity – Women

This operation may have a negative effect on your sexual activity. After a radical cystectomy:

- You will probably not be able to get pregnant. This is because the vagina, uterus and ovaries are usually removed during surgery. If you are planning on becoming pregnant, talk to your Surgeon about options.
- Intercourse is affected. As well, if the front vaginal wall is removed with the bladder, the vagina will be much shorter and narrower.
- Wait 6 weeks before putting anything into your vagina. This allows the vagina to heal.

You may notice clear drainage coming from your vagina. This can be managed with a simple pad and rest.

## Sexual Activity – Men

After a radical cystectomy men are infertile.

- In some cases the Surgeon may do a 'nerve sparing' procedure during the surgery. This procedure may allow you to still have erections. If the nerves are spared, you can resume sexual activity after surgery as soon as you feel ready.
  - If you have trouble getting an erection after you heal from surgery, talk to your Urologist; there are many options that may help, such as oral medications, vacuum pumps, penile rings, penile injections and, in some cases, penile prosthesis (which can result in an artificial erection).



## Intimacy after ostomy surgery

As you recover you will be getting used to the way your stoma and pouch look. Your partner will also need to get used to how your stoma and pouch look. Feeling comfortable with these changes to your body is an important first step in resuming intimacy.

- If you have a Ileal conduit you will have a stoma. Never have intercourse through the stoma.



## Bathing

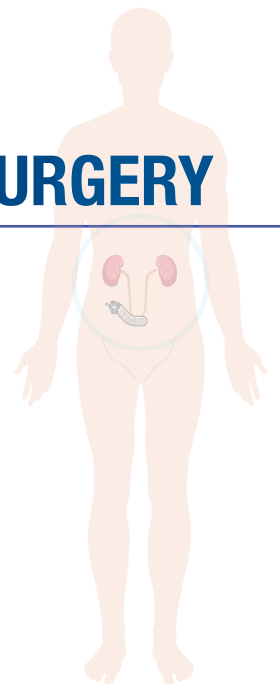
You may shower daily when you get home, but follow these instructions:

- Wash your hands and remove any dressing(s) before showering. It is okay to get the incision wet and to wash the area gently.
- Avoid aiming the showerhead at your incision.
- After showering, check your incision to ensure that there are no signs of infection. Gently pat the incision with a clean towel. Do not rub the area.
- Put on a new dressing only if the incision is draining, or if you want to protect the wound from rubbing on your clothing.
- Avoid soaking your incision in a bath, hot tub or swimming pool for 2 weeks, or until it is completely healed.



## 1 ILEAL CONDUIT SURGERY

### Care at home



### Enterostomal Therapy

Enterostomal Therapy Nurses (ET Nurses) provide specialized care for people with ostomies.

#### Before surgery, the ET nurse will:

- Offer you pre-operative (pre-surgery) counselling.
- Mark where your stoma will be.

## After surgery, the ET nurse will:

- Help you select the pouch that is right for you.
- Teach you how to take care of your ostomy.
- Offer you support.
- Order your ostomy supplies for when you get home.

## After you are discharged from the hospital, the ET nurse will:

- Follow up with you at the ET Outpatient Clinic.

Home nursing care will be set up for you. Home nursing care can help you change your pouch, or teach you more about how to care for yourself at home.

The ET nurse may set an appointment date for the ET outpatient clinic 2-3 weeks after discharge to see how you are doing.



**If you have any questions or concerns about your stoma or pouch, contact the ET nurse. If the ET nurse is not available, leave a brief message with your name and phone number; the ET nurse will call you back as soon as possible.**

## When you should call the ET nurse

You should call the ET nurse if:

- The pouch is leaking.
- The skin around your stoma is sore.
- You want to look at different pouches.
- Your Physician wants a urine sample.
- Your surgeon needs to move where your stoma is, or needs to repair your stoma, due to a hernia around it.

### Enterostomal Services on Vancouver Island:

#### Royal Jubilee Hospital Victoria

250-370-8235

#### Nanaimo Regional Hospital

250-716-7709

#### Comox Valley Hospital

250-331-5900 extension 65353





# Hernia prevention

The surface of your skin will heal quickly, but it will take longer for the area under the skin to heal properly. If you strain your abdominal muscles before you are completely healed, you could get a hernia around the stoma or along the incision.

