



# About Your Total Pelvic Exenteration

This guide will help you get ready for your total pelvic exenteration (eg-ZEN-teh-RAY-shun) 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.

## Your surgery

Surgery date: \_\_\_\_\_

Surgery location: Presurgical Center (PSC) on the 6th floor  
1275 York Ave. (between East 67th and East 68th streets)  
New York, NY 10065  
Take the B elevator to the 6th floor.

Expected discharge date: \_\_\_\_\_

It's best to plan your ride home from the hospital ahead of time. This will help you keep from waiting for your ride after you're discharged from (leave) the hospital. For more information, read the section "Leaving the hospital."



Visit [www.msk.org/pe/total-pelvic-exenteration](http://www.msk.org/pe/total-pelvic-exenteration) to view this guide online.

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*How To Use Your Incentive Spirometer*

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# About your total pelvic exenteration

A total pelvic exenteration is a surgery to remove organs from your urinary, gastrointestinal, and gynecologic systems. You may be having this surgery because you have cancer in your cervix or another organ in your urinary, gastrointestinal, or gynecologic systems.

## About your urinary system

Your urinary system is made up of organs that make urine (pee) and get it out of your body. It includes your:

- Kidneys. These filter toxins out of your blood and make urine.
- Ureters. These carry urine from your kidneys to your bladder.
- Bladder. This stores your urine until you feel like you need to urinate.
- Urethra. This carries urine from your bladder out of your body. In females, it's located in front of the vagina.

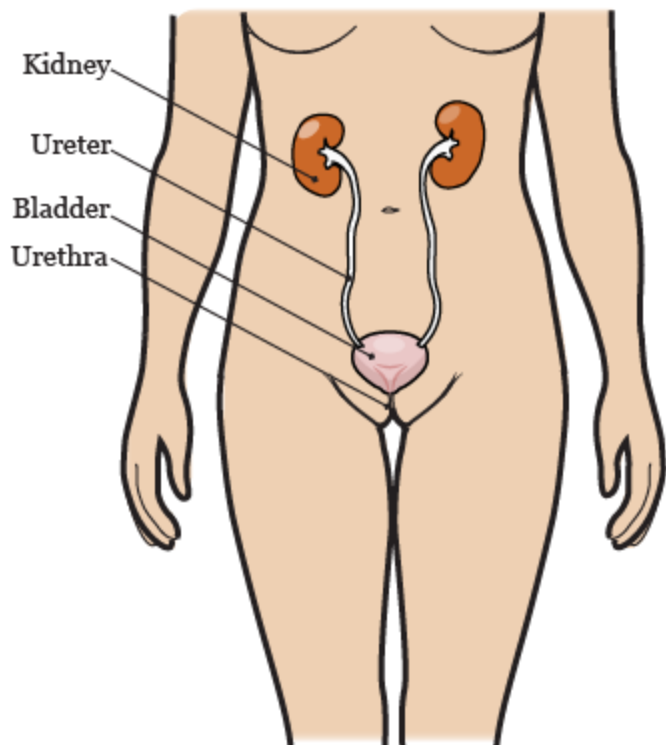


Figure 1. Your urinary system

Figure 1 shows the parts of your urinary system.

During your surgery, your surgeon will remove your bladder and urethra. This means you'll need a new place for urine to leave your body. Your surgeon will connect your ureters to a new urinary collection system called a urinary diversion or urostomy.

## Types of urinary diversions

There are 2 types of urinary diversions: an ileal conduit and a urinary pouch. Each type opens onto your abdomen (belly). The opening is called a stoma.

- With an ileal conduit, your urine will drain into a bag that you put around your stoma. You'll drain the bag as needed.
- With a urinary pouch, you'll put a drainage catheter (thin, flexible tube) into the stoma several times a day to drain your urine.

Your healthcare provider will talk with you about which urinary diversion you'll have. Your nurse will give you a resource that describes the type of diversion you'll have. They'll also teach you how to care for it.

