

# Radical cystectomy with ileal conduit formation

Name: \_\_\_\_\_

Surgeon: Dr. Jehonathon Pinthus

Primary Nurse: \_\_\_\_\_

Office: 905-387-9495, ext. 64902

Follow-up appointment: \_\_\_\_\_

To help you prepare, this book provides information about what to expect before, during and after your surgery. We encourage you to ask us questions and let us know your concerns.

If you are interested, we can arrange for you to meet with a person who has had the surgery.

For more information visit: [www.bladdercancerCanada.org](http://www.bladdercancerCanada.org)



*"Riding the Dragon" A Cancer Journey | by Conrad Furey*

## Table of Contents

	<b>Page</b>
What are the main reasons for this surgery? .....	1
What is a radical cystectomy with ileal conduit formation? .....	1
Who does my surgery? .....	3
What will my abdomen look like after surgery?.....	4
How long will it take to recover and heal?.....	4
Will I have a lot of pain? .....	5
How will surgery affect having sex?.....	6
Supportive Care .....	6
Getting prepared for surgery .....	7
On the day of your surgery .....	10
Home care or CCAC .....	13
When you go home .....	13
Before you leave, you need to know.....	16
Questions to ask follow-up visits .....	16
When to call the surgeon and seek medical attention.....	17
Follow-up visits.....	17
Follow-up schedule after a radical cystectomy .....	18

---

## What are the main reasons for this surgery?

The main reasons for this surgery include:

- cancer of the bladder
- when other cancers that are in the uterus, vagina or bowel involve the bladder
- too much bleeding from the bladder due to radiation damage

## What is a radical cystectomy with ileal conduit formation?

There are 2 parts to this surgery:

1. **A radical cystectomy** is the removal of the bladder and several body parts around the bladder.
  - **In women**, the bladder, urethra, uterus and ovaries are removed. The vagina is shortened. Surrounding lymph nodes are also removed.
  - **In men**, the bladder, prostate gland and seminal vesicles are removed. The seminal vesicles are small tubes near the prostate. Surrounding lymph nodes are also removed.

Since the bladder is being removed, another way for urine to leave the body must be made.

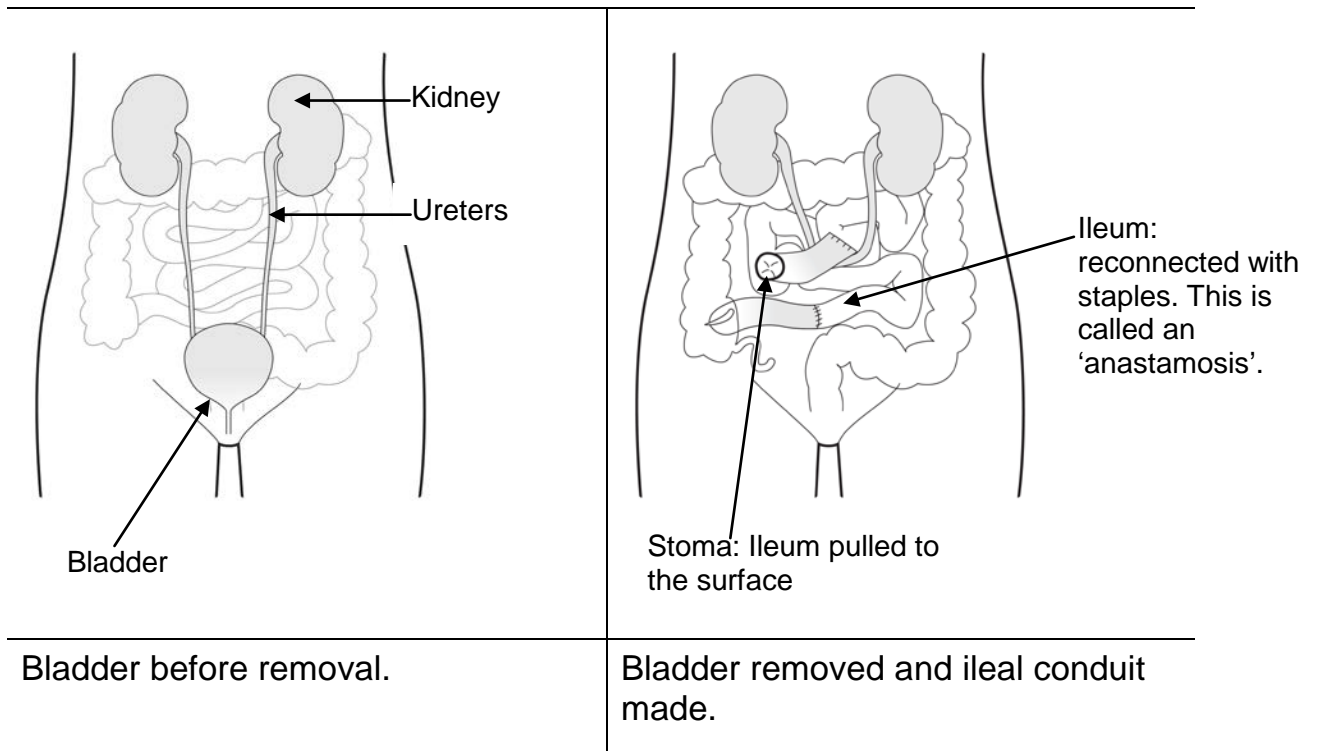
During the surgery, the surgeon makes an ileal conduit or passageway for urine to leave the body.

