

About Your Bladder Surgery With an Ileal Conduit (Urostomy)

This guide will help you get ready for your bladder surgery at MSK. It will also help you know what to expect as you recover.

Use this guide as a source of information in the days leading up to your surgery. Bring it with you on the day of your surgery. You and your care team will use it as you learn more about your recovery.

Emergency information

At night (from 5 p.m. to 9 a.m.), on weekends, and on holidays, call 212-639-2000. Ask for the urology surgeon on call.

MSK's Urgent Care Center is located at:
425 E. 67th St. (between 1st and York avenues)
New York, NY 10065



Visit www.msk.org/pe/bladder_surgery_urostomy to view this guide online.

Your care team

Doctor: _____

Nurse: _____

Phone number: _____

Fax number: _____

Your caregiver

Your caregiver will learn about your surgery with you. They'll also help you care for yourself while you're healing after surgery. Write their name below.

Caregiver: _____

Notes _____

Table of contents

About your bladder surgery	5
Removing your bladder	6
Creating your ileal conduit	7
Getting ready for your bladder surgery	9
Getting ready for your surgery	10
Within 30 days of your bladder surgery	14
7 days before your bladder surgery	19
2 days before your bladder surgery	20
1 day before your bladder surgery	20
The day of your bladder surgery	25
Recovering after your bladder surgery	31
In the Post-Anesthesia Care Unit (PACU)	32
In your hospital room	33
At home	37
When to call your healthcare provider	47
Support services	49
Bladder cancer support group	50
MSK support services	50
External support services	55
Bladder cancer support services	55

Educational resources 57

About Your Urostomy

General Exercise Program: Level 2

Herbal Remedies and Cancer Treatment

*How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs,
Vitamin E, or Fish Oil*

How To Use Your Incentive Spirometer

Notes _____

About your bladder surgery

Your urinary system is made up of organs that make urine and get it out of your body (see Figure 1).

- Your kidneys clean the toxins out of your blood and make urine.
- Your ureters are tubes that carry urine from your kidneys to your bladder.
- Your bladder stores urine until you feel the need to urinate.
- Your urethra is a tube that carries the urine in your bladder out of your body when you urinate.
 - In women, the urethra is very short. It's located above the vagina.
 - In men, the tube is longer. It passes through the prostate gland and penis.

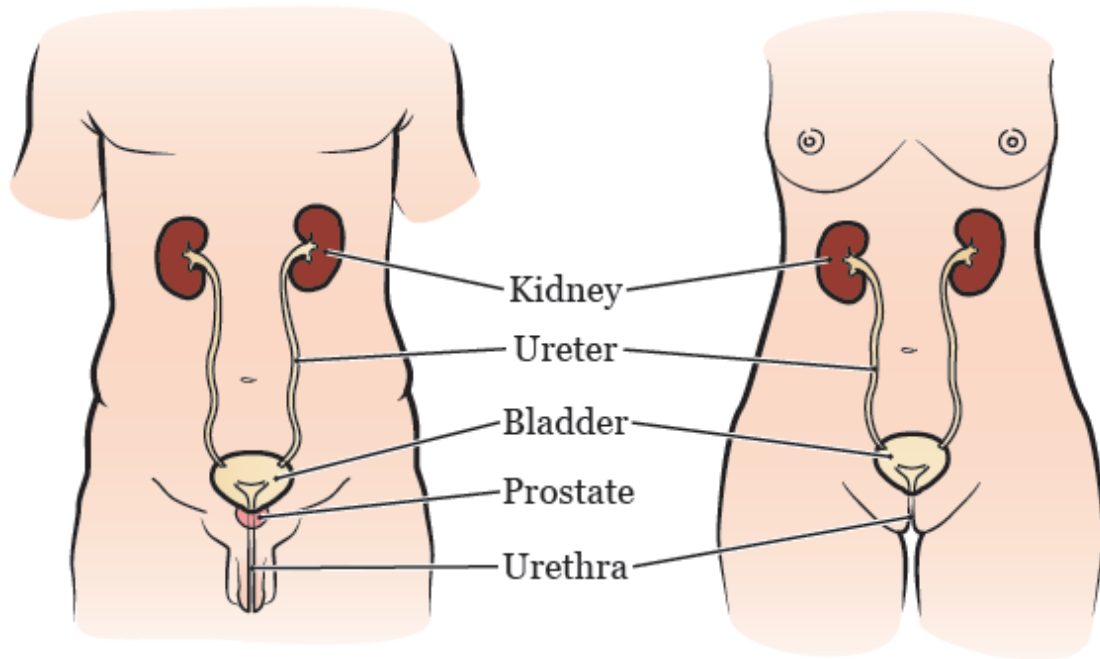


Figure 1. Your urinary system

Removing your bladder

Surgery to remove your entire bladder is called a radical cystectomy.

During your surgery, your doctor will remove your bladder and some of the lymph nodes near your bladder. Then, they will rebuild your urinary system.

About lymph nodes

Lymph nodes are small, bean-shaped glands that are located throughout your body. They're part of your lymphatic system, which is part of your body's immune system. Lymph nodes are removed during your surgery because they may also contain cancer cells.

If you've had surgery or radiation therapy to your pelvis in the past, your doctor may remove fewer lymph nodes. This is done to avoid problems after your surgery.

Removing other organs near your bladder

In addition to your bladder and lymph nodes, your doctor may need to remove other organs near your bladder. This is done to make sure all of the cancer is removed.

In men, the following organs may be removed:

- Prostate
- Seminal vesicles
- Part of the vasa deferentia
- Urethra

In women, the following organs may be removed:

- Uterus
- Fallopian tubes
- Ovaries
- Part of the vagina

Creating your ileal conduit

After your bladder is removed, your doctor will create a new passage where urine will leave your body. This is called a urostomy. The type of urostomy you will have is called an ileal conduit.

Your doctor will use a small piece of your intestine called the ileum to create the ileal conduit. One end of the ileum will be attached to your ureters. The other end will be attached to a small opening in your abdomen called a stoma (see Figure 2). Your doctor will create the stoma during your surgery.

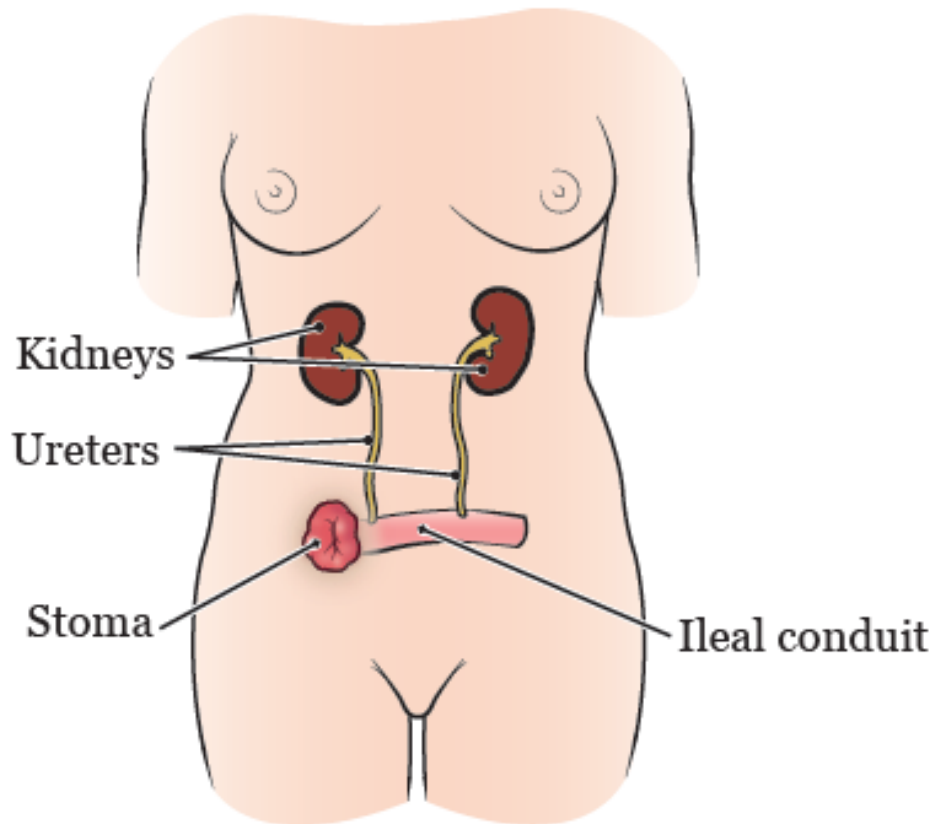


Figure 2. Your ileal conduit

After your surgery, your urine will flow from your kidneys, through your ureters and ileal conduit, and out of your stoma. You will wear a urostomy pouching system (appliance) over your stoma to catch and hold the urine.

This surgery usually takes about 3 to 6 hours. It may take longer if you have other medical conditions or have had past surgeries.

Getting ready for your bladder surgery

This section will help you get ready for your surgery. Read it when your surgery is scheduled. Refer to it as your surgery gets closer. It has important information about what to do to get ready.



As you read this section, write down questions to ask your healthcare provider. You can use the space below.

Notes _____

Getting ready for your surgery

You and your care team will work together to get ready for your surgery. Help us keep you safe by telling us if any of these things apply to you, even if you're not sure.

- I take an anticoagulant (blood thinner), such as:
 - Aspirin
 - Heparin
 - Warfarin (Jantoven®, Coumadin®)
 - Clopidogrel (Plavix®)
 - Enoxaparin (Lovenox®)
 - Dabigatran (Pradaxa®)
 - Apixaban (Eliquis®)
 - Rivaroxaban (Xarelto®)
- I take an SGLT2 inhibitor, such as:
 - Canagliflozin (Invokana®)
 - Dapagliflozin (Farxiga®)
 - Empagliflozin (Jardiance®)
 - Ertugliflozin (Steglatro®)
- I take prescription medicine(s), including patches and creams. A prescription medicine is one you can only get with a prescription from your healthcare provider.
- I take over-the-counter medicine(s), including patches and creams. An over-the-counter medicine is one you can buy without a prescription.
- I take dietary supplements, such as herbs, vitamins, minerals, or natural or home remedies.

These are examples of medicines. There are others.

Be sure your healthcare provider knows all the medicines you're taking.

- I have a pacemaker, automatic implantable cardioverter-defibrillator (AICD), or other heart device.
- I have sleep apnea.
- I have had a problem with anesthesia (A-nes-THEE-zhuh) in the past. Anesthesia is medicine to make you sleep during a surgery or procedure.
- I'm allergic to certain medicines or materials, including latex.
- I'm not willing to receive a blood transfusion.
- I drink alcohol.
- I smoke or use an electronic smoking device, such as a vape pen or e-cigarette.
- I use recreational drugs, such as marijuana.

About drinking alcohol

It's important to talk with your healthcare providers about how much alcohol you drink. This will help us plan your care.

If you drink alcohol regularly, you may be at risk for problems during and after your surgery. These include bleeding, infections, heart problems, and a longer hospital stay.

If you drink alcohol regularly and stop suddenly, it can cause seizures, delirium, and death. If we know you're at risk for these problems, we can prescribe medicine to help prevent them.

Here are things you can do before your surgery to keep from having problems.

- Be honest with your healthcare providers about how much alcohol you drink.

- Try to stop drinking alcohol once your surgery is planned. Tell your healthcare provider right away if you:
 - Get a headache.
 - Feel nauseous (like you're going to throw up).
 - Feel more anxious (nervous or worried) than usual.
 - Cannot sleep.

These are early signs of alcohol withdrawal and can be treated.

- Tell your healthcare provider if you cannot stop drinking.
- Ask your healthcare provider questions about drinking and surgery. All your medical information will be kept private, as always.

About smoking

If you smoke, you can have breathing problems when you have surgery. Stopping for even a few days before surgery can help.

Your healthcare provider will refer you to our Tobacco Treatment Program if you smoke. You can also reach the program by calling 212-610-0507 or visit www.msk.org/tobacco to learn more.

About sleep apnea

Sleep apnea is a common breathing problem. If you have sleep apnea, you stop breathing for short lengths of time while you're asleep. The most common type is obstructive sleep apnea (OSA). With OSA, your airway becomes fully blocked during sleep.

OSA can cause serious problems during and after surgery. Tell us if you have or think you might have sleep apnea. If you use a breathing device, such as a CPAP machine, bring it on the day of your surgery.

Using MyMSK

MyMSK (my.mskcc.org) is your MSK patient portal. You can use it to send and read messages from your care team, view your test results, see your appointment dates and times, and more. You can also invite your caregiver to make their own account so they can see information about your care.

If you do not have a MyMSK account, you can sign up at my.mskcc.org. You can get an enrollment ID by calling 646-227-2593 or your doctor's office.

Watch *How to Enroll in MyMSK: Memorial Sloan Kettering's Patient Portal* at www.msk.org/pe/enroll_mysk to learn more. You can also contact the MyMSK Help Desk by emailing mymask@mskcc.org or calling 800-248-0593.

About Enhanced Recovery After Surgery (ERAS)

ERAS is a program to help you get better faster after your surgery. It's important to do certain things before and after your surgery as part of the ERAS program.

Before your surgery, make sure you're ready by:

- **Reading this guide.** It will help you know what to expect before, during, and after your surgery. If you have questions, write them down. You can ask your healthcare provider at your next visit or call their office.
- **Exercising and following a healthy diet.** This will help get your body ready for your surgery.

After your surgery, help yourself recover more quickly by:

- **Reading your recovery pathway.** This is an educational resource your healthcare provider will give you. It has goals for your recovery. It will help you know what to do and expect each day.

- **Starting to move around as soon as you can.** The sooner you get out of bed and walk, the quicker you can get back to your usual activities.

Within 30 days of your bladder surgery

Presurgical testing (PST)

You'll have a PST appointment before your surgery. You'll get a reminder from your surgeon's office with the appointment date, time, and location.

You can eat and take your usual medicine(s) the day of your PST appointment.

It's helpful to bring these things to your appointment:

- A list of all the medicines you're taking, including prescription and over-the-counter medicines, patches, and creams.
- Results of any medical tests done outside of MSK in the past year, if you have them. Examples include results from a cardiac stress test, echocardiogram, or carotid doppler study.
- The names and telephone numbers of your healthcare providers.