# About your gastrointestinal system

Your gastrointestinal system includes your:

- Mouth
- Esophagus (food pipe)
- Small intestine
- Colon (large intestine)
- Rectum (bottom end of your colon)
- Anus

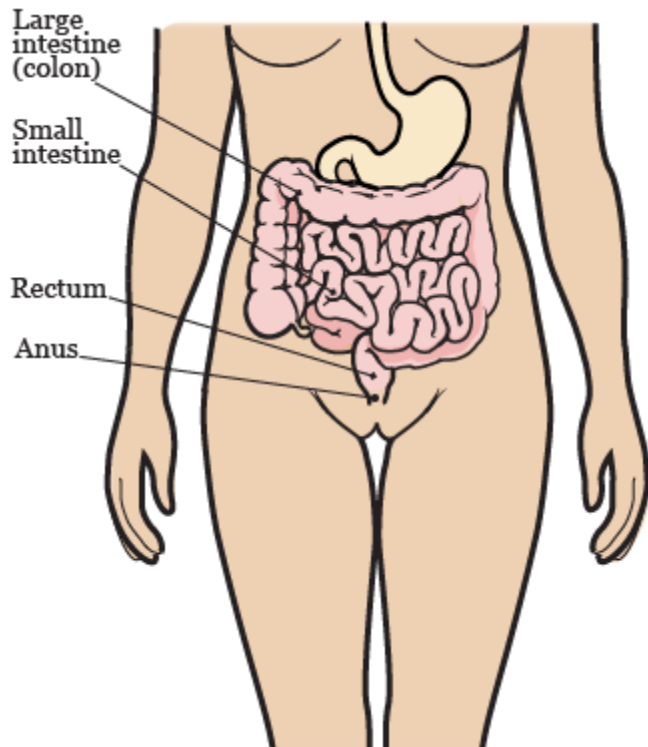


Figure 2 shows the parts of your gastrointestinal system.

During your surgery, your surgeon will remove part of your colon. They'll also remove your rectum and anus. This means you'll need a new place for stool (poop) to leave your body.

Figure 2. Your gastrointestinal system

Your surgeon will bring the end of your remaining colon to the outside of your abdomen (belly). This creates a colostomy, which is a new place for stool to leave your body. The opening itself is called a stoma. A pouch will cover the stoma to collect your stool.

Your healthcare team will teach you how to care for your stoma as you recover. Read *Caring for Your Ileostomy or Colostomy* to learn more about living with a colostomy. You can find it in the “Educational resources” section of this guide.

# About your gynecologic system

Your gynecologic system includes your:

- Ovaries
- Fallopian tubes
- Uterus
- Cervix
- Vagina

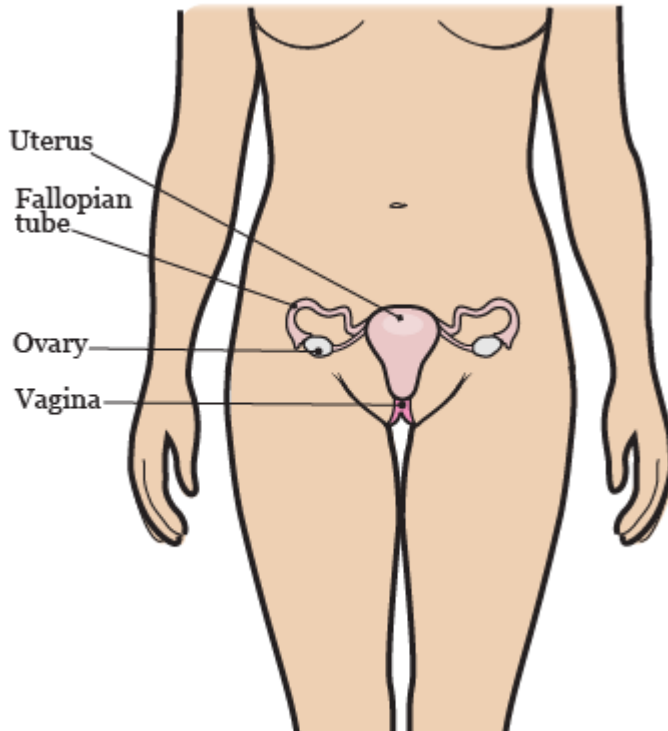


Figure 3 shows the parts of your gynecologic system.