---

**Ileal conduit**

The ileal conduit is made with a part of the small intestine (bowel) called the ileum. About 10 to 20 cms of intestine are used. One end of the ileum is closed with staples and the ureters from the kidneys are attached to it.

The other end is brought to the outside surface of the skin. This outside end is called a stoma.

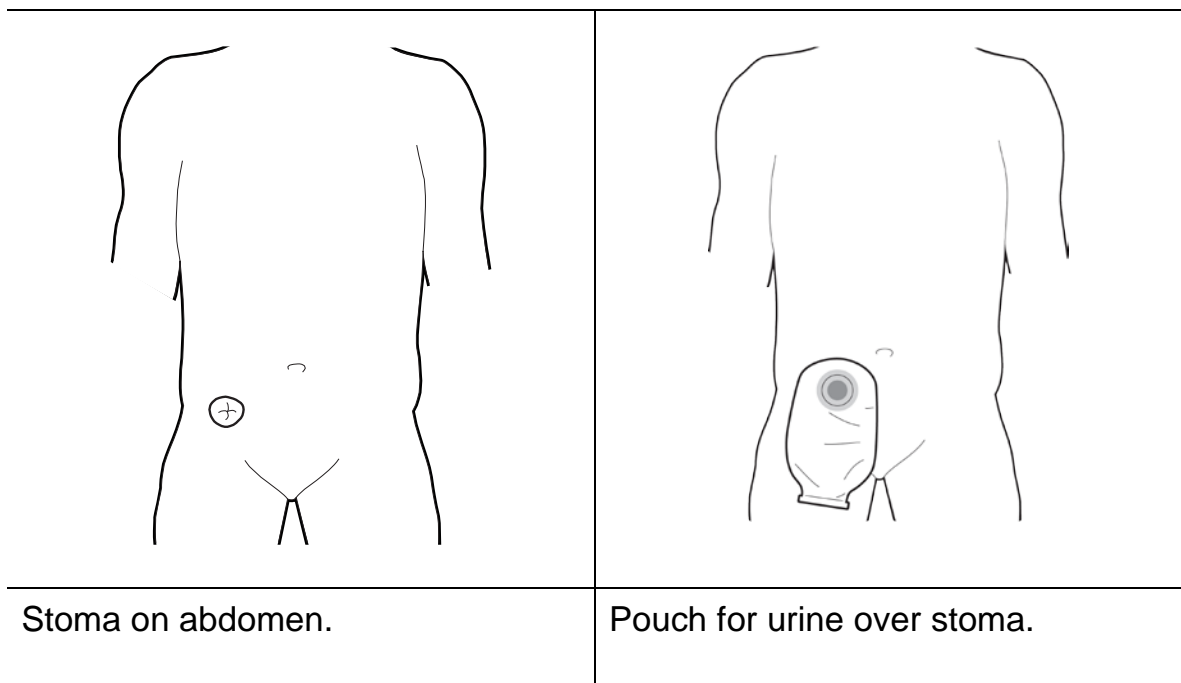


## Ileal conduit pouch

A pouch is placed over the stoma to collect the urine. The bag is called a urostomy pouch.