You will know you have a hernia if you see a bulge under the surface of the skin. There are 2 types of hernias: a parastomal hernia and an incisional hernia.

- A parastomal hernia is when you see a bulge under the skin around the stoma.
- An incisional hernia is when you see a bulge under the skin around the incision.



**After you leave the hospital, your body still needs time to heal completely.**

## Tips on preventing hernias

Avoid activities that strain the abdominal muscles for 8-12 weeks after surgery.

- Continue using the method shown to you in the hospital for getting out of bed – turn onto your side, lower your legs over the edge of the bed and use your arm to push your upper body into a sitting position.

The ET nurse might ask you to wear a support belt after surgery, even after you leave the hospital. The support belt is a wide piece of elastic that supports your abdominal area. It fits around your stoma. The belt might need to be altered to fit your body. Women usually find a customized panty girdle more comfortable.

Belts are not covered by Pharmacare but may be covered by the Department of Veterans' Affairs (DVA) or third-party insurance.

You will need to wear a support belt if you get a hernia; the elastic puts pressure around the stoma and can stop the hernia from getting bigger.



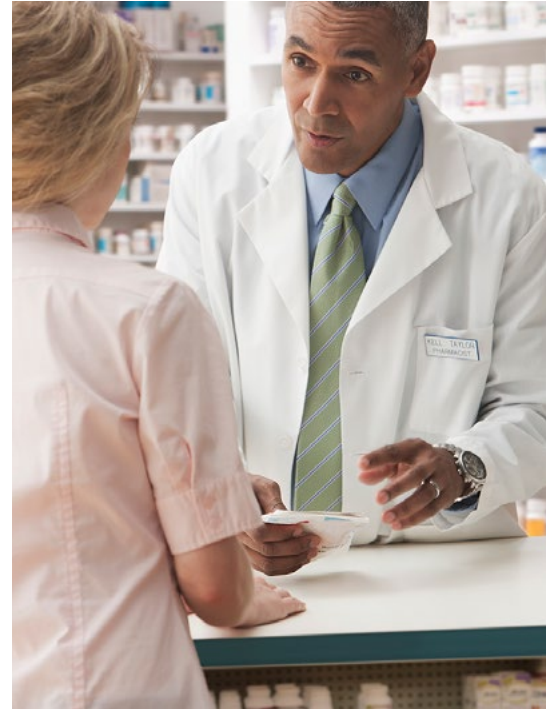
# Ostomy supplies

Ostomy supplies are partially covered in BC under the Fair Pharmacare system.

- Please be sure you are registered with Fair Pharmacare.
  - You can register for Fair Pharmacare on-line, or ask at your pharmacy for a registration form.
  - Your supplies will be covered based on your income. There will be a deductible.
- The amount you pay for supplies depends on your income (people with higher incomes pay more; people with lower incomes pay less).
- If your income goes down you can re-apply, based on your new income.
- If you have third-party coverage (such as Blue Cross® or Sun Life), more of your supply costs might be covered.
  - If you have third-party coverage, check with your provider and see what kind of coverage you have for ostomy supplies.

## Where to get ostomy supplies

- **Full-service** suppliers. There are many suppliers on Vancouver Island that offer a full spectrum of services. They each have an Enterostomal specialist on staff, and should have all supplies in stock (in case you need them quickly). You can exchange supplies if you need to.
- **Pharmacies.** Most pharmacies will bring in supplies. Because pharmacies are not specialists in ostomy supplies, we suggest that you use a full-service supplier for at least the first year after surgery.