During your surgery, your surgeon will remove your ovaries, fallopian tubes, uterus, and cervix. This means you

Figure 3. Your gynecologic system

won't be able to have children naturally. If you'd like information about fertility (ability to get pregnant) options and your cancer treatment, read *Fertility Preservation Before Cancer Treatment: Options for People Born with Ovaries and a Uterus*. You can ask for a printed copy or find it [www.msk.org/pe/fertility\\_starting\\_treatment](http://www.msk.org/pe/fertility_starting_treatment)

Your surgeon may also remove all or part of your vagina during your surgery. They'll talk with you about this if it's needed.

For some people, the vagina can be reconstructed. Ask your surgeon if this is an option for you. If it is, you'll meet with a plastic surgeon to discuss this surgery. The reconstruction would be done at the end of your surgery. Your plastic surgeon will create a new vaginal canal from the muscles and skin of other areas of your body. Your nurse will tell you about how to care for your



new vagina. If you don't want your vagina reconstructed, the area can be closed or covered with a flap of skin.

If your vagina isn't removed, you should be able to have vaginal intercourse (sex). If you have vaginal reconstruction, you should be able to have vaginal intercourse again when the area heals. If you don't have vaginal reconstruction, remember that sex can include other forms of intimacy. Ask your surgeon if your clitoris will be removed and how much feeling you'll still have in your vaginal area.

Your healthcare providers will tell you what to expect after surgery. For example, sensations in your vaginal area may not be the same as they were before your surgery. Your surgeon can refer you to our Female Sexual Medicine and Women's Health Program so you can meet with a therapist and discuss your concerns.

## Meeting with your healthcare team

You'll see many different healthcare providers before your surgery. Each one will describe their role in your care and answer your questions. You may see team members such as:

- Surgeons from other departments who will work with your surgeon to complete your surgery.
- A psychologist who works with people having this surgery.
- A wound, ostomy, and continence (WOC) nurse who will talk with you about the stoma you'll have.

It may be helpful for you to write down questions as you think of them. Bring your list of questions to your appointments.

You may also be able to speak with someone who has had the surgery. Your social worker can help plan this for you.





# 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](http://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](http://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](http://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\\_mymsk](http://www.msk.org/pe/enroll_mymsk) to learn more. You can also contact the MyMSK Help Desk by emailing [mymask@mskcc.org](mailto:mymask@mskcc.org) or calling 800-248-0593.

## Within 30 days of your 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.

Visit [www.msk.org/parking](http://www.msk.org/parking) for parking information and directions to all MSK locations.

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](http://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](http://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](http://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](http://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.

## 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.

## 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 bowel prep supplies, if needed

Your healthcare provider may tell you to do a bowel prep (clear the stool from your body) before your surgery. If they do, they'll tell you what to do.

Your healthcare provider will give you a prescription for antibiotics to take as part of your bowel prep. You'll also need to buy the following supplies:

- 1 (238-gram) bottle of polyethylene glycol (MiraLAX®). You can buy this at your local pharmacy. You don't need a prescription.
- 1 (64-ounce) bottle of a clear liquid. For examples of clear liquids, read the "Follow a clear liquid diet, if needed" section.
- Extra clear liquids to drink while you're following a clear liquid diet.

## 7 days before your 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 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 surgery

## Follow a clear liquid diet, if needed

Your healthcare provider will tell you if you need to follow a clear liquid diet the day before your surgery. A clear liquid diet includes only liquids you can see through. You can find examples in the “Clear liquid diet” table.

While you’re following a clear liquid diet:

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

## How to follow a clear liquid diet if you have diabetes

Ask the healthcare provider who manages your diabetes:

- What to do while you’re following a clear 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 clear liquids.