While you are in the hospital nurses will help you learn:

- about the ileal conduit
- how to change and empty the pouch



## Who does my surgery?

Dr. Pinthus will be doing your surgery. He is a specialist in cancer care and diseases of the kidneys and bladder (urology).

He and your primary nurse will coordinate the care and other services you may need.

## What will my abdomen look like after surgery?

<p>The stoma will be on the right side of the abdomen just below the belt line.</p> <p>You will have a drain to collect fluid from the abdomen.</p> <p>There will be stitches from the level of your belly button to the pubic bone.</p> <p>The stitches are usually removed 7 to 10 days after surgery.</p>	
<p>Your surgeon may decide that the wound needs retention sutures. These sutures help with recovery and are removed in about 6 weeks after surgery.</p>	

## How long will it take to recover and heal?

It will take time to heal and return to your normal energy level. It also takes time (up to 2 months) to get back to having an appetite, eating your normal diet, and having regular bowel movements (poop). Most patients will be back to their usual work and social activities in about 8 to 12 weeks.

## Will I have a lot of pain?

This is a common concern. It is normal to have pain after surgery. The pain lessens over time as you heal. The more comfortable you are, the more you can move and take an active part in getting well again. During your preop visit, the anesthesiologist (the doctor who puts you to sleep during surgery) will talk to you about pain control.

There are 2 main types of pain control used after surgery: Patient Controlled Analgesia (PCA) and Epidural Analgesia.

You will most likely have one of these types of pain control when you wake up after surgery.

### **Patient Controlled Analgesia, or PCA**

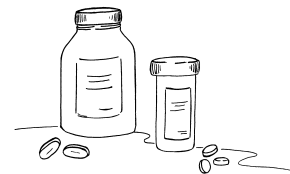
PCA uses a pump that delivers morphine by intravenous (IV) when you push a button. The IV is usually in your hand or arm. PCA's are usually used for 2 or 3 days.

### **Epidural Analgesia**

Epidural analgesia consists of a small tube placed in your back by the anesthesiologist during your surgery. The tube is then taped to your back and over your shoulder. A pump delivers medication continuously so that you will feel less pain in the surgical area. Epidurals are usually used for 2 or 3 days.

### **Pain medication**

There are other medications that can be used to make sure that you are comfortable so that you can move, walk and participate in your care. Please let the nurse know when you are in pain and not comfortable.



At times, pain medication can make you feel sick to your stomach (nauseous) or lightheaded/confused. Let the nurse know that you have these feelings.

## How will surgery affect having sex?

With this surgery, there is usually some damage to the nerves that are a part of having sex.

### Women

For women, the vagina may be shortened and there is loss of sensation. The ability to have an orgasm may be affected. If the ovaries and uterus are removed, women can no longer get pregnant.

### Men

For men, this surgery means that there is no semen because of the removal of the prostate gland and seminal vesicles. Men are infertile (no sperm) and most men are impotent (cannot have an erection). Erections may be recovered after surgery with special medication or by having penis implant surgery.

## Supportive Care

Dealing with cancer and the needed treatments can be overwhelming. Patients and families often have very strong and upsetting feelings at this time. The social worker can help you recognize and express those feelings.

Sometimes the illness and recovery can affect your role in the home, either as breadwinner, spouse or caretaker of older parents or dependent children. The social worker is aware of the stress this creates in the family and can support you in finding other sources of help.

We encourage you to find out about your sick benefits. You may have sick benefits either from your employer plans or other sources. If needed, the social worker can help you sort out your benefits.