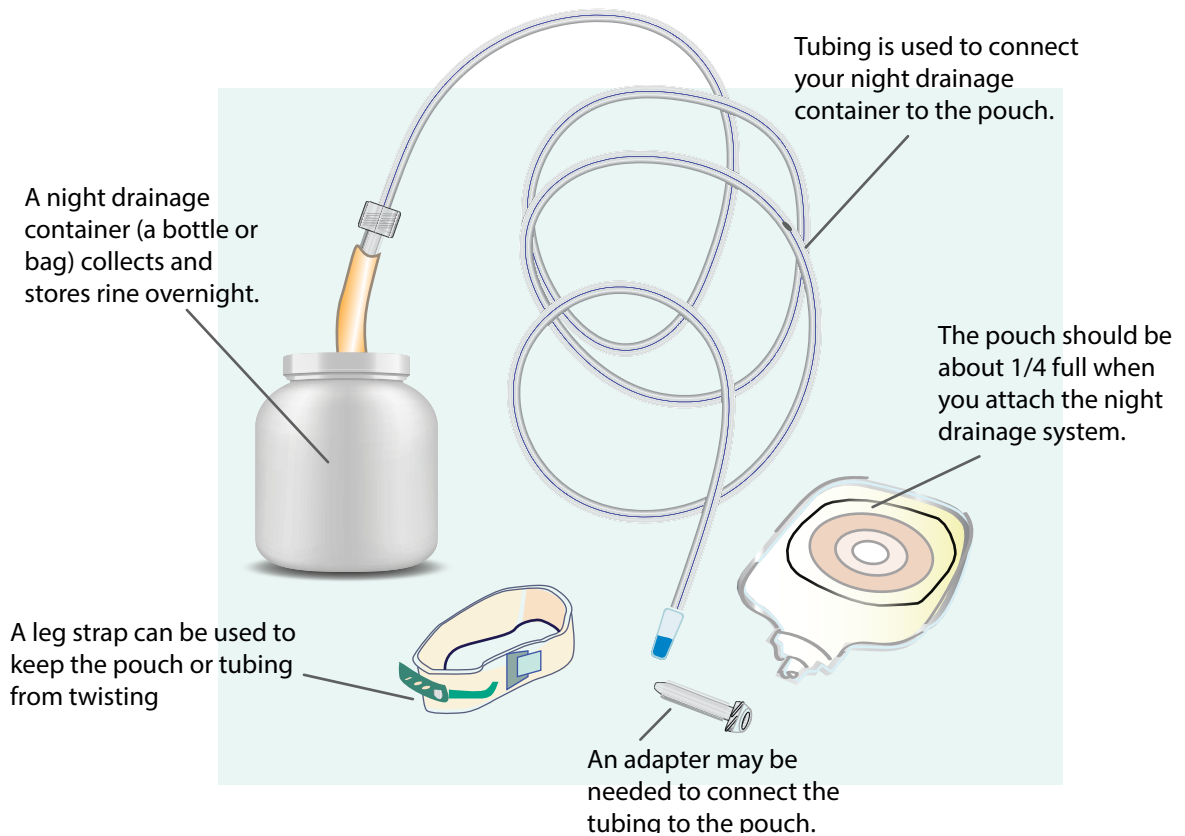






# Using your night drainage system

A night drainage system can be attached to the pouch before you go to bed. This system collects and stores urine. This allows you to sleep through the night without having to worry about emptying your pouch.



## Setting up the night drainage system

There are several types of night drainage systems. Each type needs to be set up before you can use it.

- If the tubing in the system you choose comes in 2 pieces, put one end of the tubing into the lid of the container.



## Every night

- Connect the tubing to your pouch using the adapter that is for your brand of pouch.
- If you use an adapter, put it on the tubing. Keep the adapter connected until the container must be replaced.

### TIP

**The pouch should be about one-fourth (1/4) full when you attach the drainage system to it at night. This will help get the urine flowing into the tubing from the pouch.**

### To attach the system to your pouch:

1. Place the night drainage container in a basin or a small waste can on the floor next to your bed.
  - This is to keep it from tipping over during the night.
2. Connect the tubing to the pouch.
3. Open the closure on the pouch drain.
  - This way, urine can flow through the tubing.
4. Thread the tubing through your pajama pant leg.
  - This will help stop the bag end and night drain from twisting. If they twist, the system will overfill and leak.