You'll meet with an advance practice provider (APP) during your PST appointment. They work closely with MSK's anesthesiology (A-nes-THEE-zee-AH-loh-jee) staff. These are healthcare providers with special training in using anesthesia during a surgery or procedure.

Your APP will review your medical and surgical history with you. You may have tests to plan your care, such as:

- An electrocardiogram (EKG) to check your heart rhythm.
- A chest X-ray.
- Blood tests.

Your APP may recommend you see other healthcare providers. They'll also talk with you about which medicine(s) to take the morning of your surgery.

Identify your caregiver

Your caregiver has an important role in your care. Before your surgery, you and your caregiver will learn about your surgery from your healthcare providers. After your surgery, your caregiver will take you home when you're discharged. They'll also help you care for yourself at home.



For caregivers

Caring for a person going through cancer treatment comes with many responsibilities. We offer resources and support to help you manage them.

Visit www.msk.org/caregivers or read *A Guide for Caregivers* to learn more. You can ask for a printed copy or find it at www.msk.org/pe/guide_caregivers

Fill out a Health Care Proxy form

If you have not already filled out a Health Care Proxy form, we recommend you do now. If you already filled one out or have any other advance directives, bring them to your next appointment.

A health care proxy is a legal document. It says who will speak for you if you cannot communicate for yourself. This person is called your health care agent.

- To learn about health care proxies and other advance directives, read *Advance Care Planning for Cancer Patients and Their Loved Ones*. You can find it at www.msk.org/pe/advance_care_planning or ask for a printed copy.

- To learn about being a health care agent, read *How to Be a Health Care Agent*. You can find it at www.msk.org/pe/health_care_agent or ask for a printed copy.

Talk with a member of your care team if you have questions about filling out a Health Care Proxy form.

Meet with a wound, ostomy, and continence (WOC) nurse

A WOC nurse is a nurse who specializes in caring for stomas. Before your surgery, your WOC nurse will mark a site on your abdomen where your stoma may be placed. The site will be the best possible location, away from scars, creases, folds, and if possible, in an area that will make it easy for you to care for it.

Do breathing and coughing exercises

Practice taking deep breaths and coughing before your surgery. Your healthcare provider will give you an incentive spirometer to help expand your lungs. To learn more, read *How to Use Your Incentive Spirometer*. You can find it in the “Educational resources” section of this guide.

Consider our sexual health programs

Bladder surgery will affect your sexual health. If you have any concerns about how it will affect you, talk with a member of your care team. They can refer you to one of our sexual health clinics.

Information for men

Bladder surgery can cause changes in erectile function (your ability to get and keep an erection). Most men have erectile dysfunction (ED) after surgery. ED is when you have trouble getting or keeping an erection.

Your doctor will talk with you about what to expect about having erections again after surgery. There are many types of treatments for ED, including pills, injections (shots), or a prosthesis (implant). Your doctor can discuss these options with you.

Because your prostate will be removed during your surgery, you won't be able to father children after your surgery. If you want to have children in the future, you may want to bank your sperm before surgery. Ask your nurse for information about sperm banking if you want to bank your sperm.

To see a specialist in the Male Sexual & Reproductive Medicine Program, ask a member of your care team for a referral or call 646-888-6024 to learn more.

Information for women

If your reproductive organs are removed, you won't be able to bear children after your surgery. If you want to have children in the future, you may want to think about family planning options (such as egg freezing) before your surgery. Your doctor can discuss these options with you.

You may also have changes in sexual function after your surgery. These may include a shorter vagina and menopause. Menopause is when you no longer have a menstrual period. Your doctor will talk with you about what to expect. They can also discuss your treatment options with you in more detail.

To see a specialist in the Female Sexual Medicine & Women's Health Program, ask a member of your MSK care team for a referral or call 646-888-5076 to learn more.

Do physical activity

Try to do aerobic exercise every day. Examples of aerobic exercise include walking at least 1 mile (1.6 kilometers), swimming, or biking. If it's cold outside, use stairs in your home or go to a mall or shopping market. Exercising will help your body get into its best condition for your surgery and make your recovery faster and easier.

To learn more, read *General Exercise Program: Level 2*. You can find it in the “Educational resources” section of this guide.

Follow a healthy diet

Follow a well-balanced, healthy diet before your surgery. If you need help with your diet, talk with your healthcare provider about meeting with a clinical dietitian nutritionist.

Buy a 4% chlorhexidine gluconate (CHG) solution antiseptic skin cleanser, such as Hibiclens®

4% CHG solution is a skin cleanser that kills germs for 24 hours after you use it. Showering with it before your surgery will help lower your risk of infection after surgery. You can buy a 4% CHG solution antiseptic skin cleanser at your local pharmacy without a prescription.

Buy liquids

You'll need to follow a full liquid diet before your surgery. It's helpful to buy liquids ahead of time. Read the “Follow a full liquid diet” section below for a list of liquids you can drink.

7 days before your bladder surgery

Follow your healthcare provider's instructions for taking aspirin

Aspirin can cause bleeding. If you take aspirin or a medicine that has aspirin, you may need to change your dose or stop taking it 7 days before your surgery. Follow your healthcare provider's instructions. **Do not stop taking aspirin unless they tell you to.**

To learn more, read *How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil*. You can find it in the “Educational resources” section of this guide.

Stop taking vitamin E, multivitamins, herbal remedies, and other dietary supplements

Vitamin E, multivitamins, herbal remedies, and other dietary supplements can cause bleeding. Stop taking them 7 days before your surgery. If your healthcare provider gives you other instructions, follow those instead.

To learn more, read *Herbal Remedies and Cancer Treatment*. You can find it in the “Educational resources” section of this guide.

2 days before your bladder surgery

Stop taking nonsteroidal anti-inflammatory drugs (NSAIDs)

NSAIDs, such as ibuprofen (Advil® and Motrin®) and naproxen (Aleve®), can cause bleeding. Stop taking them 2 days before your surgery. If your healthcare provider gives you other instructions, follow those instead.

To learn more, read *How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil*. You can find it in the “Educational resources” section of this guide.

1 day before your bladder surgery

Follow a full liquid diet

You’ll need to follow a full liquid diet the day before your surgery. Examples of liquids you can drink are listed in the “Full liquid diet” table below. Your healthcare provider will tell you if you need to start your liquid diet earlier or do any other bowel preparation.

While you’re following a full liquid diet:

- Do not eat any solid foods.
- Try to drink at least 1 (8-ounce) cup of liquid every hour you’re awake.
- Drink different types of liquids. Do not just drink water, coffee, and tea. You can drink liquids of any color.
- Do not drink sugar-free liquids unless you have diabetes and a member of your care team tells you to.

How to follow a full liquid diet if you have diabetes

Ask the healthcare provider who manages your diabetes:

- What to do while you're following a full liquid diet.
- If you need to change your dose of insulin or other diabetes medicine(s), if you take them.
- If you should drink sugar-free liquids.

Check your blood sugar level often while you're following a full liquid diet. If you have questions, talk with your healthcare provider.

Full liquid diet

	OK to have	Do not have
Soups	<ul style="list-style-type: none">• Broth, bouillon, and consommé.• Smooth blenderized soups (such as cream of potato, carrot, and broccoli).	<ul style="list-style-type: none">• Soups that have whole food pieces.
Dairy	<ul style="list-style-type: none">• Pudding.• Smooth ice cream.• Smooth yogurt (such as vanilla, lemon, or coffee flavors).• Milk, Lactaid® milk, soy milk, almond milk, and rice milk.• Milkshakes.	<ul style="list-style-type: none">• Dairy that has fruit, nuts, granola, or whole food pieces.

	OK to have	Do not have
Grains	<ul style="list-style-type: none"> Hot cereals (such as farina, strained oatmeal, grits, and Wheatena®). 	<ul style="list-style-type: none"> Grains that have fruit, nuts, granola, or whole food pieces.
Nutritional supplements	<ul style="list-style-type: none"> Liquid nutritional supplements (such as Ensure®, Boost®, and Carnation Breakfast Essentials® drinks). Pudding nutritional supplements (such as Boost pudding and Ensure Original Pudding). 	<ul style="list-style-type: none"> Supplements that have fruit, nuts, granola, or whole food pieces.
Other	<ul style="list-style-type: none"> Mild mustard, ketchup, mayonnaise, sugar, salt, or a dash of pepper blended into the food and drinks above. 	<ul style="list-style-type: none"> Bubble teas. Drinks with alcohol.

Note the time of your surgery

A staff member will call you after 2 p.m. the day before your surgery. If your surgery is scheduled for a Monday, they'll call you the Friday before. If you do not get a call by 7 p.m., call 212-639-5014.

The staff member will tell you what time to get to the hospital for your surgery. They'll also remind you where to go. This will be:

The Presurgical Center (PSC) at Memorial Hospital
 1275 York Ave. (between East 67th and East 68th streets)
 New York, NY 10065
 Take the B elevator to the 6th floor.

Shower with a 4% CHG solution antiseptic skin cleanser, such as Hibiclens

Shower with a 4% CHG solution antiseptic skin cleanser before you go to bed the night before your surgery.

1. Wash your hair with your usual shampoo and conditioner. Rinse your head well.
2. Wash your face and genital (groin) area with your usual soap. Rinse your body well with warm water.
3. Open the 4% CHG solution bottle. Pour some into your hand or a clean washcloth.
4. Move away from the shower stream. Rub the 4% CHG solution gently over your body from your neck to your feet. Do not put it on your face or genital area.
5. Move back into the shower stream to rinse off the 4% CHG solution. Use warm water.
6. Dry yourself off with a clean towel.

Do not put on any lotion, cream, deodorant, makeup, powder, perfume, or cologne after your shower.

Instructions for eating and drinking: 8 hours before your arrival time



- Stop eating 8 hours before your arrival time, if you have not already.
 - Your healthcare provider may tell you to stop eating earlier. If they do, follow their instructions.
- 8 hours before your arrival time, do not eat or drink anything except these clear liquids:
 - Water.
 - Soda.
 - Clear juices, such as lemonade, apple, and cranberry juices. Do not drink orange juice or juices with pulp.
 - Black coffee or tea (without any type of milk or creamer).
 - Sports drinks, such as Gatorade®.
 - ClearFast CF(Preop)® or Ensure® Pre-Surgery clear carbohydrate drink.
 - Gelatin, such as Jell-O®.

You can keep having these until 2 hours before your arrival time.

The day of your bladder surgery

Remember, starting 8 hours before your arrival time, do not eat or drink anything except the things listed above.

Instructions for drinking: 2 hours before your arrival time



If your healthcare provider gave you a ClearFast CF (Preop) or Ensure Pre-Surgery clear carbohydrate drink, finish it 2 hours before your arrival time.



Stop drinking 2 hours before your arrival time. This includes water.

Take your medicines as instructed

A member of your care team will tell you which medicines to take the morning of your surgery. Take only those medicines with a sip of water. Depending on what you usually take, this may be all, some, or none of your usual morning medicines.

Shower with a 4% CHG solution antiseptic skin cleanser, such as Hibiclens

Shower with a 4% CHG solution antiseptic skin cleanser before you leave for the hospital. Use it the same way you did the night before.

Do not put on any lotion, cream, deodorant, makeup, powder, perfume, or cologne after your shower.

Things to remember

- Wear something comfortable and loose-fitting.
- If you wear contact lenses, wear your glasses instead. Wearing contact lenses during surgery can damage your eyes.
- Do not wear any metal objects. Take off all jewelry, including body piercings. The tools used during your surgery can cause burns if they touch metal.
- Remove nail polish and wraps.
- Leave valuable items at home.
- If you're menstruating (have your monthly period), use a sanitary pad, not a tampon. We'll give you disposable underwear and a pad if you need them.

What to bring

- ☐ A pair of loose-fitting pants (such as sweatpants).
- ☐ Sneakers that lace up. You may have some swelling in your feet. Lace-up sneakers can fit over this swelling.
- ☐ Your breathing device for sleep apnea (such as your CPAP machine), if you have one.
- ☐ Your incentive spirometer, if you have one.
- ☐ Your Health Care Proxy form and other advance directives, if you filled them out.
- ☐ Your cell phone and charger.
- ☐ Only the money you may want for small purchases, such as a newspaper.

- A case for your personal items, if you have any. Eyeglasses, hearing aids, dentures, prosthetic devices, wigs, and religious articles are examples of personal items.
- This guide. You'll use it to learn how to care for yourself after surgery.

Where to park

MSK's parking garage is on East 66th Street between York and 1st avenues. If you have questions about prices, call 212-639-2338.

To get to the garage, turn onto East 66th Street from York Avenue. The garage is about a quarter of a block in from York Avenue. It's on the right (north) side of the street. There's a tunnel you can walk through that connects the garage to the hospital.

There are other parking garages on:

- East 69th Street between 1st and 2nd avenues.
- East 67th Street between York and 1st avenues.
- East 65th Street between 1st and 2nd avenues.

Once you're in the hospital

When you get to the hospital, take the B elevator to the 6th floor. Check in at the desk in the PSC waiting room.

Many staff members will ask you to say and spell your name and birth date. This is for your safety. People with the same or a similar name may be having surgery on the same day.

We'll give you a hospital gown, robe, and nonskid socks to wear when it's time to change for surgery.



For caregivers, family, and friends

Read *Information for Family and Friends for the Day of Surgery* to help you know what to expect on the day of your loved one's surgery. You can ask for a printed copy or find it at www.msk.org/pe/info_family_friends

Meet with a nurse

You'll meet with a nurse before surgery. Tell them the dose of any medicines you took after midnight (12 a.m.) and the time you took them. Make sure to include prescription and over-the-counter medicines, patches, and creams.

Your nurse may place an intravenous (IV) line in one of your veins, usually in your arm or hand. If your nurse does not place the IV, your anesthesiologist (A-nes-THÉE-zee-AH-loh-jist) will do it in the operating room.

Marking your surgical site

In addition to being asked your name and birth date, you may also be asked the name of your doctor, what surgery you're having, and which side is being operated on. Your doctor or another member of your surgical team will use a marker to initial the site on your body that will be operated on. This is for your safety. We do this to make sure that all members of the surgical staff are clear about the plan for your surgery.

Meet with an anesthesiologist

You'll also meet with an anesthesiologist before surgery. They will:

- Review your medical history with you.
- Ask if you've had any problems with anesthesia in the past, such as nausea or pain.
- Talk with you about your comfort and safety during your surgery.
- Talk with you about the kind of anesthesia you'll get.