A social worker is available on request from yourself, your family or your health care team.

Supportive Care can be reached at 905-387-9495, ext. 64315.

---



## Getting prepared for surgery

### Plan ahead

We encourage you to plan for your recovery before surgery. Rest is important for healing for a few weeks after surgery. Be sure to get groceries and banking done a few days before your surgery. Arrange for help with meals, child care, pets, gardening and housework.

Surgery does stress your body and energy is needed to heal. Much like a runner training for a race, you are encouraged to eat more pasta and carbohydrates (whole wheat, complex carbohydrates) during the week before your surgery.

Please remember not to eat solid food the day before surgery. What you can eat and drink before surgery will be reviewed during your preop appointment.

### Driving

After surgery your surgeon may not advise driving for a couple of weeks. Be sure you have someone to drive you where you need to go.



### Alcohol

Your surgeon advises that you do not drink alcohol while recovering from surgery. Please discuss drinking with your surgeon.

### Smoking

If you smoke, quitting as early as possible before surgery will help in a better recovery and decrease the potential complications of surgery. **Smoking is the most common and important risk factor for bladder cancer. Continuing smoking puts you at risk for the cancer to return.** For support or help to stay smoke-free:



- talk with a member of your health care team
- talk with a pharmacist at the JCC Pharmacy or your local drug store
- contact Smokers' Helpline toll free at 1-877-513-5333 or [www.smokershelpline.ca](http://www.smokershelpline.ca)

## Preop Clinic

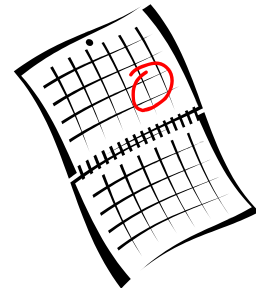
Before your surgery you will be seen at the Preop Clinic at McMaster University Medical Centre. During this visit the nurse will:

- review your surgery and consent form
- ask you specific questions about your health
- tell you when to stop eating and drinking before surgery
- discuss the medications you take the morning of your surgery
- describe the tubes and drains you may have after surgery
- instruct you on the bowel prep, if needed

You will also need to have blood taken, a chest x-ray and an EKG (electrocardiogram) to check your heart.

## Enterostomal nurse

An appointment will be made for you to see an enterostomal nurse who will look at your abdomen and make a mark to suggest where the stoma should be placed.



## Practice your exercises before surgery

For several days after surgery, your activity will be less than normal. During this time, fluid may build up in your lungs and your blood circulation in your legs slows down. This could lead to complications such as a lung infection and blood clots.

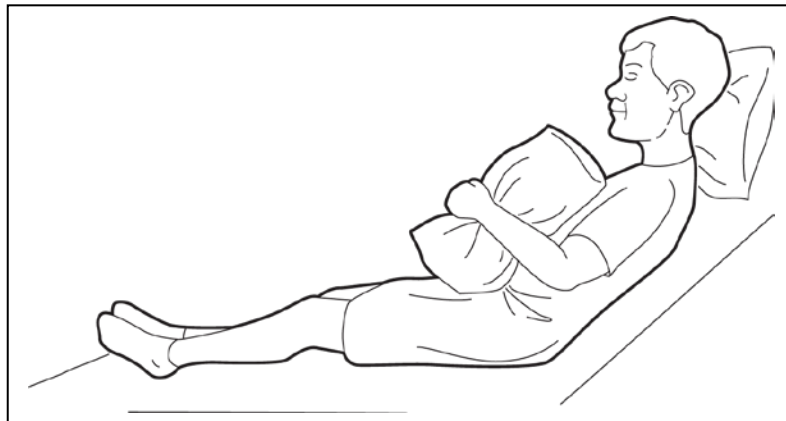
To keep your lungs healthy and to regain your strength it is very important to exercise and move.

---

### Deep breathing and coughing exercises

It is helpful to do these exercises with the head of your bed raised, sitting in a chair or on the edge of the bed.