### TIP

**You can also use a leg strap to help prevent the tubing from twisting.**



## Every morning

1. Return the pouch drain to the “closed” position to prevent leakage.
2. Empty the night drainage container’s contents into the toilet.
3. Detach the tubing.

## Cleaning the night drainage system

You need to clean the night drainage system every day.

### To clean the system:

1. Using a small funnel, add a bit of mild detergent and water to the bag.
2. Swish the sudsy fluid around and then drain the fluid in to the toilet.
3. Next, fill the drainage bag with 1-part vinegar and 4-parts water.
4. Swish the solution and let it sit for 10 minutes, then empty it.
5. Hang the bag to dry until next use.

## How often you need to replace supplies

- Replace the *drainage bag* every month.
- Replace the *drainage container* every few months or when rough, cracked, or damaged.
  - You can buy drainage containers at pharmacies that sell medical supplies.

## More about Ileal conduit (Ileal Loop) care at home

When you have an ileal conduit, the urine drains through your ureters into the ileal conduit and out of your body through your stoma. You may see bits of mucous in your urine. This is normal.

You always need to wear a pouch when you've had an ileal conduit. The pouching system sticks to your skin. You will be taught how to remove and replace it. You need to replace the pouch every 3-4 days.

Every night you will need to attach the pouch to a drainage bottle to make sure it does not get too full. If the pouch gets too full, it could leak. This also helps to prevent urine flow from being blocked. Blockages can cause infection or damage to your kidneys.

Urine is always draining into the pouch because there is nowhere to store urine in your body.

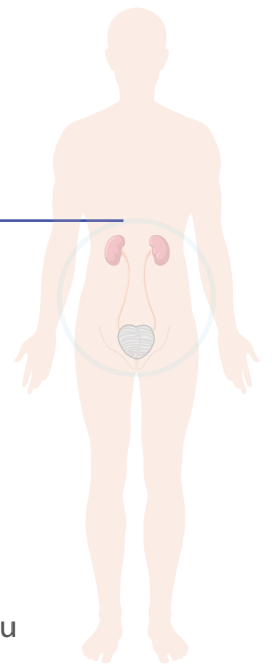
**ALWAYS** carry a spare pouching system with you just in case you need to change it when you are not expecting to.



**Your Ostomy Nurse will help you learn self-care and help you get the supplies you need.**

## 2 NEOBLADDER

### Care at home



If you have a neobladder (a new bladder made of part of your small bowel), you might see mucous in your urine. Too much mucous in the neobladder can cause blockage and infection.

After your surgery you may have 2 catheters put inside the pouch. One will be removed before you leave the hospital. The one that is left in will go out through your urethra. The catheter will be left in place for about 3 weeks after surgery. The nurse will “irrigate” (clean out with saline [water and salt]) the pouch through the catheters, to clean out the mucous.

- Nurses at the hospital will teach you how to irrigate your neobladder. You will need to do this at home
- You can buy normal saline at the pharmacy or make your own solution (see page 29 of this booklet for the recipe and instructions on how to irrigate your neobladder).

While the catheter is in, some urine may leak out of your urethra. This is common. If this happens, simply wrap gauze or tissue around the catheter where it comes out of the urethra, to soak up this urine.



## Cystogram X-Ray and catheter removal

Three weeks after surgery, you will have a special x-ray called a “cystogram.” This x-ray is to make sure that there are no leaks in the neobladder and to see if the site is healed.

- If the site is healed, the catheter will be removed.
- If the site is not healed, the catheter will stay in longer, until the leaks settle down.



The amount of time that is needed to heal is different for everyone.

Bring an incontinent brief with you to the Radiology Department when you come for your cystogram in case your catheter is removed. You will be given 1 incontinent brief before you leave the hospital and you can buy more at any drugstore.

After the catheter is out will you begin to pee through your urethra. At first, most men need to sit down to urinate. After a while they will be able to stand to pee.

You will be taught to put a catheter into your new bladder. You will need to do this 2 times every day at first. This is to make sure that your bladder is emptying completely.

At first you will probably leak urine, especially at night. This is normal. You will be told to do pelvic muscle (Kegel) exercises to improve your ability to hold back urine. Most people achieve day continence within the first 3 months.