- Answer your questions about your anesthesia.

Your doctor or anesthesiologist may also talk with you about placing an epidural catheter (thin, flexible tube) in your spine (back). An epidural catheter is another way to give you pain medicine after your surgery.

Get ready for surgery

When it's time for your surgery, you'll take off your eyeglasses, hearing aids, dentures, prosthetic devices, wig, and religious articles.

You'll either walk into the operating room or a staff member will bring you there on a stretcher. A member of the operating room team will help you onto the operating bed. They'll put compression boots on your lower legs. These gently inflate and deflate to help blood flow in your legs.

Once you're comfortable, your anesthesiologist will give you anesthesia through your IV line and you'll fall asleep. You'll also get fluids through your IV line during and after your surgery.

During your surgery

After you're fully asleep, your care team will place a breathing tube through your mouth into your airway. It will help you breathe.

Your surgeon will close your incisions with staples or stitches once they finish your surgery. They may also place Steri-Strips™ (thin pieces of surgical tape) or Dermabond® (surgical glue) over your incisions. They'll cover your incisions with a bandage.

Your care team will usually take out your breathing tube while you're still in the operating room.

Recovering after your bladder surgery

This section will help you know what to expect after your surgery. You'll learn how to safely recover from your surgery both in the hospital and at home.



As you read this section, write down questions to ask your healthcare provider. You can use the space below.

Notes _____

In the Post-Anesthesia Care Unit (PACU)

You'll be in the PACU when you wake up after your surgery. A nurse will be keeping track of your temperature, pulse, blood pressure, and oxygen levels. You may get oxygen through a tube resting below your nose or a mask over your nose and mouth. You'll also have compression boots on your lower legs.

Pain medicine

You'll get epidural or IV pain medicine while you're in the PACU.

- If you're getting epidural pain medicine, it will be put into your epidural space through your epidural catheter. Your epidural space is the space in your spine just outside your spinal cord.
- If you're getting IV pain medicine, it will be put into your bloodstream through your IV line.

You'll be able to control your pain medicine using a button called a patient-controlled analgesia (PCA) device. Read *Patient-Controlled Analgesia (PCA)* to learn more. You can find it at www.msk.org/pe/pca or ask for a printed copy.

Tubes and drains

You will have several different types of drainage tubes in your body. Your healthcare provider will talk with you about what to expect. They will also check off the boxes next to the tubes that you may have.

- ☐ **Jackson-Pratt (JP) drain:** This is a small, egg-shaped container that's connected to a tube in the lower part of your abdomen. It drains liquid from your pelvis.
- ☐ **Stents:** These are 2 small tubes that come out of your stoma. They drain urine from your kidneys.

- **Drainage catheter in your stoma:** This is a tube that comes out of your stoma. It drains urine from your ileal conduit.

Moving to your hospital room

You will probably stay in the PACU overnight. How long you stay depends on the type of surgery you had. A staff member will bring you to your hospital room after your stay in the PACU.

In your hospital room

The length of time you're in the hospital after your surgery depends on your recovery. Most people stay in the hospital for 3 to 4 days.

In your hospital room, you'll meet one of the nurses who will care for you during your stay. A nurse will help you out of bed and into your chair soon after you get there.

Your care team will teach you how to care for yourself while you're healing from your surgery. You can help yourself recover more quickly by:

- **Reading your recovery pathway.** We will give you a pathway with goals for your recovery if you do not already have one. It will help you know what to do and expect on each day during your recovery.
- **Starting to move around as soon as you can.** The sooner you get out of bed and walk, the quicker you can get back to your usual activities.

Managing your pain

You'll have some pain after your surgery. At first, you'll get your pain medicine through your epidural catheter or IV line. You'll be able to control your pain medicine using a PCA device. Once you can eat, you'll get oral pain medicine (pain medicine you swallow).

We will ask you about your pain often and give you medicine as needed. Tell one of your healthcare providers if your pain is not relieved. It's important to control your pain so you can use your incentive spirometer and move around. Controlling your pain can help you recover faster.

If you had a robotic surgery, you may have pain in your shoulder. This is called referred pain and is common. It's caused by the gas that was put into your abdomen during your surgery. If you have pain in your shoulder, tell one of your healthcare providers. They'll bring you a hot pack to put on your shoulder to help with the pain.

You'll get a prescription for pain medicine before you leave the hospital. Talk with your healthcare provider about possible side effects. Ask them when to start switching to over-the-counter pain medicine.

Moving around and walking

Moving around and walking will help lower your risk for blood clots and pneumonia (lung infection). It will also help you start passing gas and having bowel movements (pooping) again. Your nurse, physical therapist, or occupational therapist will help you move around, if needed.

To learn more about how walking can help you recover, read *Frequently Asked Questions About Walking After Your Surgery*. You can find it at www.msk.org/pe/walking_after_surgery or ask for a printed copy.

To learn what you can do to stay safe and keep from falling while you're in the hospital, read *Call! Don't Fall!* You can ask for a printed copy or find it at www.msk.org/pe/call_dont_fall

Try to follow the moving and walking goals below. These goals are also in your recovery pathway.

Day	Goals
The day of surgery	<ul style="list-style-type: none"> • Dangle your legs over the edge of your bed.
1 day after surgery	<ul style="list-style-type: none"> • Sit in your chair for 2 to 3 hours. • Walk to the bathroom and brush your teeth. • Walk 3 or more laps around the nursing unit.
2 days after surgery	<ul style="list-style-type: none"> • Sit in your chair for 3 or more hours. • Sit in your chair during your meals. • Walk to the bathroom and brush your teeth. • Walk 7 or more laps around the nursing unit.
3 days after surgery	<ul style="list-style-type: none"> • Sit in your chair for 4 or more hours. • Sit in your chair during your meals. • Walk to the bathroom and do all self-care activities, such as brushing your teeth and washing your face. • Walk 10 or more laps around the nursing unit.
4 days after surgery	<ul style="list-style-type: none"> • Sit in your chair for 5 or more hours. • Sit in your chair during your meals. • Walk 14 or more laps around the nursing unit (1 mile).

Exercising your lungs

It's important to exercise your lungs so they expand fully. This helps prevent pneumonia.

- Use your incentive spirometer 10 times every hour you're awake. Read *How to Use Your Incentive Spirometer* to learn more. You can find it in the "Educational resources" section of this guide.
- Do coughing and deep breathing exercises. A member of your care team will teach you how.

Eating and drinking

You may be able to start drinking liquids the day after your procedure. Depending on how your bowels are working, you will slowly start eating solid foods again over the next few days.

While you're recovering, your appetite may be smaller than it was before your surgery. Eat several small meals throughout the day instead of 3 large meals. Eating this way will help your digestion and give you energy throughout the day.

If you have questions about your diet, ask to see a clinical dietitian nutritionist.

Swelling and discharge

Right after surgery, you may have some swelling in your genitals and groin. You may also have some discharge from your penis or vagina. This is normal. The swelling and discharge should go away over a few weeks.

Learning to care for your ileal conduit

While you're in the hospital, your nurse will teach you how to care for your ileal conduit. They will also teach you how to care for any tubes or drains you will have at home. If your nurse gives you any written information, you can put it in this folder to review when you're at home.

It's very helpful if your caregiver also learns how to care for your ileal conduit. This will make it easier for them to help you at home.

Planning for discharge

You will have a case manager who will help you with your discharge planning (plan for leaving the hospital). They will work with you to arrange for a home care nurse to visit you after you're discharged from the hospital.

Before you leave the hospital, your nurse will give you enough supplies to care for yourself at home for about 3 weeks. They will also give you a list of companies you can contact to order more supplies. The nurse who works with your doctor will also help you order more supplies after you're discharged.

Leaving the hospital

Before you leave, look at your incision with one of your healthcare providers. Knowing what it looks like will help you notice any changes later.

On the day of your discharge, plan to leave the hospital around 11 a.m. Your healthcare provider will write your discharge order and prescriptions before you leave. You'll also get written discharge instructions. One of your healthcare providers will review them with you before you leave.

If your ride isn't at the hospital when you're ready to leave, you may be able to wait in the Patient Transition Lounge. A member of your care team will give you more information.

At home

Read *What You Can Do to Avoid Falling* to learn what you can do to keep from falling at home and during your appointments at MSK. You can find it at www.msk.org/pe/avoid_falling or ask for a printed copy.

A home care nurse will visit you when you're home from the hospital. They will keep track of how you're recovering. They will also help you practice caring for your ileal conduit. Read *About Your Urostomy* to learn more. You can find it in the "Educational resources" section of this guide.

The nurse that works with your doctor will call you 1 to 4 days after you're discharged to see how you're doing. They will also tell you when to schedule your first appointment after surgery.

Managing your pain

People have pain or discomfort for different lengths of time. You may still have some pain when you go home and will probably be taking pain medicine. Some people have soreness, tightness, or muscle aches around their incision for 6 months or longer. This doesn't mean something is wrong.

Follow these guidelines to help manage your pain at home.

- Take your medicine(s) as directed and as needed.
- Call your healthcare provider if the medicine prescribed for you does not help your pain.
- Do not drive or drink alcohol while you're taking prescription pain medicine. Some prescription pain medicines can make you drowsy (very sleepy). Alcohol can make the drowsiness worse.
- You'll have less pain and need less pain medicine as your incision heals. An over-the-counter pain reliever will help with aches and discomfort. Acetaminophen (Tylenol®) and ibuprofen (Advil® or Motrin®) are examples of over-the-counter pain relievers.
 - Follow your healthcare provider's instructions for stopping your prescription pain medicine.
 - Do not take too much of any medicine. Follow the instructions on the label or from your healthcare provider.
 - Read the labels on all the medicines you're taking. This is very important if you're taking acetaminophen. Acetaminophen is an ingredient in many over-the-counter and prescription medicines. Taking too much can harm your liver. Do not take more than one medicine that has acetaminophen without talking with a member of your care team.

- Pain medicine should help you get back to your usual activities. Take enough to do your activities and exercises comfortably. You may have a little more pain as you start to be more active.
- Keep track of when you take your pain medicine. It works best 30 to 45 minutes after you take it. Taking it when you first have pain is better than waiting for the pain to get worse.

Some prescription pain medicines, such as opioids, may cause constipation. Constipation is when you poop less often than usual, have a harder time pooping, or both.

Preventing and managing constipation

Talk with your healthcare provider about how to prevent and manage constipation. You can also follow these guidelines.

- Go to the bathroom at the same time every day. Your body will get used to going at that time. But if you feel like you need to go, don't put it off.
- Try to use the bathroom 5 to 15 minutes after meals. After breakfast is a good time to go. That's when the reflexes in your colon are strongest.
- Exercise, if you can. Walking is a great type of exercise that can help prevent and manage constipation.
- Drink 8 to 10 (8-ounce) cups (2 liters) of liquids daily, if you can. Choose water, juices (such as prune juice), soups, and milkshakes. Limit liquids with caffeine, such as coffee and soda. Caffeine can pull fluid out of your body.
- Slowly increase the fiber in your diet to 25 to 35 grams per day. Unpeeled fruits and vegetables, whole grains, and cereals contain fiber. If you have an ostomy or recently had bowel surgery, ask your healthcare provider before changing your diet.

- Both over-the-counter and prescription medicines can treat constipation. Ask your healthcare provider before taking any medicine for constipation. This is very important if you have an ostomy or have had bowel surgery. Follow the instructions on the label or from your healthcare provider. Examples of over-the-counter medicines for constipation are:
 - Docusate sodium (Colace®). This is a stool softener (medicine that makes your bowel movements softer) that causes few side effects. You can use it to help prevent constipation. Do not take it with mineral oil.
 - Polyethylene glycol (MiraLAX®). This is a laxative (medicine that causes bowel movements) that causes few side effects. Take it with 8 ounces (1 cup) of a liquid. Only take it if you're already constipated.
 - Senna (Senokot®). This is a stimulant laxative, which can cause cramping. It's best to take it at bedtime. Only take it if you're already constipated.

If any of these medicines cause diarrhea (loose, watery bowel movements), stop taking them. You can start again if you need to.

To learn more, read *Constipation*. You can ask for a printed copy or find it at www.msk.org/pe/constipation

Call your healthcare provider if you're not passing gas or if you haven't had a bowel movement in 3 days.

Diarrhea and other changes in bowel function

When part of your colon is removed, the part that's left adapts to the change. Your colon will start to adapt soon after your surgery. During this time, you may have gas, cramps, or changes in your bowel habits (such as

diarrhea or frequent bowel movements). These changes may take weeks to months to go away.

If you're having problems with changes in your bowel function, talk with your healthcare provider. You can also try the tips below.

Tips for managing gas

If you have gas or feel bloated, avoid foods that can cause gas. Examples include beans, broccoli, onions, cabbage, and cauliflower.

Tips for managing diarrhea

If you have diarrhea, it's important to drink at least 8 to 10 (8-ounce) cups of liquids every day. Drink water and drinks with salt, such as broth and Gatorade®. This will help you keep from becoming dehydrated and feeling weak.

Following the BRATY diet can also help control diarrhea. The BRATY diet is made up mostly of:

- Bananas (B)
- Rice (R)
- Applesauce (A)
- Toast (T)
- Yogurt (Y)

If you're having diarrhea more than 4 to 5 times a day, or if it smells worse than normal, call your doctor's office.

Tips for managing soreness

If you have soreness around your anus:

- Soak in warm water 2 to 3 times a day.

- Apply zinc oxide ointment (such as Desitin®) to the skin around your anus. This helps prevent irritation.
- Don't use harsh toilet tissue. You can use a nonalcohol wipe (such as a baby wipe) instead.
- Take medication, if your doctor prescribes it.

Caring for your incision

Take a shower every day to clean your incision. Follow the instructions in the "Showering" section below.

It's common for the skin below your incision to feel numb. This happens because some of your nerves were cut during your surgery. The numbness will go away over time.

Call your healthcare provider's office if:

- The skin around your incision is very red or getting more red.
- The skin around your incision is warmer than usual.
- The area around your incision is starting to swell or getting more swollen.
- You see drainage that looks like pus (thick and milky).
- Your incision smells bad.

If you go home with staples in your incision, your healthcare provider will take them out during your first appointment after surgery. It's OK to get them wet.