1. Hold your incision with a pillow or folded blanket.
2. Take a slow deep breath and fill your lungs.
3. Slowly blow out through your mouth.
4. Repeat 5 times.
5. Then take a deep breath and make a strong, deep cough. Just clearing your throat is not enough.



### Leg exercises

1. Tighten the buttocks. Hold for a count of 5. Relax. Repeat 10 times.
2. Lie with legs straight. Tighten your right leg muscles and push knee down into the bed. Hold for a count of five. Relax. Repeat 10 times. Now repeat the exercise with the other leg.
3. Turn your ankle in a circle 10 times in one direction then 10 times in the opposite direction. Do this first with the right foot, then the left. Flex your foot up and then point your toes down. Repeat 10 times each foot.

## On the day of your surgery

Once you arrive in Same Day Surgery at the Juravinski Hospital, you will:

- change into a hospital gown
- empty your bladder
- remove dentures and contact lenses (if you wear them)

Your nurse will start an intravenous (IV) to give you fluids and medication. You may receive medication to make you sleepy. Once these preparations are completed, you will go to a holding area near the operating room. Usually, one person may stay with you at this time.

Your name will be put on your belongings and taken to the unit that you will be in after surgery. It is important not to bring anything of value (money or personal). All rings and jewelry must be taken off before surgery, so it is best to leave them at home or with a family member for safekeeping.

**We cannot be sure of the exact time of your surgery. The time may be slightly earlier or later than planned.**

### Recovery after the surgery

After the surgery, you will go to the Post-Anesthesia Care Unit (PACU) where the nurses will look after you.

When awake, most patients after this surgery go to the Intensive Care Unit (ICU) for one night.

From the ICU patients are transferred to Ward F4 or E4.

---

**As you recover**

The nurses will:

- Check your blood pressure, heart rate, breathing and temperature (vital signs).
- Watch for drainage from the incision after surgery and change your dressing as needed. You will have a drain to collect fluid near the wound.
- Ask you to wear special boots called moon boots on your legs. These boots help prevent blood clots.
- Give you fluids and medications through your IV.
- Check the nasogastric (NG) tube that goes down your nose and into your stomach. This will stay in until you pass gas.
- Ask you about your pain and comfort, and provide pain medication on a regular basis.
- Give a blood thinning medication by needle in your upper thigh to help prevent blood clots from forming.

**Urostomy pouch**

For about 7 to 14 days you will notice small plastic tubes or stents coming out of the stoma into the pouch. These stents pass through the ileal conduit into each ureter and support the conduit while healing after surgery.

---

## Walking and exercises

Walking helps you to regain your general strength and independence. You will feel better if you get up and walk more each day. Walking also decreases the chance of blood clots and a lung infection (pneumonia). Walking also helps to pass gas which helps the bowel.



When you first start walking after surgery a nurse or therapist will help you until you are safe to walk on your own. Continue to do your breathing and leg exercises as discussed on page 9.

## Nutrition

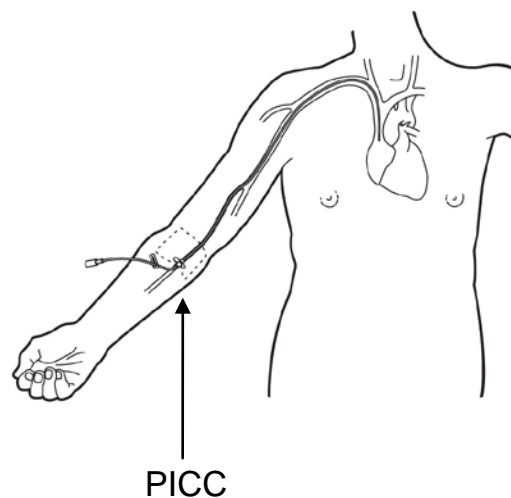
Right after surgery the nurses will encourage you to drink clear fluids. Nutrition is very important to your recovery. You may not feel like eating or have much of an appetite after surgery. This is normal. It takes the body a while to adjust and it may take a few months before you get back your appetite. You will meet with a dietitian to discuss your nutritional needs.