Please try to be patient during this time; do your Kegel exercises, and you should be able to gain continence after a couple of months.

Your neobladder will eventually hold more than 450 milliliters (almost 2 cups) of urine, which is about the same as a natural bladder. At first, you may need to go to the bathroom as often as every 2 hours, even during the night. Since your neobladder does not send the same message to your brain to wake you when it is full, you should set your alarm clock to wake you up.





You will probably feel very tired during this time, so try to let others help you with any household chores. The interrupted sleep is like having a newborn baby at home.

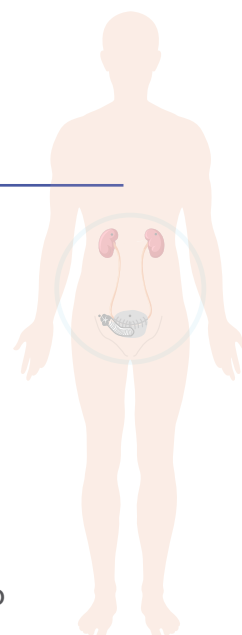
After a while, the neobladder will stretch to its full amount, and you should be able to hold your urine longer with less leakage. You will, however, probably always need to get up at least once during the night to pass urine.

Note that when your neobladder is full and distended the feeling is not the same as needing to urinate. Instead, you may feel nausea.



### 3 INDIANA POUCH

## Care at home



The piece of small bowel used to make the Indiana Pouch produces mucous. Too much mucous in the pouch can block the catheter and cause infection.

After your surgery you may have 2 catheters put inside the pouch. One will be removed before you leave the hospital. The one that is left in will go out through your stoma. While the catheters are still in your pouch, this mucous must be taken out through “irrigations.”

The nurses will “irrigate” (clean out with saline [water and salt]) the pouch through both of the catheters. The nurse will teach you how to irrigate the pouch before you leave the hospital, so you can do this at home.

- Nurses at the hospital will teach you how to irrigate your bladder, you will need to do this at home.
- You can buy normal saline at the pharmacy or make your own solution (see page 29 of this booklet for the recipe and instructions on how to irrigate your pouch).



Three weeks after surgery, you will have a special x-ray called a “pouchogram.” This x-ray is to make sure there are no leaks in the pouch.

- If the site is healed, the catheter will be removed.
- If the site is not healed, the catheter will stay in longer, until the leaks settle.

The amount of time that is needed to heal is different for everyone.

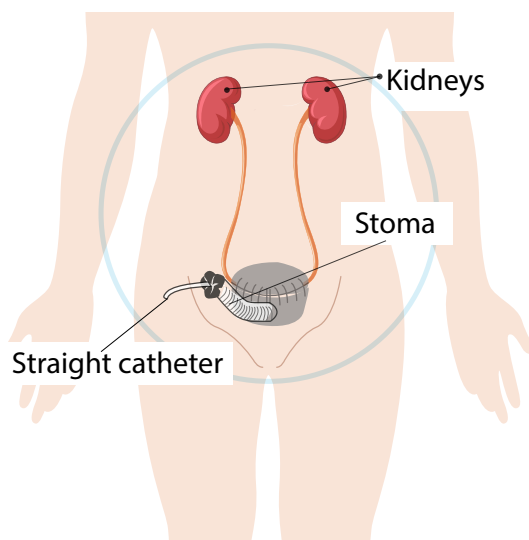
You will be taught to put a catheter through your stoma and into the pouch to empty urine. This is called catheterization. You will need to catheterize your new pouch every 2-4 hours, day and night, for at least 2 months after surgery.

You will probably feel very tired during this time, so try to let others help you with any household chores. The interrupted sleep is like having a newborn baby at home.

With each passing week, you will be able to go a longer time between catheterizations. Eventually you may be able to empty your pouch every 4 hours during the day and up to every 8 hours during the night.