If you have Steri-Strips or Dermabond on your incision, they'll loosen and fall or peel off on their own. If they haven't fallen off after 10 days, you can take them off.

Showering



Take a shower every day to clean your incision. If you have staples or stitches in your incision, it's OK to get them wet.

Take your bandage(s) off before you shower. Use soap during your shower, but do not put it directly on your incision. Do not rub the area around your incision.

After you shower, pat the area dry with a clean towel. If your clothing may rub your incision, cover it with a small bandage. Otherwise, leave it uncovered.

Do not take a bath for the first 4 weeks after your surgery.

Eating and drinking

You can eat all the foods you did before your surgery, unless your healthcare provider gives you other instructions. Eating a balanced diet with lots of calories and protein will help you heal after surgery. Try to eat a good protein source (such as meat, fish, or eggs) at each meal. You should also try to eat fruits, vegetables, and whole grains.

To learn more, read *Eating Well During Your Cancer Treatment*. You can find it at www.msk.org/pe/eating_cancer_treatment or ask for a printed copy.

It's also important to drink plenty of liquids. Choose liquids without alcohol or caffeine. Try to drink 8 to 10 (8-ounce) cups of liquids every day. You should drink enough so that the urine in your pouch is very light yellow or clear. If it becomes dark yellow or orange, you need to drink more.

If you have questions about your diet, ask to see a clinical dietitian nutritionist.

Physical activity and exercise

Your incision may look like it's healed on the outside when you leave the hospital. It will not be healed on the inside.

- Do not lift anything heavier than 10 pounds (4.5 kilograms) for the first 6 to 8 weeks after your surgery.
- Do not do any high-energy activities (such as jogging and tennis) for the first 3 months after your surgery.
- Do not play any contact sports (such as football) for the first 3 months after your surgery.

Doing physical activity, such as walking and stair climbing, will help you gain strength and feel better. Try to get 20 to 30 minutes of physical activity at least 2 to 3 times a day. For example, you can walk outside or indoors at your local mall or shopping center.

To learn more, read *General Exercise Program: Level 2*. You can find it in the "Educational resources" section of this guide.

It's common to have less energy than usual after surgery. Recovery time is different for everyone. Do more activity each day as much as you can. Always balance activity periods with rest periods. Rest is an important part of your recovery.

Driving

Ask your healthcare provider when you can drive. Most people can start driving again 6 weeks after surgery. Do not drive while you're taking pain medicine that may make you drowsy.

You can ride in a car as a passenger at any time after you leave the hospital. To protect your stoma from your seatbelt, place a small pillow next to it. Your WOC nurse can give you more information.

Going back to work

Talk with your healthcare provider about your job. They'll tell you when it may be safe for you to start working again based on what you do. If you move around a lot or lift heavy objects, you may need to stay out a little longer. If you sit at a desk, you may be able to go back sooner.

Sexuality

Sexuality includes many aspects of caring and closeness. It isn't only having sex. You and your partner can build other forms of sexual and emotional expression. Most important, remember that your surgery doesn't change your feelings for each other. Sexual counseling to talk about these issues can help. To see a counselor at one of our sexual health clinics, ask a member of your care team for a referral.

The American Cancer Society (ACS) offers free booklets on cancer and sexual health called *Sex and the Adult Male with Cancer* and *Sex and the Adult Female with Cancer*. You can get copies by visiting the ACS website at www.cancer.org or by calling 800-ACS-2345 (800-227-2345).

You can't harm your stoma during sex as long as there isn't constant pressure on it. Don't put anything into the opening of your stoma.

Managing your feelings

You may have new and upsetting feelings after a surgery for a serious illness. Many people say they felt weepy, sad, worried, nervous, irritable, or angry at one time or another. You may find that you cannot control some of these feelings. If this happens, it's a good idea to seek emotional support. Your healthcare provider can refer you to MSK's Counseling Center. You can also reach them by calling 646-888-0200.

The first step in coping is to talk about how you feel. Family and friends can help. We can also reassure, support, and guide you. It's always a good idea to let us know how you, your family, and your friends are feeling emotionally. Many resources are available to you and your family. We're here to help you and your family and friends handle the emotional aspects of your illness. We can help no matter if you're in the hospital or at home.

Many people join MSK's online bladder cancer support group. To learn more about our support group, read the "Support services" section of this guide. To learn more about other resources, such as the Bladder Cancer Advocacy Network (BCAN), read the "External support services" section of this guide.

When to call your healthcare provider



Call your healthcare provider if:

- You have a fever of 101 °F (38.3 °C) or higher.
- You have chills.
- You have any bleeding. This includes bleeding at your incision site, bright red blood in your urine, or large blood clots in your urine.
- You have shortness of breath.
- The skin around your incision is very red or getting more red.
- The skin around your incision is warmer than usual.
- The area around your incision is starting to swell or getting more swollen.
- You have new drainage or more drainage than usual from your incision.
- You see drainage from your incision that looks like pus (thick and milky).
- Your catheter or drainage tubes are not draining.
- Your catheter or drainage tubes become dislodged or fall out.
- Your incision smells bad.
- You have increased pain.
- You have swelling or pain in your legs.
- You feel nauseous (like you're going to throw up) or you're vomiting (throwing up).

- You're not passing gas or haven't had a bowel movement in 3 days.
- You have lower urine output (when the amount you pee is less than usual).
- You have any problems you didn't expect.
- You have any questions or concerns.

Contact information

Monday through Friday from 9 a.m. to 5 p.m., call your healthcare provider's office.

After 5 p.m., during the weekend, and on holidays, call 212-639-2000. Ask to speak to the person on call for your healthcare provider.

Notes _____

Support services

This section has a list of support services. They may help you as you get ready for your surgery and recover after your surgery.



As you read this section, write down questions to ask your healthcare provider. You can use the space below.

Notes _____

Bladder cancer support group

This is a live, online support and education group for people who have bladder cancer or who have been treated for bladder cancer. People share their personal experiences and provide practical and emotional support for one another. Discussions are led by an MSK social worker, nurse, and WOC nurse.

This group meets the 2nd Thursday of each month from noon (12 p.m.) to 1 p.m. For more information or to register, contact your MSK social worker. You can also send a message to your care team through MSK's patient portal, MyMSK. They can connect you with an MSK social worker. A member of your care team will review your message and respond within 2 business days (Monday through Friday).

MSK support services

Admitting Office

212-639-7606

Call if you have questions about your hospital admission, such as asking for a private room.

Anesthesia

212-639-6840

Call if you have questions about anesthesia.

Blood Donor Room

212-639-7643

Call for information if you're interested in donating blood or platelets.

Bobst International Center

332-699-7968

We welcome patients from around the world and offer many services to help. If you're an international patient, call for help arranging your care.

Counseling Center

www.msk.org/counseling

646-888-0200

Many people find that counseling helps them. Our Counseling Center offers counseling for individuals, couples, families, and groups. We can also prescribe medicine to help if you feel anxious or depressed. Ask a member of your care team for a referral or call the number above to make an appointment.

Food Pantry Program

646-888-8055

We give food to people in need during their cancer treatment. Talk with a member of your care team or call the number above to learn more.

Integrative Medicine Service

www.msk.org/integrativemedicine

Our Integrative Medicine Service offers many services to complement (go along with) traditional medical care. For example, we offer music therapy, mind/body therapies, dance and movement therapy, yoga, and touch therapy. Call 646-449-1010 to make an appointment for these services.

You can also schedule a consultation with a healthcare provider in the Integrative Medicine Service. They'll work with you to make a plan for creating a healthy lifestyle and managing side effects. Call 646-608-8550 to make an appointment for a consultation.

MSK Library

library.mskcc.org

212-639-7439

You can visit our library website or call to talk with the library reference staff. They can help you find more information about a type of cancer. You can also visit the library's Patient and Health Care Consumer Education Guide at libguides.mskcc.org/patienteducation

Nutrition Services

www.msk.org/nutrition

212-639-7312

Our Nutrition Service offers nutritional counseling with one of our clinical dietitian nutritionists. Your clinical dietitian nutritionist will talk with you about your eating habits. They can also give advice on what to eat during and after treatment. Ask a member of your care team for a referral or call the number above to make an appointment.

Patient and Community Education

www.msk.org/pe

Visit our patient and community education website to search for educational resources, videos, and online programs.

Patient Billing

646-227-3378

Call if you have questions about preauthorization with your insurance company. This is also called preapproval.

Patient Representative Office

212-639-7202

Call if you have questions about the Health Care Proxy form or concerns about your care.

Perioperative Nurse Liaison

212-639-5935

Call if you have questions about MSK releasing any information while you're having surgery.

Private Duty Nurses and Companions

917-862-6373

You can request private nurses or companions to care for you in the hospital and at home. Call to learn more.

Rehabilitation Services

www.msk.org/rehabilitation

Cancers and cancer treatments can make your body feel weak, stiff, or tight. Some can cause lymphedema (swelling). Our physiatrists (rehabilitation medicine doctors), occupational therapists (OTs), and physical therapists (PTs) can help you get back to your usual activities.

- **Rehabilitation medicine doctors** diagnose and treat problems that affect how you move and do activities. They can design and help coordinate your rehabilitation therapy program, either at MSK or somewhere closer to home. Call Rehabilitation Medicine (Physiatry) at 646-888-1929 to learn more.
- An **OT** can help if you're having trouble doing usual daily activities. For example, they can recommend tools to help make daily tasks easier. A **PT** can teach you exercises to help build strength and flexibility. Call Rehabilitation Therapy at 646-888-1900 to learn more.

Resources for Life After Cancer (RLAC) Program

646-888-8106

At MSK, care does not end after your treatment. The RLAC Program is for patients and their families who have finished treatment.

This program has many services. We offer seminars, workshops, support groups, and counseling on life after treatment. We can also help with insurance and employment issues.

Sexual Health Programs

Cancer and cancer treatments can affect your sexual health, fertility, or both. MSK's sexual health programs can help you before, during, or after your treatment.

- Our **Female Sexual Medicine and Women's Health Program** can help with sexual health problems such as premature menopause or fertility

issues. Ask a member of your MSK care team for a referral or call 646-888-5076 to learn more.

- **Our Male Sexual and Reproductive Medicine Program** can help with sexual health problems such as erectile dysfunction (ED). Ask a member of your care team for a referral or call 646-888-6024 to learn more.

Social Work

www.msk.org/socialwork

212-639-7020

Social workers help patients, families, and friends deal with common issues for people who have cancer. They provide individual counseling and support groups throughout your treatment. They can help you communicate with children and other family members.

Our social workers can also help refer you to community agencies and programs. If you're having trouble paying your bills, they also have information about financial resources. Call the number above to learn more.

Spiritual Care

212-639-5982

Our chaplains (spiritual counselors) are available to listen, help support family members, and pray. They can contact community clergy or faith groups, or simply be a comforting companion and a spiritual presence. Anyone can ask for spiritual support. You do not have to have a religious affiliation (connection to a religion).

MSK's interfaith chapel is located near Memorial Hospital's main lobby. It's open 24 hours a day. If you have an emergency, call 212-639-2000. Ask for the chaplain on call.

Tobacco Treatment Program

www.msk.org/tobacco

212-610-0507

If you want to quit smoking, MSK has specialists who can help. Call to learn more.

Virtual Programs

www.msk.org/vp

We offer online education and support for patients and caregivers. These are live sessions where you can talk or just listen. You can learn about your diagnosis, what to expect during treatment, and how to prepare for your cancer care.

Sessions are private, free, and led by experts. Visit our website to learn more about Virtual Programs or to register.

External support services

There are many other services available to help you before, during, and after your cancer treatment. Some offer support groups and information. Others can help with transportation, lodging, and treatment costs.

Visit www.msk.org/pe/external_support_services for a list of these support services. You can also call 212-639-7020 to talk with an MSK social worker.

Bladder cancer support services

Bladder Cancer Advocacy Network

www.bcan.org

This website has bladder cancer education and resources, such as fact sheets, podcasts, and webinars. It also has bladder cancer support services, such as a toll-free support line and a list of support groups by state.

National Association for Continence

www.nafc.org

This website has information and resources for people with continence problems, such as incontinence supplies you can buy. It also has a directory that can refer you to doctors in your area who can treat your continence problems.

Wound, Ostomy, and Continence Nurses Society

www.wocn.org/learning-center/patient-resources

Visit this website to find a WOC nurse in your area. Please note that many WOC nurses can only see you if there's an outpatient clinic at their hospital or if you have a doctor at their hospital.

The website also has information on resources and support groups for people with wounds, ostomies, and continence problems.

Notes _____

Educational resources

This section lists the educational resources mentioned in this guide. It also has copies of the resources that are most important for you to read. They will help you get ready for your surgery and recover after your surgery.



As you read these resources, write down questions to ask your healthcare provider. You can use the space below.

Notes _____

These are the educational resources that were mentioned in this guide. You can find them online or ask a member of your care team for a printed copy.

- ***A Guide for Caregivers*** (www.msk.org/pe/guide_caregivers)
- ***About Your Urostomy*** (www.msk.org/pe/about_your_urostomy)
- ***Advance Care Planning for Cancer Patients and Their Loved Ones*** (www.msk.org/pe/advance_care_planning)
- ***Call! Don't Fall!*** (www.msk.org/pe/call_dont_fall)
- ***Constipation*** (www.msk.org/pe/constipation)
- ***Eating Well During Your Cancer Treatment*** (www.msk.org/pe/eating_cancer_treatment)
- ***Frequently Asked Questions About Walking After Your Surgery*** (www.msk.org/pe/walking_after_surgery)
- ***General Exercise Program: Level 2*** (www.msk.org/pe/general_exercise_2)
- ***Herbal Remedies and Cancer Treatment*** (www.msk.org/pe/herbal_remedies)
- ***How to Be a Health Care Agent*** (www.msk.org/pe/health_care_agent)
- ***How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil*** (www.msk.org/pe/check-med-supplement)
- ***How to Enroll in MyMSK: Memorial Sloan Kettering's Patient Portal*** (www.msk.org/pe/enroll_mymask)
- ***How To Use Your Incentive Spirometer*** (www.msk.org/pe/incentive_spirometer)
- ***Information for Family and Friends for the Day of Surgery*** (www.msk.org/pe/info_family_friends)
- ***Patient-Controlled Analgesia (PCA)*** (www.msk.org/pe/pca)
- ***What You Can Do to Avoid Falling*** (www.msk.org/pe/avoid_falling)

About Your Urostomy

This information will help you learn about your urostomy and urostomy pouching system.