Diarrhea is common and usually settles down in a few weeks.

You may need to have intravenous fluids and nutrition in the hospital and/or at home. These fluids and nutrients may be given through an IV called a PICC (Peripherally Inserted Central Catheter).

This is a long thin tube that can provide fluids and nutrition. It can stay in your arm for a few weeks or longer if needed.



## When you go home

Most patients are ready to go home 7 days after surgery. You will need to go on medication to prevent blood clots. Usually, patients are on this medication for 28 days after surgery. A nurse from the Thrombosis Team will discuss this medication with you.



You may also see an enterostomal nurse to learn about stoma care.

Healing takes time. If you need nursing care for your incision and/or urostomy pouch, home care will be provided.

You may feel anxious as you get ready to go home. So much to remember and do. Please ask us to repeat information you do not understand or clarify what you need to do.

## Home care or CCAC

CCAC stands for Community Care Access Centre. CCAC helps the healing process continue in your own home.

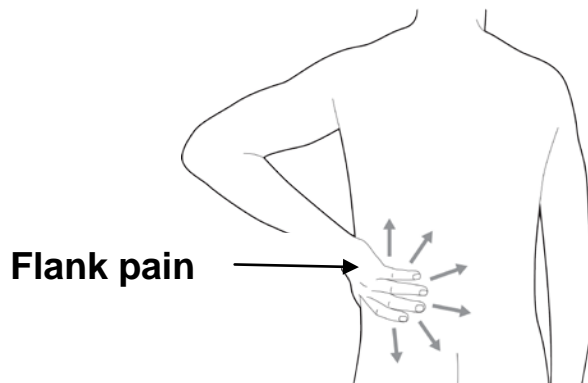
If needed, CCAC arranges nursing, physiotherapy, nutrition and social services when you go home.

The CCAC case manager will meet with you to review your needs so that the right services can be provided once you are home. If you are not eligible for the program, the case manager can help find other sources of care.

You may wish to make arrangements with friends and family to help you during your recovery.

## Follow-up care and appointments

- Your follow-up appointment with your surgeon will be in 1 to 2 weeks after you get home. Your staples/stitches are removed by your home care nurse or during your follow-up appointment with your surgeon. Blood work will be done at this appointment.
- Your drain may be removed at your follow-up visit if it has not already been removed by your home care nurse.
- The retention sutures, will be removed about 6 weeks after surgery in the post-op clinic.
- Stents that you have coming out of the stoma are removed during your follow-up visit. This is not painful. A urine test for infection is also done at this time.
- If you have a temperature of 38°C (100°F) or higher and have **flank pain** after the stents are removed, go to the emergency room.



## Pain medication and activity

- You will be given a prescription for pain pills. When you have less pain, you may prefer to take plain acetaminophen (Tylenol). If you find that an activity gives you pain, stop and rest. Wait a few days before trying that activity again.
- Once home, you can continue to increase your activity level slowly. Your need for relaxation and rest will still be greater than normal. At first you may find activities such as climbing stairs or vacuuming too hard for you. If you feel tired, stop and rest.



**Exercise**

- Exercise can help your recovery as well. Walking is an excellent exercise that benefits most patients. You can gradually walk farther or faster each day.
- Do not do stomach exercises, high intensity aerobic activities or weight training for 8 to 12 weeks after surgery. Do not lift more than 10 pounds (full laundry bin, bag of groceries) for 8 to 12 weeks after surgery.

**Incision and pouch care**

- It is very important to keep clean. Water will not get into your abdomen. Having daily showers will keep your incision clean and help it heal. When you take a shower, take the dressing off, wash with warm water and mild soap, pat dry.
- Be sure to completely and carefully pat dry your incision after washing. Use a clean cloth and towel each time you shower.
- You may have a bath for the first few weeks, but for the first few weeks patients usually prefer showers.
- Your incision should be a clean, dry and closed line. Look at your incision before you leave the hospital so that you will be able to see if there are any changes to it when you are at home.
- A hair dryer on low setting is helpful to dry the pouch area so that the pouch sticks better.