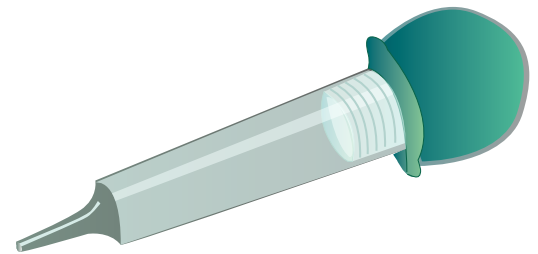
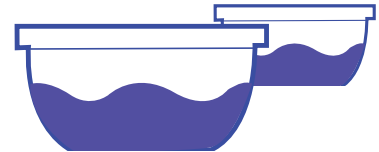
You may have some urine leakage out of your stoma between catheterizations, especially if your pouch is very full. You may want to wear a pad over your stoma.

**ALWAYS** carry a catheter with you.



## How to irrigate your Neobladder or Indiana Pouch

1. Wash your hands well with warm, soapy water.
2. Pour some **normal saline** in a clean bowl.
3. Draw up saline in a bulb syringe.
4. Place the tip of the syringe into the catheter.
5. Gently squeeze the bulb syringe so the saline goes into the catheter.
6. Release the bulb so it pulls the fluid out of your bladder, back into the syringe and empty the syringe into a second bowl.
  - You will see bits of mucous in the fluid.
7. Repeat steps 3-6 several times, until you no longer see mucus.
8. Clean your bowls and bulb syringe with warm soapy water and allow to dry.
9. Store the bowls and bulb syringe in a clean place.



### Normal saline (saltwater) recipe

You can make your own normal saline (saltwater) solution for irrigating.

#### Ingredients

- 1 quart (litre) of water
- 1 tablespoon (15 ml) of salt

#### Directions

1. Boil water.
2. Add salt and stir until it dissolves.
3. Pour boiling water into a new or very clean container that has a lid, and then pour it out.
  - You may use a glass jar or plastic container that is safe for your dishwasher or microwave.
4. Pour the salt water into this container.
5. Store the saltwater solution in the fridge.

**Note:** After 48 hours, throw out any saltwater solution that you have not used.

*(Adapted from Foothills Hospital)*



## Supplies for Self-Catheterization

You can purchase catheters at a full-service pharmacy.



Catheters come in many different styles and sizes. You need to purchase *16french straight* catheters and *water soluble lubricant*.

- A “straight catheter” means it has no balloon. For more information about self-catheterization, ask your nurse for a copy of the patient education booklet that is right for you:

- *Self-Catheterization (Man)*
- *Self-Catheterization (Woman)*



## Follow-up visit



**Your Surgeon will usually call you about 2 weeks after you are discharged from the hospital. They will talk to you about your pathology results, ask how you are, and decide on a follow-up plan.**

If you are admitted to a different hospital because of a complication due to your surgery, please have a family member tell your Surgeon’s office.

## Complications

Complications are normal after this type of surgery. About 50-60% of people have minor complications; about 10-15% of people have more major complications. Complications might happen soon after surgery, a long time after surgery, or never.

- Major complications can include things like heart problems, lung problems, wound breakdowns, blood clots, a narrowing or leak of either the digestive tract or the urinary tract requiring drainage or repair, or even the need to have the surgery again.
- Complications that you may get a long time after surgery can include things like urinary infections and poor kidney function.

If you feel that you are having a complication from the surgery, please contact your Surgeon. It is very important that you talk to them about any concerns you have!

If your Surgeon is not available and you are not sure what to do, the emergency room at the hospital where you had your surgery is the safest place to go.



## Health concerns

**Call your Surgeon if you have any of the following symptoms:**

**Contact your surgeon or family doctor if:**

- Your pain gets worse or does not go away with pain medicine.
- You have a fever over 38.5° C (101.3° F).
- Your incision becomes red, swollen, or hot to touch.
- You notice a lot of clear or foul-smelling liquid coming from your incision.
- You start bleeding from your incision (enough to soak through a tissue).
- You feel sick to your stomach (nauseated) or throw up (vomit) often for more than 24 hours.
- You have diarrhea that lasts for more than 2 days.
- If you have a drain that is accidentally pulled out.
- If you have no urine for 6 hours.

# Who to Contact

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## If you can not reach your surgeon:

- Call your family doctor, or
- Go to a walk-in medical clinic, or
- If it is after clinic hours, go to a hospital emergency department.