Table of Contents

About Your Urostomy 2

About Your Urostomy Pouching System..... 2

 In the hospital..... 3

 At home 3

 Ordering supplies 4

 Ostomy accessory products..... 4

 Night drainage system..... 5

 Leg drainage bag..... 5

 Finding out about new products 5

Changing Your Urostomy Pouching System..... 6

Showering with Your Urostomy..... 7

Problems Related to Your Urostomy 7

 Skin problems..... 7

 Urinary tract infections (UTIs) 9

 Hernias 9

Traveling with Your Urostomy 10

Preparing for Medical Tests 10

 Imaging scan with contrast..... 10

 Chemotherapy 11

 Other procedures..... 11

Resources 11

About Your Urostomy

A urostomy is an opening in your abdomen (belly) where urine leaves your body. After your bladder surgery with a urostomy (ileal conduit), your urine (pee) will flow from your kidneys, through your ureters and ileal conduit, and out of a small opening in your abdomen called a stoma (see Figure 1).

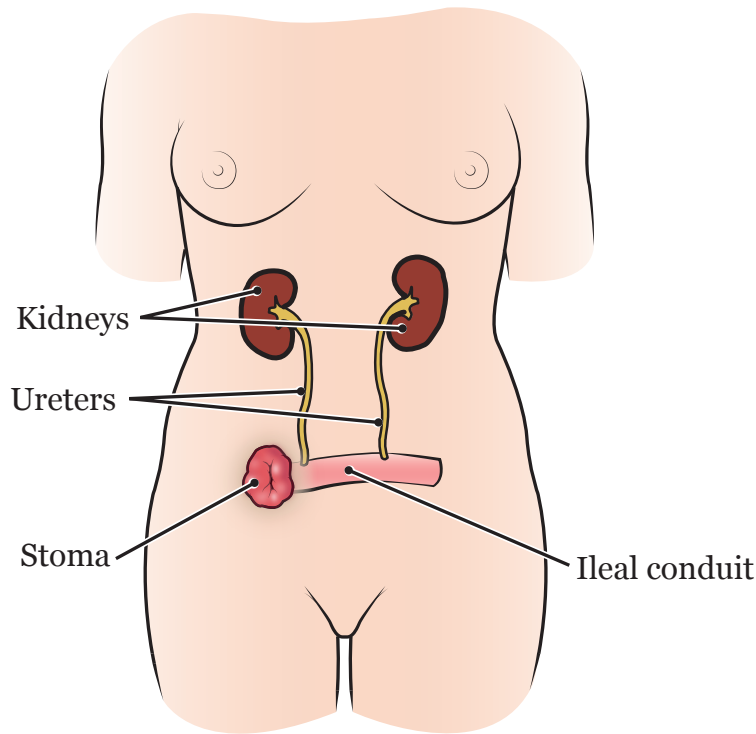


Figure 1. Your urinary system after your bladder surgery with a urostomy (ileal conduit)

Your stoma should be a deep pink or red color all the time. If your stoma looks grey, brown, or black, contact your doctor right away.

You won't be able to control the flow of urine from your stoma. You will wear a urostomy pouching system (appliance) over your stoma to catch and hold the urine.

There are a few different types of urostomy stomas. Your wound, ostomy, and continence (WOC) nurse will tell you which type you have and answer your questions.

About Your Urostomy Pouching System

A urostomy pouching system has 2 parts: a wafer (the part that sticks to your skin) and a pouch (the bag that holds your urine). With a 2-piece pouching system, the wafer and the pouch are separate pieces that can be taken apart. With a 1-piece system, the wafer and pouch are connected.

You will use different types of pouching systems in the hospital and at home. This is because your stoma will get smaller as it heals. It usually takes about 6 to 8 weeks for your stoma to get to its permanent size.

In the hospital

While you're in the hospital, you will learn how to care for your urostomy stoma and pouching system.

Most people use a 2-piece pouching system and an extender called a low-pressure adaptor while they're in the hospital. The low-pressure adaptor goes between the wafer and pouch to create extra space. This makes it easier for your doctor and nurses to take the pouch off the wafer and put it back on without pushing hard on your abdomen. It will help you be more comfortable when your doctor checks your stoma.

At home

After you're discharged from the hospital, you will use either a 2-piece or a 1-piece pouching system. A home care nurse will visit you to help you keep learning how to care for your stoma and pouching system.

You may use different pouching systems as your body heals and your stoma gets smaller. You will have appointments with an outpatient WOC nurse. They will look at your stoma with you, keep track of how your stoma is healing, and help you choose the pouching system and ostomy accessory products (products that you can use along with your pouching system) that are best for your body.

Follow-up appointments

Your first appointment with your outpatient WOC nurse will be 2 weeks after you're discharged from the hospital. It's also helpful to schedule follow-up appointments with your outpatient WOC nurse 2 to 3 months and 6 months after your surgery. You should also contact your WOC nurse if you have skin issues or questions about your pouching system.

You may lose some weight when you're first recovering after surgery. Over the 3 to 6 months after surgery, you will probably gain back some of this weight. During this time, you may notice some small changes in the shape of your abdomen. These changes can cause your pouching system to fit differently and be uncomfortable. If this happens, contact your WOC nurse. They can recommend a pouching system that's more flexible and moves with your body.

You may also want to choose a more flexible pouching system if your pouching system is uncomfortable when you bend, twist, or work out. Your WOC nurse will help you find a system that works best with your body and activities.

Always contact your doctor's office to tell them about your questions or concerns and to make an appointment with your WOC nurse.

After you're discharged from the hospital, contact your doctor's office if you need to speak with your WOC nurse.

If your WOC nurse isn't available when you contact your doctor's office, your doctor's office will give them your message and they will contact you.

Positioning your pouching system

Position your pouch so it points down and can be tucked into your pants or underwear. You can also fold it, if you prefer. You can also try special underwear or concealment bands such as those from www.ostomysecrets.com or www.steathbelt.com.

Wearing a belt or suspenders

You can wear a belt or suspenders on your pants when you're wearing your pouching system. If you choose to wear a belt, wear it above or below your stoma. If the belt is directly on your stoma, it may cause irritation, bleeding, or an overgrowth of tissue.

Preparing an emergency kit

Prepare a small emergency kit with a pre-cut wafer, a pouch, and several gauze pads. Keep the emergency kit with you at all times so you can change your pouch if it leaks.

Keep your emergency kit out of direct sunlight or heat.

Ordering supplies

Ostomy supply companies

There are 2 main types of ostomy supply companies.

- **Ostomy supply distributors** are companies that sell ostomy products. They sell supplies made by many different manufacturers. You will order your urostomy supplies from an ostomy supply distributor.
- **Ostomy supply manufacturers** are companies that make ostomy products. You can call an ostomy supply manufacturer for information about their products or to ask for a sample of their products. You can't buy products right from the manufacturer.

When to order supplies

Order more supplies when you have only 1 box of pouches or wafers left. You can order from one of the following ostomy supply distributors:

180 Medical 877-688-2729	Edgepark Medical Supplies 800-321-0591
Byram Healthcare 877-902-9726	McKesson 800-451-6510

Choose an ostomy supply distributor that accepts your health insurance. You can find out by calling the distributor.

Ostomy accessory products

There are many different ostomy accessory products. Examples of ostomy accessory products include:

- **Barrier ring:** This goes around the base of your stoma and helps the wafer fit better. It can help keep urine from leaking underneath the wafer.
- **Elastic barrier strips:** These go over the wafer and help keep it from coming off your skin. They also help to waterproof the wafer.
- **Ostomy belt:** This attaches to the wafer and wraps around your waist. It helps to secure the pouching system.
- **Stoma guard:** This goes over your stoma and pouching system to provide extra protection. It can be helpful if you play contact sports.

You probably won't need to use all of these accessory products. Your WOC nurse will give you more information about the accessory products that may be most useful for you.

Night drainage system

A night drainage system is a pouch or bottle that connects to the bottom of your pouch. It holds more urine than your normal pouch.

It's important to use a night drainage system when you sleep to keep your pouch from getting too full. If your pouch gets too full, it may leak, or urine may flow back into your stoma and cause an infection. Using a night drainage system can also help you avoid needing to get up at night to empty your pouch.

You will need to use an adaptor to connect the night drainage system to your pouch. The adaptor will be included in your box of pouches.

Caring for your night drainage system

Each morning, empty the urine from the night drainage bag or bottle into the toilet. After you empty the bag or bottle, wash the night drainage system. You can use warm water or a mixture of ¼ cup white vinegar and 1 cup water. You can also buy cleansers such as M9™ Crystallizer cleansing system. After you wash the night drainage system, let it air dry.

Replace your night drainage system every 2 to 4 weeks.

If you're having problems with your night drainage system tubing coming loose, you can tape the connections between the night drainage system and your pouch. If you move around a lot while you sleep, use a leg stabilizer or Foley® catheter holder. You can order these accessories when you order your supplies.

Leg drainage bag

A leg drainage bag is a pouch that holds more urine than your normal pouch. You may want to use a leg drainage bag if you're traveling or if you may not be able to get to a toilet to empty your pouch (such as when you're golfing or in a traffic jam).

Leg drainage bags may not be covered by your insurance plan. You can call the ostomy supply distributor to find out if leg drainage bags are covered by your insurance.

Caring for your leg drainage bag

When the pouch is getting full, empty the urine from the leg drainage bag into the toilet. After you empty the bag, wash it. You can use warm water or a mixture of ¼ cup white vinegar and 1 cup water. You can also buy cleansers such as M9™ Crystallizer cleansing system. After you wash the drainage bag, let it air dry.

Replace your leg drainage bag every week, no matter how many times you use it.

Finding out about new products

You can find out about new products by asking your WOC nurse, calling ostomy supply manufacturers and asking for samples of their latest products, or searching for urostomy products online. If you contact an ostomy supply manufacturer or search online, make sure you're looking at urostomy products, not fecal pouches.

You can also find out about new products by joining an online chat room or local support group for people with urostomies. Often, other people dealing with the same issues know of products that might meet your needs. Read the “Resources” section of this resource for a list of online support groups and websites to help you find local support groups. Make sure you talk with your WOC nurse before trying any new urostomy products.

Changing Your Urostomy Pouching System

You should change your pouching system about every 3 to 4 days. If urine is leaking from your pouching system, change it right away. It's best to change your pouching system in the morning before you drink any liquids. There's usually less urine coming out of your stoma in the morning.

The first few times you change your pouching system, you will be in your hospital bed. As you heal, you can start changing your pouching system wherever you're most comfortable. Many people like to stand in the bathroom in front of the mirror. You can also remove your pouching system and clean around your stoma as part of your normal shower routine.

For more information about changing your pouching system, read the resource *Changing Your Two-Piece Disposable Urostomy Appliance* (www.mskcc.org/pe/2_piece_urostomy_appliance).

What to do if you see blood on your stoma

Your stoma has many blood vessels and may bleed easily. It's normal to see a small amount of blood on the gauze or tissue when you're cleaning the stoma. The bleeding should stop on its own within a few minutes. If you take a blood thinner or aspirin, you may bleed more easily and for a longer time. Apply pressure to your stoma to help stop the bleeding.



Call your doctor if the bleeding doesn't stop after 10 to 15 minutes. You may need to go to MSK's Urgent Care Center or your local emergency room. Your doctor will tell you what to do.

Call your doctor right away if there's blood in your urine or coming from the inside of your stoma.

About wearing gloves

You can decide if you want to wear gloves when you change your pouching system. Just as you didn't wear gloves when urinating (peeing) before your urostomy, you don't need to wear them now. However, you may prefer to wear gloves when you change your pouch because some urine could get on your fingers.

Showering with Your Urostomy

It's very important that you shower every day. This will help keep your skin clean.

Your pouching system is waterproof. Keep your pouching system on while you shower, except on the days you're changing your pouching system. On the days you're changing your pouching system, you can take your pouching system off and shower without it, if you choose. Urine will keep flowing from your stoma while you shower.

Shower the same way you did before your surgery. Don't use perfumed or oil-based soaps around your stoma.

Problems Related to Your Urostomy

Contact your doctor's office if you have any of the problems below. They will share your message with your WOC nurse, and your WOC nurse will reach out to you.

Skin problems

Tell your WOC nurse if you have any problems with the skin around your stoma (peristomal skin). The most common skin problems happen if urine gets under the wafer or if you have allergies to your ostomy products.

- If urine is leaking under your wafer, change the wafer right away. Don't use tape to stop the leakage.
- If the leakage doesn't stop after you change your wafer, contact your WOC nurse. You may need a different system that fits better to avoid leakage.

Tissue build-up

One common skin problem is a build-up of tissue on the skin around your stoma. The tissue may look greyish, purplish, wart-like, or have white spots (see Figure 2). It can cause pain around your stoma. The build-up is caused when your skin is exposed to urine all the time. If you have tissue build-up, call your doctor's office to make an appointment with your WOC nurse.

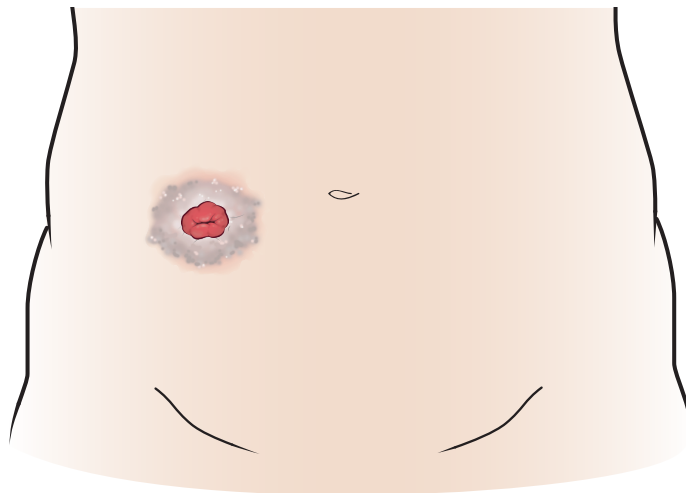


Figure 2. Tissue build-up around your stoma

If you're having problems with tissue build-up around your stoma, you may need to:

- Cut or mold your wafer or get a different pre-cut wafer.
- Use a different type of wafer.
- Apply a barrier to your wafer (such as a Colly-Seel™ disc, Coloplast Brava® Protective Seal, or Coloplast Brava moldable ring).