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

## Clear liquid diet

	OK to have	Do not have
Soups	<ul style="list-style-type: none"> <li>• Clear broth, bouillon, and consommé.</li> </ul>	<ul style="list-style-type: none"> <li>• Anything with pieces of food or seasoning.</li> </ul>
Sweets	<ul style="list-style-type: none"> <li>• Gelatin, such as Jell-O®.</li> <li>• Flavored ices.</li> <li>• Hard candies, such as Life Savers®, lemon drops, and peppermints.</li> </ul>	<ul style="list-style-type: none"> <li>• All others.</li> </ul>
Drinks	<ul style="list-style-type: none"> <li>• Clear fruit juices, such as lemonade, apple, cranberry, and grape juices.</li> <li>• Soda, such as ginger ale, 7UP®, Sprite®, and seltzer.</li> <li>• Sports drinks, such as Gatorade® and Powerade®.</li> <li>• Black coffee.</li> <li>• Tea.</li> <li>• Water, including carbonated (fizzy) and flavored water.</li> <li>• Clear nutritional drinks, such as Boost® Breeze, Ensure Clear™, Pedialyte®, and Diabetishield®.</li> </ul>	<ul style="list-style-type: none"> <li>• Juices with pulp.</li> <li>• Nectars.</li> <li>• Smoothies or shakes.</li> <li>• Milk, cream, and other dairy products.</li> <li>• Nut milks, plant milks, non-dairy creamers, and other dairy alternatives.</li> <li>• Drinks with alcohol.</li> </ul>

## Start your bowel prep, if needed

Your healthcare provider will tell you if you need to do a bowel prep the day before your surgery. If you do, follow these instructions.

The morning of the day before your surgery, mix all 238 grams of MiraLAX with 64 ounces of clear liquid until the MiraLAX powder dissolves. Once the powder is dissolved, you can put the mixture in the refrigerator if you want to.

At 5 p.m. on the day before your surgery, start drinking the MiraLAX mixture. It will cause frequent bowel movements, so make sure you're near a bathroom.

- Drink 1 (8-ounce) cup of the mixture every 15 minutes until it's gone.
- When you finish the MiraLAX mixture, drink 4 to 6 cups of clear liquids.
- Apply zinc oxide ointment or Desitin® to the skin around your anus after every bowel movement. This helps prevent irritation.

At 7 p.m. on the day before your surgery, take your antibiotics as instructed.

At 10 p.m. on the day before your surgery, take your antibiotics as instructed.

## 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.

Visit [www.msk.org/parking](http://www.msk.org/parking) for parking information and directions to all MSK locations.

## 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



Stop eating at midnight (12 a.m.) the night before your surgery. This includes hard candy and gum.

If your healthcare provider told you to stop eating earlier than midnight, follow their instructions. Some people need to fast (not eat) for longer before their surgery.

# The day of your surgery

## Instructions for drinking

Between midnight (12 a.m.) and 2 hours before your arrival time, only drink the liquids on the list below. Do not eat or drink anything else. Stop drinking 2 hours before your arrival time.

- Water.
- Clear apple juice, clear grape juice, or clear cranberry juice.
- Gatorade or Powerade.
- Black coffee or plain tea. It's OK to add sugar. Do not add anything else.
  - Do not add any amount of any type of milk or creamer. This includes plant-based milks and creamers.
  - Do not add honey.
  - Do not add flavored syrup.

If you have diabetes, pay attention to the amount of sugar in these drinks. It will be easier to control your blood sugar levels if you include sugar-free, low-sugar, or no added sugar versions of these drinks.

It's helpful to stay hydrated before surgery, so drink if you are thirsty. Do not drink more than you need. You will get intravenous (IV) fluids during your surgery.



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.
- 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

- 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.

## 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](http://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-THEE-zee-AH-loh-jist) will do it in the operating room.

## 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. They'll also place a urinary (Foley) catheter in your bladder. It will drain your urine (pee) during your surgery.

Once your surgery is finished, your surgeon will close your incisions with staples or sutures (stitches). They may also place Steri-Strips™ (thin pieces of surgical tape) or Dermabond® (surgical glue) over them and cover them with a bandage.

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

# After your total pelvic exenteration

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.

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# 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](http://www.msk.org/pe/pca) or ask for a printed copy.