**Infection**

- Prevent infection by keeping the incision clean. Doing deep breathing exercises and moving as much as possible after surgery helps to prevent a lung infection.
  - You may have drainage from your penis or urethra after surgery. This is normal. If it starts to smell, change colour (yellowish/green) or seems to be getting worse, or if you have a fever greater than 38°C (100°F) call your surgeon.
-

**Before you leave, you need to know:**

- About the medication you were on before surgery and any new medication you will need to take now.
- About what to eat and drink.
- How to relieve your pain and increase your activity around the house.
- How to take care of your incision and dressing.
- How to care for your stoma and pouch (home care may be needed).
- When to go back to your regular activities such as lifting, driving.
- What symptoms are medical emergencies and what signs to watch for.
- Who is going to help you out once you are home.
- Who to call if you have questions or concerns.

We want to make sure that you know what to do when you go home. Please ask us questions and discuss with us your needs and concerns.

**Questions to ask during follow-up visits:**

---

---

---

---

---

---

---

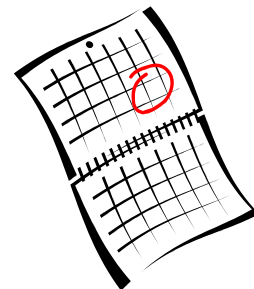


## When to call the surgeon and seek medical attention

- fever 38°C or 100°F or higher
- chest pain, cough, difficulty breathing or coughing up blood
- vomiting, abdominal distention (bloating) and not passing gas
- pain, swelling or tenderness in your calf or thigh
- dizziness for more than a few seconds or fainting
- concerns about your incisions such as: swelling with warmth and hardness, or leaking thick fluid or bleeding
- pain, which does not get better with pain pills
- failing to improve, not eating, not drinking
- not urinating very much, less than a few times a day
- lots of blood in your urine or stool
- flank pain (see page 14)

## Follow-up visits

You will be followed closely for the first few years after surgery. You will be seen a few weeks after your surgery and your surgeon will determine how often you need to be seen there after. **You will be given an appointment to see your surgeon before you leave the hospital.**



Follow-up care depends on factors such as the type of cancer and treatments you have. These visits may vary from a single visit to a few times per year or yearly, depending on your personal situation. Regular follow-up appointments are made in the Cancer Centre.

## Follow-up schedule after a radical cystectomy

<b>Year 1</b> Tests every 3 months	<b>2 to 3 weeks</b>	<b>6 weeks</b>	<b>3 months</b> Chest x-ray Blood work Ultrasound abdominal and pelvis	<b>6 months</b> Chest x-ray Blood work Ultrasound abdominal and pelvis	<b>9 months</b> Chest x-ray Blood work Ultrasound abdominal and pelvis	<b>12 months</b> Chest x-ray Blood work Ultrasound abdominal and pelvis
<b>Year 2</b> Tests every 4 months	<b>4 months</b> Chest x-ray Ultrasound abdominal and pelvis		<b>8 months</b> Chest x-ray Ultrasound abdominal and pelvis		<b>12 months</b> Chest x-ray Ultrasound abdominal and pelvis	
<b>Year 3</b> Tests every 6 months	<b>6 months</b> Blood work Chest x-ray Ultrasound abdominal and pelvis			<b>12 months</b> Blood work Chest x-ray Ultrasound abdominal and pelvis		
<b>Year 4</b> Tests every 6 months	<b>6 months</b> Blood work Chest x-ray Ultrasound abdominal and pelvis			<b>12 months</b> Blood work Chest x-ray Ultrasound abdominal and pelvis		
<b>Year 5</b> Tests every 6 months	<b>6 months</b> Blood work Chest x-ray Ultrasound abdominal and pelvis			<b>12 months</b> Blood work Chest x-ray Ultrasound abdominal and pelvis		
<b>Years 6 to 10</b> Tests once a year	Blood work Chest x-ray Ultrasound abdominal pelvis					

Please note: A CT scan may be needed as a follow-up. It depends on the type of cancer cells found at the time of your surgery or biopsy.