You may also need to treat the skin right around your stoma each time you change your pouching system. To do this:

1. Mix $\frac{1}{4}$ cup of white vinegar with $\frac{3}{4}$ cup of water.
2. Soak a gauze pad in the mixture. Place the gauze pad on your skin for 20 minutes.
3. Rinse your skin with water.
4. Dry your skin well and apply a new wafer.

Allergic reaction

Another common skin problem is an allergic reaction. If you're allergic to one of the ostomy products you're using, you may have redness or welts on the skin around your stoma (see Figure 3). You may also have itching, burning, or discomfort. If you think you're having an allergic reaction, call your doctor's office. You may need to see a dermatologist (skin doctor).

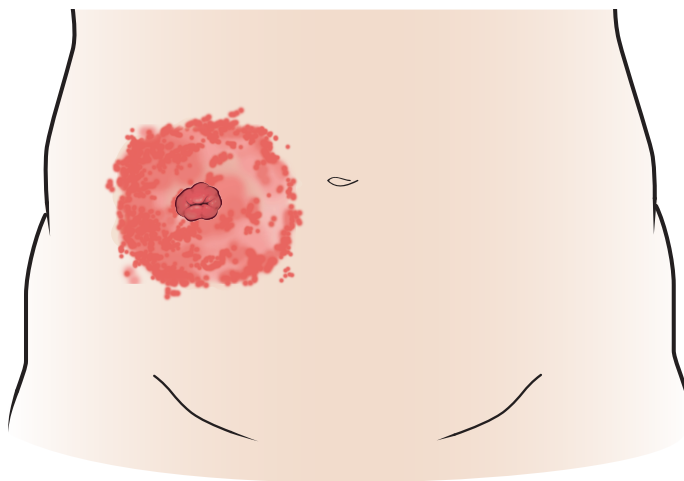


Figure 2. Tissue build-up around your stoma

If you're having an allergic reaction, you will need to try a different brand of wafer and pouch.

Rash

If you develop a rash, tell your doctor or WOC nurse. They will give you suggestions for how to treat it.

Urinary tract infections (UTIs)

The signs and symptoms of a UTI are:

- Urine that smells worse than usual
- Cloudy urine
- Back pain
- Nausea (feeling like you're going to throw up) and vomiting (throwing up)
- Loss of appetite
- Temperature of 100.4 °F (38 °C) or higher (fever)

If you think you have a UTI, call your doctor's office.

To keep from getting a UTI:

- Drink 6 to 8 (8-ounce) glasses of liquids every day. It's best to drink water.
- Limit the amount of alcohol and caffeine you drink.
- Use a pouch that has an antireflux valve, and use a night drainage system. This keeps urine from sitting on your stoma and causing an infection.
- Empty your pouch when it's $\frac{1}{3}$ to $\frac{1}{2}$ full.

You can also ask your doctor if you can take vitamin C (about 500 to 1,000 milligrams) and a sugar-free cranberry pill daily. These will make your urine more acidic and may help prevent UTIs, decrease your urine's odor (smell), and keep your skin from being damaged.

Hernias

A hernia is when a loop of bowel (intestine) pokes through a weak area of muscle. This causes a bulge to form. Hernias often don't cause any symptoms. If you see a bulge around your stoma, contact your doctor or WOC nurse.

Tips to avoid getting a hernia

Often, the abdominal muscle around your stoma is weak. To minimize the risk of developing a hernia, avoid constipation (straining to pass bowel movements), coughing a lot or very strongly, heavy lifting, or straining.

It takes up to a year for the inside of your body to heal after surgery, so pay attention to how your body feels. If you feel pain during any activities, stop doing them. Call your doctor's office if the pain doesn't go away.

Treating a hernia

If you have a hernia, your WOC nurse can suggest a hernia support belt. These belts are made to fit your body. You can also use a girdle or biking shorts to support the hernia. If you use these, you will need to cut out a hole for your urostomy pouch.

Using a hernia support belt, girdle, or biking shorts won't cure the hernia or keep it from getting worse. But, they can make you feel more comfortable and pull in the bulge to help your clothes fit better.

Hernias usually aren't treated unless they become blocked, twisted, or cause pain or other problems. Call your doctor right away if you have:

- Nausea
- Vomiting
- Pain in your abdomen
- Swelling in your abdomen

Traveling with Your Urostomy

Your travel decisions shouldn't be based on the fact that you have a urostomy. Here are some tips to help you manage traveling with your pouching system:

- Bring extra supplies, just in case you have trouble getting them while you're away.
- If you're taking an airplane, train, or bus, carry your supplies with you. Don't put them in your checked luggage. This will help you be prepared if you're separated from your luggage.
- Avoid driving a car for 4 to 6 weeks after your surgery, unless your doctor tells you otherwise. You may wear a seat belt loosely or place a small pillow over your stoma and under your seat belt. You can also use an ostomy seat belt protector. Check with your distributor or ask your WOC nurse for more information.
- Discuss travel options with your WOC nurse. You may want to use a leg bag if you think you may have trouble getting to a toilet to empty your bag.
- If you're traveling by airplane, you may want to get a travel card from the United Ostomy Associations of America (UOAA) by visiting www.ostomy.org/uploaded/files/travel_card/Travel_Communication_Card.pdf.

For more information, visit the UOAA webpage at www.ostomy.org or call 800-826-0826.

Preparing for Medical Tests

Always bring extra urostomy supplies with you. Many pharmacies and medical centers don't have urostomy supplies, and you may need an extra set.

Imaging scan with contrast

If you're having a scan with contrast, bring an extra set of urostomy supplies, as well as a leg bag or night drainage system. For the scan, you will need to drink more liquids than usual. This will help the contrast leave your body, but it will also increase the amount of urine your body makes. You may need to change your pouching system if you have a leak because you're making more urine than usual.

If you live an hour or more away from the hospital, empty your bag before leaving. You may also need to empty it on the trip home or use a leg bag. You may also want to keep a portable urinal or other container in your car in case of an emergency.

Chemotherapy

If you're having chemotherapy, bring an extra set of urostomy supplies. Chemotherapy may cause your body to make more urine. It may also make your skin more sensitive or change the way the wafer sticks to your skin. You may need to change your wafer more often during chemotherapy to protect your skin and prevent leakage.

Other procedures

If you're having a procedure where the doctor or nurse needs to access your stoma, you may need to switch to a different type of pouching system. For example, you may need to switch from a 1-piece system to a 2-piece system. Your doctor or nurse will talk with you before the procedure.

If you have any problems, contact your WOC nurse.

Resources

MSK Support Groups

Bladder Cancer Support Group

646-422-4628 or 646-888-8106

This is a live, in-person support and education group for people who have bladder cancer or who have been treated for bladder cancer. People share their personal experiences and provide practical and emotional support for one another. Discussions are led by a social worker, nurse, and WOC nurse.

This group meets the 2nd Thursday of each month from 12:00 to 1:30 PM. For more information, or to register, call the numbers above or email RLAC@mskcc.org.

Online Bladder Cancer Support Group

This is a live, online support and education group for people undergoing treatment for bladder cancer. People share their personal experiences and provide practical and emotional support for one another. Discussions are led by a social worker and a WOC nurse.

This group meets the 4th Thursday of each month from 4:00 to 5:00 PM. For more information, or to register, email virtualprograms@mskcc.org.

Resources for Finding WOC Nurses

Wound Ostomy and Continence Nurses Society

www.wocn.org/patients

Visit this website to find a WOC nurse in your area.

You can also call your ostomy supply manufacturer or distributor to ask for information about WOC nurses in your area.

Please note that many WOC nurses can only see you if there's an outpatient clinic at their hospital or if you have a doctor at their hospital.

Resources for Finding Urostomy Support Groups

United Ostomy Associations of America (UOAA)

www.ostomy.org

Visit this website to find an ostomy support group, including both online support groups and groups in your area. You can also find tips for traveling with an ostomy and download the UOAA's Travel Communication Card.

Bladder Cancer Advocacy Network (BCAN)

www.bacn.org

Visit this website for information about bladder cancer. To join an online support group sponsored by the BCAN, go to www.inspire.com/groups/bladder-cancer-advocacy-network.

Inspire

www.inspire.com

Visit this website to find online ostomy support groups.

Resources for Managing Skin Irritation Around Your Stoma

Peristomal Skin Assessment Guide

<http://psag-consumer.wocn.org>

Visit this website if the skin around your stoma is irritated. On the website, you will answer a series of questions to find out more about the type of skin irritation you have and what you can do to manage it. **Remember to always contact your WOC nurse if you think the skin around your stoma is irritated.**

Resources for Ostomy Supplies

Contact the ostomy supply manufacturer that makes the pouching system you're using. Every ostomy supply manufacturer has an assistance program for their supplies. Some manufacturers also have WOC nurses that can help you.

Some ostomy supply distributors also have a WOC nurse who can help you. Call your distributor for more information.

Resources for Ostomy Concealment Garments

Ostomy concealment garments are clothes to make your pouching system less noticeable.

Ostomysecrets

www.ostomysecrets.com

Visit this website to buy ostomy garments.

Stealth Belt

www.stealthbelt.com

Visit this website to buy ostomy garments.

C&M Ostomy Supplies

www.cmostomysupply.com

Visit this website to buy ostomy garments, including pouch covers and stoma guards.

Safe n' Simple

www.sns-medical.com/products/support-belts

Visit this website to buy a hernia support belt.



PATIENT & CAREGIVER EDUCATION

General Exercise Program: Level 2

This information explains Level 2 of a general exercise program that will help you with your physical recovery.

This exercise program works the major muscle groups that you use for everyday activities. Regular exercise with resistance (from gravity, elastic bands, or hand weights) will help you:

- Get back to doing your everyday activities.
- Increase your muscle strength.

You should also do other exercises, such as walking, to help build your strength. Your rehabilitation (rehab) therapist may change your exercise program to meet your needs. Talk with your healthcare provider before you start this program.

Exercise Tips

- Dress comfortably. You should wear clothing that won't limit your movements. You can wear a hospital gown, pajamas, or athletic clothing.
- Breathe in through your nose and out through your mouth. Do the exercise movements when you breathe out.
- Don't hold your breath while doing any of these exercises. Count out loud during the exercises to keep your breaths evenly paced.
- Do some of the exercises in front of a mirror to keep the right form and posture.
- Your therapist may give you an elastic exercise band (Thera-Band®). Use the

band for resistance during the exercises. Follow your therapist's instructions.

- Move slowly through all movements. Slow, controlled movements will:
- Use more muscle fibers.
- Help you strengthen every part of your muscle.
- Put as much effort into releasing from the movement as you did starting it. Do this especially during strengthening exercises.
- For example, when doing bicep curls, lower your arm as slowly and with as much control as when you lifted it. When you lower your arm in this way, it's called a "lengthening contraction." This strengthens the muscle more than just doing an upward curl.
- Stop any exercise that causes you pain or discomfort and tell your physical therapist. You can continue to do the other exercises.

Special Instructions

Exercises

Bridging

1. Lie on your back with both knees bent and your feet on the bed. Keep your arms at your sides (see Figure 1).



Figure 1. Lying on your back with your knees bent

2. Tighten the muscles in your abdomen (belly) and buttocks.
3. Push through your feet and lift your buttocks 3 to 4 inches off the bed (see Figure 2).



Figure 2. Pushing up through your feet

4. Hold the position for 5 seconds.
5. Then, slowly lower your buttocks back onto the bed.
6. Repeat 10 times.

Mini squats

1. While standing, hold on to the back of a stable chair, locked bed rail, or handrail in the hallway for balance.
2. Place your feet 6 to 12 inches away from the bed or counter. Your feet should be shoulder-width apart. Keep your back straight (see Figure 3)



Figure 3. Bending your hips and knees

3. Slowly bend your hips and knees until your knees are at about a 45-degree angle (see Figure 3).
4. Hold this position for 5 seconds.
5. Slowly straighten your hips and knees until you're standing upright.
6. Repeat 10 times.

Heel raises

1. While standing, hold on to the back of a stable chair, locked bed rail, or handrail in the hallway for balance.
2. Place your feet about 6 inches apart.
3. Slowly push up onto your toes, lifting your heels off of the floor (see Figure 4).

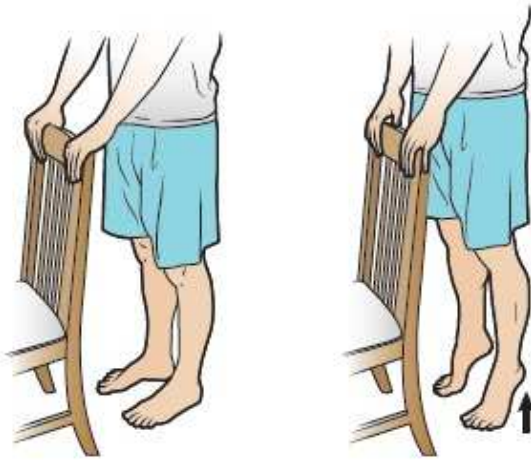


Figure 4. Lifting your heels off the floor

4. Hold the position for 5 seconds.
5. Slowly lower your heels back down to the floor.
6. Repeat 10 times.

Standing hamstring curls

1. While standing, hold on to the back of a stable chair, locked bed rail, or handrail in the hallway for balance.
2. Bend your left knee, bringing your heel toward your buttocks. Keep your knees even with each other (see Figure 5). Stand tall and don't bend your hips.



Figure 5. Bending your knee

3. Lower your foot back down to the floor.
4. Repeat 10 times
5. Repeat with your right leg.

Standing hip extensions

1. While standing, hold on to the back of a stable chair, locked bed rail, or handrail in the hallway for balance.
2. Extend your left leg behind you at the hip, while keeping your knee straight. Stand up straight (see Figure 6). Don't lean forward.



Figure 6. Extending your leg behind you

3. Hold for 5 seconds.
4. Bring your leg forward to rest on the floor next to your other leg.
5. Repeat 10 times.
6. Repeat with your right leg.

Standing side kicks

1. Hold on to the backrest of a stable chair, a locked bed rail, or handrail in the hallway for balance. Stand up straight. Don't lean to the side or forward.
2. Lift your right leg out to the side while keeping your toe pointed forward (see

Figure 7).