## For non-emergency health information and services:

Contact HealthLink BC – a free-of-charge health information and advice phone line available in British Columbia.



### HealthLinkBC

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- **Phone:** 8.1.1 from anywhere in BC.  
7.1.1 for deaf and hearing-impaired assistance (TTY)
- **Email:** [www.healthlinkbc.ca](http://www.healthlinkbc.ca)  
**Translation services are available in over 130 languages.**



## Compliments and concerns

Quality care is important to all of us. You have the right to give feedback about your care and know you will be treated fairly. Your feedback gives us an opportunity to improve the care and services we provide. If you have a compliment, complaint or concern, you can speak directly to the person providing your care, or you may contact the Patient Care Quality Office.



**Patient Care Quality Office**  
**Royal Jubilee Hospital**  
**1952 Bay Street Victoria, BC V8R 1J8**  
**Memorial Pavilion, Watson Wing, Rm 315**  
**Toll-free: 1.877.977.5797**  
**Greater Victoria: 250.370.8323**  
**[patientcarequalityoffice@viha.ca](mailto:patientcarequalityoffice@viha.ca)**

[www.islandhealth.ca/patients-visitors/patient-care-quality-office](http://www.islandhealth.ca/patients-visitors/patient-care-quality-office)





## Resources

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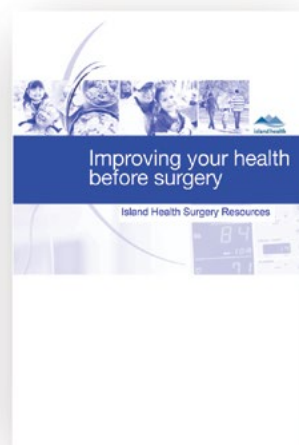
### Island Health Resources

Ask a member of your healthcare team about getting a copy of these Island Health resources:

- Meeting your surgeon
- Improving your health before surgery
- Getting ready for and recovering from Surgery

### Other Resources

- Bladder Cancer Canada: [www.bladdercancercanada.org/en/](http://www.bladdercancercanada.org/en/)
- Bladder Cancer Advocacy Network: [www.bcan.org/](http://www.bcan.org/)
- The Canadian Urology Association: [www.cua.org/en](http://www.cua.org/en)



### Island Health Surgery Resources

[www.islandhealth.ca/learn-about-health/surgery/getting-ready-surgery](http://www.islandhealth.ca/learn-about-health/surgery/getting-ready-surgery)

# Tell us what you think!

After reading this booklet please respond to the following statements. Your answers and comments will help us improve the information.

Circle one number for each statement:

strongly  
disagree

strongly  
agree

I read all of the information provided.

1 2 3 4 5  
|----->

Comments

\_\_\_\_\_  
\_\_\_\_\_

The information is easy to read.

1 2 3 4 5  
|----->

Comments

\_\_\_\_\_  
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The information is easy to understand.

1 2 3 4 5  
|----->

Comments

\_\_\_\_\_  
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Reading this information helped me  
prepare for and recover from my surgery.

1 2 3 4 5  
|----->

Comments

\_\_\_\_\_  
\_\_\_\_\_

The information answered my questions.

1 2 3 4 5  
|----->

Comments

\_\_\_\_\_  
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I would recommend this information to  
other patients.

1 2 3 4 5  
|----->

Comments

\_\_\_\_\_  
\_\_\_\_\_



I prefer to have this information in:

\_\_\_\_\_ A book just like this one

\_\_\_\_\_ Separate handouts on each topic that I need

Comments

\_\_\_\_\_  
\_\_\_\_\_

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I would have liked MORE information about:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I would have liked LESS information about:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What changes would you make in this booklet to make it better?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I am: \_\_\_ a patient \_\_\_ a family member



**Thank you!**

**Please mail this evaluation form to:  
Surgical Services 2nd Floor, Memorial Pavillon  
Royal Jubilee Hospital  
1952 Bay Street  
Victoria, BC V8R 1J8**



**island health**

[islandhealth.ca](http://islandhealth.ca)