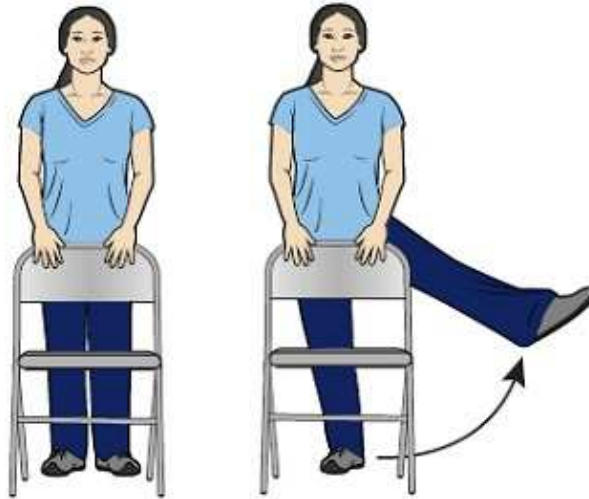


Figure 7. Lifting your leg to the side

3. Hold for 5 seconds.
4. Bring your raised leg back in to meet your other leg.
5. Repeat 10 times
6. Repeat the exercise with your left leg.

Arm raises

1. Sit or stand comfortably with your back straight, shoulders back, and your head facing forward.
2. Raise your arms out to the side, up to the level of your shoulders, while keeping your elbows straight (see Figure 8).

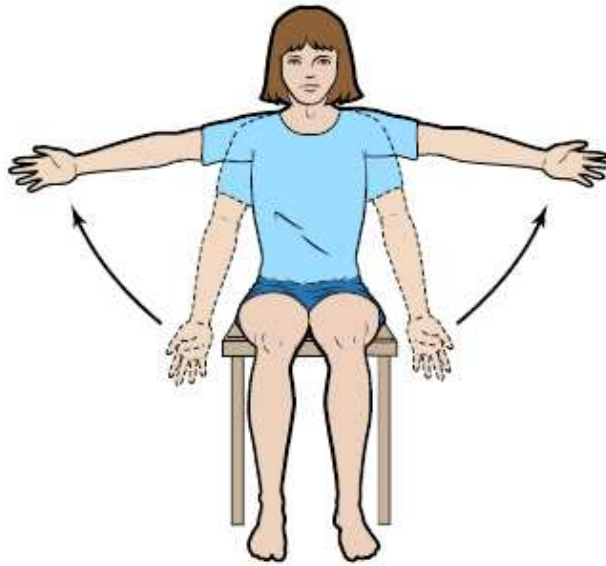


Figure 8. Raising your arms out to the side

3. Hold for 5 seconds.
4. Lower your arms to your sides.
5. Repeat this 10 times.

Tricep extensions

1. Sit comfortably with your back straight, shoulders back, and head facing forward.
2. Pick up an elastic exercise band with both hands. Position your hands in front of your chest with your elbows raised out to your sides, parallel with the floor (see Figure 9).

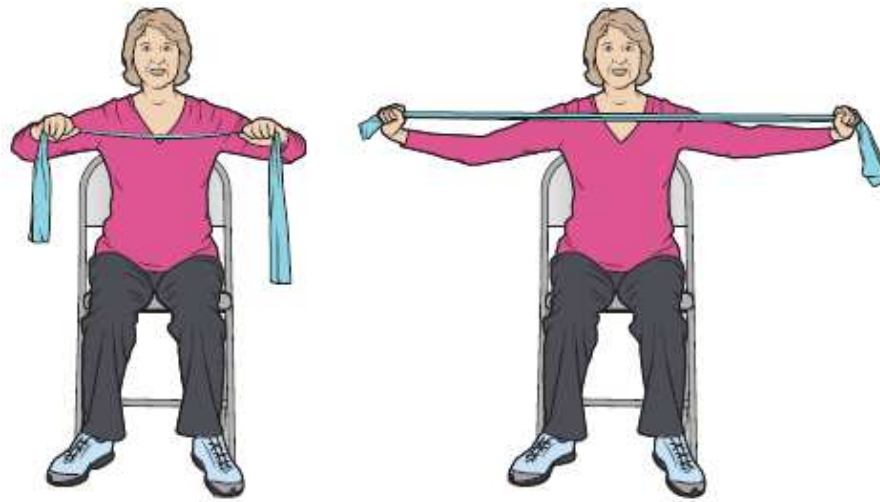


Figure 9. Stretching your arms out using an elastic band

3. Straighten your elbows fully until your arms are extended out to your sides. Keep the stretched band at chest level (see Figure 9).
4. Bend your elbows and slowly bring your hands back in toward your chest while keeping your upper arms raised.
5. Repeat 10 times.

Bicep curls

1. Sit comfortably with your back straight, shoulders back, and your head facing forward. Keep your right arm straight with your elbow at your side.
2. Place one end of the exercise band under your right foot. Hold the other end of the band with your right hand (see Figure 10).



Figure 10. Bicep curls with an elastic band

3. With your arm close to your side, bend your elbow, bringing your hand toward your right shoulder (see Figure 10).
4. Hold for 5 seconds.
5. Lower your hand back down to the starting position.
6. Repeat 10 times.
7. Repeat with your left hand and left foot.

Scapular retractions

1. Sit comfortably with your back straight, shoulders back, and head facing forward.
2. Hold the ends of the exercise band in each hand. Raise your arms to shoulder height, keeping your elbows bent with your hands in front of your chest. Stretch out the exercise band to provide resistance (see Figure 11).

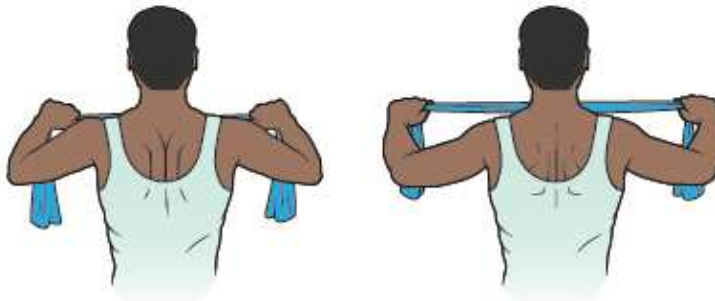


Figure 11. Moving your arms back and squeezing your shoulder blades together

3. Move your arms back so that they are slightly behind you while squeezing your shoulder blades together (see Figure 11).
4. Hold for 5 seconds.
5. While keeping your arms raised, bring them forward so that your hands are in front of your chest again.
6. Repeat 10 times.

Seated push-ups

1. Sit comfortably in a chair with armrests. Keep your back straight, shoulders back, and head facing forward.
2. Place your hands on the armrests of the chair. Place your feet shoulder distance apart, right below your knees.
3. Position yourself as if you're going to stand up (see Figure 12).



Figure 12. Lifting your body off your seat

4. Straighten your elbows and lift your buttocks off the seat until your elbows are straight. Lift your buttocks as high as you can, even if you can't get off the chair completely (see Figure 12).
5. Slowly lower yourself back onto the seat of your chair as you bend your elbows.
6. Repeat 10 times.

If you have any questions, contact a member of your healthcare team directly.
If you're a patient at MSK and you need to reach a provider after 5:00 PM,
during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

General Exercise Program: Level 2 - Last updated on February 28, 2021

All rights owned and reserved by Memorial Sloan Kettering Cancer Center

PATIENT & CAREGIVER EDUCATION

Herbal Remedies and Cancer Treatment

This information explains herbal remedies and how they can affect your treatment.

About Herbal Remedies

Herbal remedies are any herbs, botanical (plant-based) supplements, or dietary supplements you take for their health benefits. These may come as tablets, capsules, powders, teas, liquid extracts, and fresh or dried plants.

Some herbal remedies can help prevent or manage side effects of cancer or your treatment. The herbal remedies that can help you depend on what symptoms you have and what treatment you're getting.

Even though herbal remedies can feel safe, they may not all be safe. Herbal remedies do not go through the same testing as prescription medications to make sure they work and are safe.

Some herbal remedies may be harmful. This is because they can:

- Affect how your other medications work.
- Raise or lower your blood pressure.
- Thin your blood and increase your risk of bleeding.
- Keep radiation therapy from working as well as it should.
- Change how your body reacts to sedation (medication to make you calmer) or general anesthesia (medication to make you sleepy).

Talk with your healthcare provider about any herbal remedies or other

supplements you are taking. They can provide an open and safe space to talk about these products.

For more information about herbs and supplements, visit www.abouterbs.com or call MSK's Integrative Medicine Service at 646-608-8550.

Stop taking herbal remedies before your treatment

Stop taking herbal remedies and other dietary supplements 7 days (1 week) before you:

- Have surgery.
- Start chemotherapy.
- Start radiation therapy.
- Have certain procedures. Your healthcare provider will let you know if you need to stop taking herbal remedies before your procedure.

Herbal remedies and other dietary supplements can cause bleeding and affect your treatment. Follow your healthcare provider's instructions for when to restart taking herbal remedies.

You can still use some herbs in your food and drinks, such as using spices in cooking and drinking tea. Herbal remedies are stronger than the herbs you cook with.

Common Herbal Remedies and Their Effects

These are some commonly used herbs and their side effects on cancer treatments.

Echinacea (EH-kih-NAY-shuh)

- Can cause rare but serious allergic reactions, such as a rash or trouble breathing.
- Can keep medications that weaken your immune system from working as well as they should.

Garlic

- Can lower your blood pressure and cholesterol levels.
- Can increase your risk of bleeding.

Ginkgo (also known as Ginkgo biloba)

- Can increase your risk of bleeding.

Ginseng (JIN-seng)

- Can keep sedation or general anesthesia from working as well as they should.
- Can increase your blood pressure.
- Can increase your risk of bleeding.
- Can lower your blood glucose (sugar) level.

Turmeric (TER-mayr-ik)

- Can keep chemotherapy from working as well as it should.

St. John's Wort

- Can keep some medications from working as well as they should.
- Can make your skin more sensitive to radiation or laser treatment.

Valerian (vuh-LEER-ee-un)

- Can make sedation or general anesthesia affect you more than they should.

Herbal formulas

- Herbal formulas contain many different herbs and dosages.
- Stop taking these products 7 days (1 week) before treatment. Do not start taking herbal formulas again until your healthcare provider tells you it is safe.

This information does not cover all herbal remedies or possible side effects. Talk with your healthcare provider if you have any questions or concerns.

Contact Information

- To schedule a consultation with a healthcare provider in Integrative Medicine, call 646-608-8550.
- To make an appointment for Integrative Medicine Service's therapies, classes, and workshops, call 646-449-1010.

For more information, visit www.mskcc.org/IntegrativeMedicine or read *Integrative Medicine Therapies and Your Cancer Treatment* (www.mskcc.org/pe/integrative_therapies).

For more resources, visit www.mskcc.org/pe to search our virtual library.

Herbal Remedies and Cancer Treatment - Last updated on May 5, 2022

All rights owned and reserved by Memorial Sloan Kettering Cancer Center



PATIENT & CAREGIVER EDUCATION

How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil

This information will help you check if your medicines or dietary supplements have aspirin, other NSAIDs, vitamin E, or fish oil as an active ingredient. NSAID stands for nonsteroidal anti-inflammatory drug.

It's important to stop taking these medicines and supplements before many cancer treatments. They affect your platelets (blood cells that clot to prevent bleeding) and can raise your risk of bleeding.

Other dietary supplements, such as vitamins and herbal remedies, can also affect your cancer treatment. Read *Herbal Remedies and Cancer Treatment* (www.mskcc.org/pe/herbal_remedies) to learn more.

Make sure your healthcare provider always knows all the prescription and over-the-counter medicines and supplements you're taking. This includes patches and creams.

A prescription medicine is one you can only get with a prescription from your healthcare provider. An over-the-counter medicine is one you can buy without a prescription.

What is an active ingredient?

An active ingredient is the part of a medicine or supplement that makes it work. Some medicines and supplements have just one active ingredient. Others have more. For example:

- Ibuprofen is the active ingredient in Advil® and Motrin®. Ibuprofen is an NSAID.
- Naproxen is the active ingredient in Aleve®. Naproxen is an NSAID.
- Acetaminophen is the active ingredient in Tylenol®.
- Aspirin, acetaminophen, and caffeine are the active ingredients in Excedrin®.

Generic medicines sometimes use their active ingredient as their name. But people often call medicines and supplements by a brand name, even if they're generic. This can make it hard to know their active ingredients.

How to find a medicine or supplement's active ingredients

You can always find the active ingredients by reading the label.

Over-the-counter medicines

Over-the-counter medicines list their active ingredients in the “Drug Facts” label (see Figure 1). Active ingredients are always the first thing on the Drug Facts label.

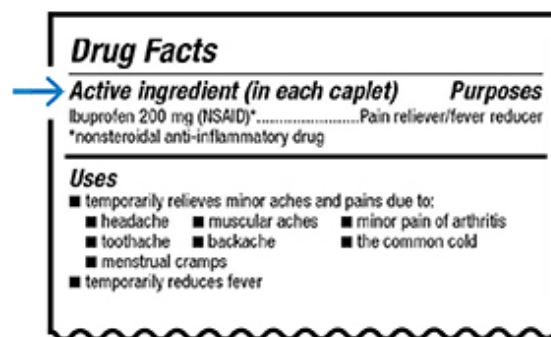


Figure 1. Active ingredients on an over-the-counter medicine label

Prescription medicines

Prescription medicines list their active ingredients on the label. Their active ingredients and their generic name are the same thing.

Labels often look different depending on which pharmacy you use. Here's an example of where to find a medicine's active ingredients (generic name) on a label from MSK's pharmacy (see Figure 2).

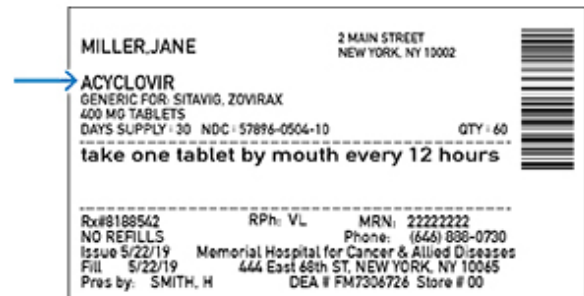


Figure 2. Active ingredients on a prescription medicine label

Dietary supplements

Dietary supplements list their active ingredients in the "Supplement Facts" label (see Figure 3). The active ingredients always have an amount per serving and % daily value included.

Supplement Facts		
Serving Size 1 Tablet		
	Amount Per Serving	% Daily Value
Vitamin A (as retinyl acetate and 50% as beta-carotene)	5000 IU	100%
Vitamin C (as ascorbic acid)	60 mg	100%
Vitamin D (as cholecalciferol)	400 IU	100%
Vitamin E (as di-alpha tocopheryl acetate)	30 IU	100%
Thiamin (as thiamin mononitrate)	1.5 mg	100%
Riboflavin	1.7 mg	100%
Niacin (as niacinamide)	20 mg	100%
Vitamin B ₆ (as pyridoxine hydrochloride)	2.0 mg	100%
Folate (as folic acid)	400 mcg	100%
Vitamin B ₁₂ (as cyanocobalamin)	6 mcg	100%
Biotin	30 mcg	10%
Pantothenic Acid (as calcium pantothenate)	10 mg	100%
Other ingredients: Gelatin, lactose, magnesium stearate, microcrystalline cellulose, FD&C Yellow No. 6, propylene glycol, propylparaben, and sodium benzoate.		

Figure 3. Active ingredients on a supplement label

Active ingredients to look for

If your medicine or supplement has any of these active ingredients, you may need to stop taking it before, during, or after your cancer treatment or surgery. Follow your care team's instructions.

Active ingredients to look for		
<ul style="list-style-type: none">• Acetylsalicylic acid• Alpha-linolenic acid (ALA)• Aspirin• Acetaminophen*• Celecoxib• Diclofenac• Diflunisal• Docosahexaenoic acid (DHA)• Eicosapentaenoic acid (EPA)	<ul style="list-style-type: none">• Etodolac• Fish oil• Fenoprofen Flurbiprofen• Ibuprofen• Indomethacin• Ketoprofen• Ketorolac• Meclofenamate• Mefenamic acid• Meloxicam	<ul style="list-style-type: none">• Nabumetone• Naproxen• Omega-3 fatty acids• Omega-6 fatty acids• Oxaprozin• Piroxicam• Sulindac• Tolmetin• Vitamin E

* The full name acetaminophen isn't always written out. Look for the common abbreviations listed below, especially on prescription pain relievers.

Common abbreviations for acetaminophen		
<ul style="list-style-type: none">• APAP• Acetamin	<ul style="list-style-type: none">• AC• Acetam	<ul style="list-style-type: none">• Acetaminop• Acetaminoph

About acetaminophen (Tylenol)

In general, acetaminophen is safe to take during cancer treatment. It doesn't affect platelets. That means it will not raise your chance of bleeding. If you're getting chemotherapy, talk with your healthcare provider before taking acetaminophen.

There is a limit to how much acetaminophen you can take in a day. Always follow the instructions from your care team or on the medicine's label.

Acetaminophen is in many different prescription and over-the-counter medicines. It's possible to take too much without knowing. **Always read the label on the medicines you take.** Do not take more than 1 medicine that has acetaminophen at a time without talking with a member of your care team.

Instructions before your cancer treatment

Tell your healthcare provider if you take aspirin, other NSAIDs, vitamin E, or fish oil. They'll tell you if you need to stop taking it. You'll also find instructions in the information about your treatment.

Before your surgery

Follow these instructions if you're having surgery or a surgical procedure. **If your healthcare provider gives you other instructions, follow those instead.**

- If you take aspirin or a medicine that has aspirin, you may need to change your dose or stop taking it 7 days before your surgery. Follow your healthcare provider's instructions. **Do not stop taking aspirin unless your healthcare provider tells you to.**
- If you take vitamin E, fish oil, or a supplement that has vitamin E or fish oil, stop taking it 7 days before your surgery or as directed by your healthcare provider.
- If you take an NSAID or a medicine that has an NSAID, stop taking it 48 hours (2 days) before your surgery or as directed by your healthcare provider.

Before your radiology procedure

Follow these instructions if you're having a radiology procedure (including Interventional Radiology, Interventional Mammography, Breast Imaging, and General Radiology). **If your healthcare provider gives you other instructions, follow those instead.**

- If you take aspirin or a medicine that has aspirin, you may need to stop taking it 5 days before your procedure. Follow your healthcare provider's instructions. **Do not stop taking aspirin unless your healthcare provider tells you to.**
- If you take an NSAID or a medicine that has an NSAID, you may need to stop taking it 24 hours (1 day) before your procedure. Follow your healthcare provider's instructions.

Before and during your chemotherapy

Chemotherapy can lower your platelet count, which can increase your risk of bleeding. No matter if you're just starting chemotherapy or have been getting it, talk with your healthcare provider before taking aspirin, other NSAIDs, vitamin E, or fish oil.

If you have any questions, contact a member of your care team directly. If you're a patient at MSK and you need to reach a provider after 5 p.m., during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil - Last updated on November 29, 2023

All rights owned and reserved by Memorial Sloan Kettering Cancer Center



PATIENT & CAREGIVER EDUCATION

How To Use Your Incentive Spirometer

This information will help you learn how to use your incentive spirometer (in-SEN-tiv spy-rah-MEE-ter). It also answers some common questions about it.

About your incentive spirometer

After your surgery you may feel weak and sore, and it may be uncomfortable to take deep breaths. Your healthcare provider may recommend using a device called an incentive spirometer (see Figure 1). It helps you practice taking deep breaths.

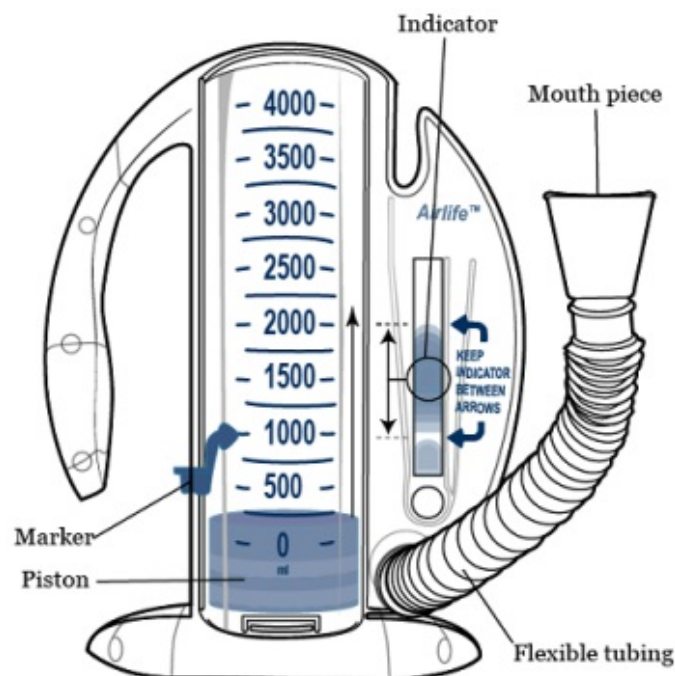


Figure 1. Parts of an incentive spirometer

It's important to use your incentive spirometer after your surgery. Using an incentive spirometer:

- Helps your lungs expand so you can take deep, full breaths.
- Exercises your lungs and makes them stronger as you heal from surgery.

If you have a respiratory infection, do not use your incentive spirometer around other people. A respiratory infection is an infection in your nose, throat, or lungs, such as pneumonia (noo-MOH-nyuh) or COVID-19. This kind of infection can spread from person to person through the air.

How to use your incentive spirometer

Here is a video that shows how to use your incentive spirometer:



Please visit www.mskcc.org/pe/incentive_spirometer_video to watch this video.

Setting up your incentive spirometer

Before you use your incentive spirometer for the first time, you will need to set it up. First, take the flexible (bendable) tubing out of the bag and stretch it out. Then, connect the tubing to the outlet on the right side of the base (see Figure 1). The mouthpiece is attached to the other end of the tubing.

Knowing what number to aim for on your incentive spirometer

Your healthcare provider will teach you how to use your incentive spirometer before you leave the hospital. They will help you set a goal and tell you what number to aim for when using your spirometer. If a goal was not set for you, talk with your healthcare provider. Ask them what number you should aim for.

You can also check the package your incentive spirometer came in. It may have a chart to help you figure out what number to aim for. To learn more, read “What number I should aim for?” in the “Common questions about your

incentive spirometer” section.

Using your incentive spirometer

When using your incentive spirometer, make sure to breathe through your mouth. If you breathe through your nose, your spirometer will not work right.

Follow these steps to use your incentive spirometer. Repeat these steps every hour you’re awake. Follow the instructions from your healthcare provider if they’re different from the ones here.

1. Sit upright in a chair or in bed. Hold your incentive spirometer at eye level.
2. Put the mouthpiece in your mouth and close your lips tightly around it. Make sure you do not block the mouthpiece with your tongue.
3. With the mouthpiece in your mouth, breathe out (exhale) slowly and fully.
 - Some people may have trouble exhaling with the mouthpiece in their mouth. If you do, take the mouthpiece out of your mouth, and then exhale slowly and fully. After you exhale, put the mouthpiece back in your mouth and go on to step 4.
4. Breathe in (inhale) slowly through your mouth, as deeply as you can. You will see the piston slowly rise inside the spirometer. The deeper you breathe in, the higher the piston will rise.
5. As the piston rises, the coaching indicator on the right side of the spirometer should also rise. It should float between the 2 arrows (see Figure 1).
 - The coaching indicator measures the speed of your breath. If it does not stay between the 2 arrows, you’re breathing in either too fast or too slow.
 - If the indicator rises above the higher arrow, you’re breathing in too fast. Try to breathe in slower.
 - If the indicator stays below the lower arrow, you’re breathing in too slow. Try to breathe in faster.

6. When you cannot breathe in any further, hold your breath for at least 3 to 5 seconds. Hold it for longer if you can. You will see the piston slowly fall to the bottom of the spirometer.
7. Once the piston reaches the bottom of the spirometer, breathe out slowly and fully through your mouth. If you want, you can take the mouthpiece out of your mouth first and then breathe out.
8. Rest for a few seconds. If you took the mouthpiece out of your mouth, put it back in when you're ready to start again.
9. Repeat steps 1 to 8 at least 10 times. Try to get the piston to the same level with each breath. After you have done the exercise 10 times, go on to step 10.
10. Use the marker on the left side of the spirometer to mark how high the piston rises (see Figure 1). **Look at the very top of the piston, not the bottom. The number you see at the top is the highest number the piston reached. Put the marker there.** This is how high you should try to get the piston the next time you use your spirometer.
 - Write down the highest number the piston reached. This can help you change your goals and track your progress over time.

Take 10 breaths with your incentive spirometer every hour you're awake.

Cover the mouthpiece of your incentive spirometer when you're not using it.

Tips for using your incentive spirometer

Follow these tips when using your incentive spirometer:

- If you had surgery on your chest or abdomen (belly), it may help to splint your incision (surgical cut). To do this, hold a pillow firmly against your incision. This will keep your muscles from moving as much while you're using your incentive spirometer. It will also help ease pain at your incision.
- If you need to clear your lungs, you can try to cough a few times. As

you're coughing, hold a pillow against your incision, as needed.

- If you feel dizzy or lightheaded, take the mouthpiece out of your mouth. Then, take a few normal breaths. Stop and rest for a while, if needed. When you feel better, you can go back to using your incentive spirometer.
- You may find it hard to use your incentive spirometer at first. If you cannot make the piston rise to the number your healthcare provider set for you, it's OK. Reaching your goal takes time and practice. It's important to keep using your spirometer as you heal from surgery. The more you practice, the stronger your lungs will get.

Common questions about your incentive spirometer

How often should I use my incentive spirometer?

How often you will need to use your incentive spirometer is not the same for everyone. It depends on the type of surgery you had and your recovery process.

Most people can take 10 breaths with their spirometer every hour they're awake.

Your healthcare provider will tell you how often to use your spirometer. Follow their instructions.

How long after my surgery will I need to use my incentive spirometer?

The length of time you will need to use your incentive spirometer is not the same for everyone. It depends on the type of surgery you had and your recovery process.

Your healthcare provider will tell you how long you need to use your spirometer. Follow their instructions.

How do I clean my incentive spirometer?

An incentive spirometer is a disposable device and only meant to be used for a short time. Because of this, you may not find cleaning instructions in the package your spirometer came in. If you have questions about cleaning your spirometer, talk with your healthcare provider.

What do the numbers on my incentive spirometer measure?

The large column of your incentive spirometer has numbers on it (see Figure 1). These numbers measure the volume of your breath in milliliters (mL) or cubic centimeters (cc). The volume of your breath is how much air you can breathe into your lungs (inhale).

For example, if the piston rises to 1500, it means you can inhale 1500 mL or cc of air. The higher the number, the more air you're able to inhale, and the better your lungs are working.

What number I should aim for?

The number you should aim for depends on your age, height, and sex. It also depends on the type of surgery you had and your recovery process. Your healthcare provider will look at these things when setting a goal for you. They will tell you what number to aim for.

Most people start with a goal of 500 mL or cc. Your healthcare provider may change your goal and have you aim for higher numbers as you heal from surgery.

The package your incentive spirometer came in may have a chart. You can use the chart to set your goal based on your age, height, and sex. If you cannot find this information, ask your healthcare provider what your goal should be.

What does the coaching indicator on my incentive spirometer measure?

The coaching indicator on your incentive spirometer measures the speed of your breath. As the speed of your breath changes, the indicator moves up and down.

Use the indicator to guide your breathing. If the indicator rises above the higher arrow, it means you're breathing in too fast. If the indicator stays below the lower arrow, it means you're breathing in too slow.

Aim to keep the indicator between the 2 arrows (see Figure 1). This means your breath is steady and controlled.

When to call your healthcare provider

Call your healthcare provider if you have any of these when using your incentive spirometer:

- Feel dizzy or lightheaded.
- Pain in your lungs or chest.
- Severe (very bad) pain when you take deep breaths.
- Trouble breathing.
- Coughing up blood.
- Fluid or blood coming from your incision site when you cough.
- Trouble using your spirometer for any reason.

If you have any questions, contact a member of your care team directly. If you're a patient at MSK and you need to reach a provider after 5 p.m., during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

How To Use Your Incentive Spirometer - Last updated on November 24, 2023

All rights owned and reserved by Memorial Sloan Kettering Cancer Center