## Tubes and drains

You'll have many tubes, drains, pouches, and bandages on your abdomen (see Figure 4). They may include:

- Jackson-Pratt (JP) drains to drain fluid from around your incisions. They'll be removed when your incisions stop draining.
- A catheter to drain urine from your urinary pouch.

- A drainage tube at the incision site. This serves as a safety catheter. It's placed in case the catheter in your urinary pouch gets blocked or comes out. It will be clamped shut.
- A colostomy pouch on your colostomy stoma to collect stool.
- A urostomy pouch on your ileal conduit stoma to collect urine.

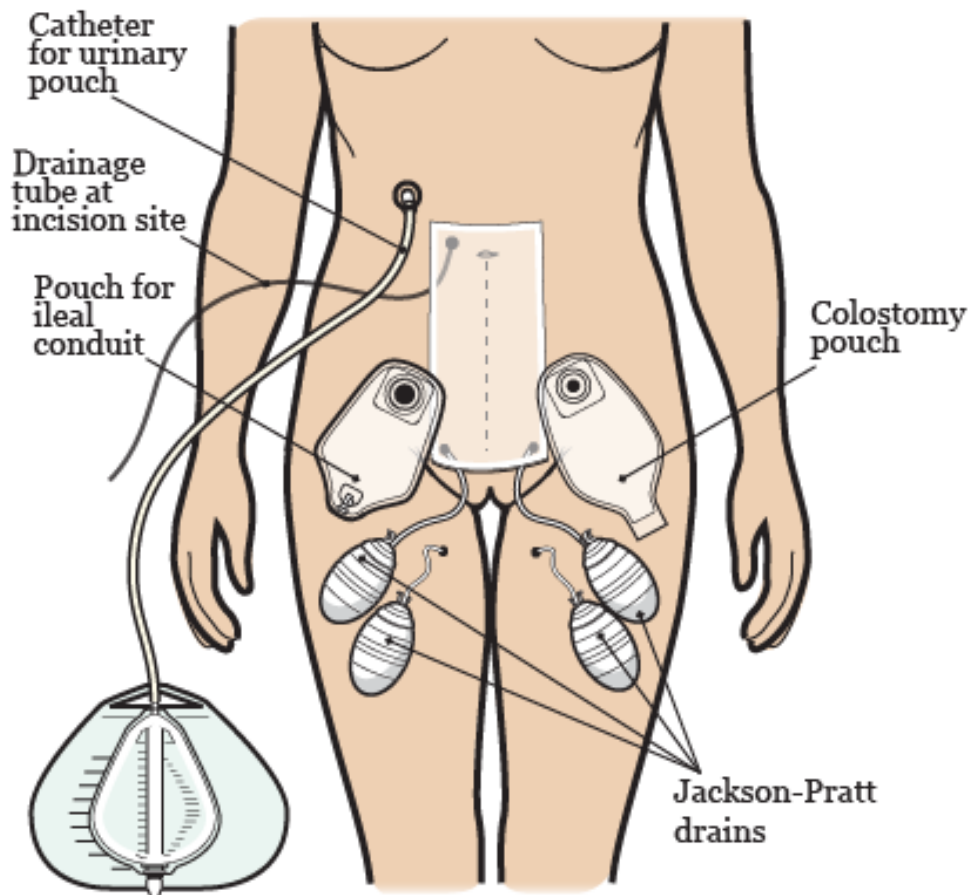


Figure 4. Drains, pouches, and bandages after your surgery

You'll also have:

- Bandages and drains on your upper inside thighs if you had your vagina reconstructed.
- An IV line to give you fluids.
- Compression boots on your calves to help your blood flow. You'll wear these whenever you're in bed.

Your abdomen and colostomy stoma will become more swollen over the next few days, and then the swelling will go down.

Most of the drains and tubes will be removed over the next days to weeks. In about 3 to 6 weeks, most people will have either 1 stoma for a urinary pouch or a pouch for the ileal conduit. Your colostomy stoma will also be covered with a pouch to collect the stool (see Figure 5).

Your WOC nurse and other nursing staff will teach you how to care for your stomas and pouches as you recover.

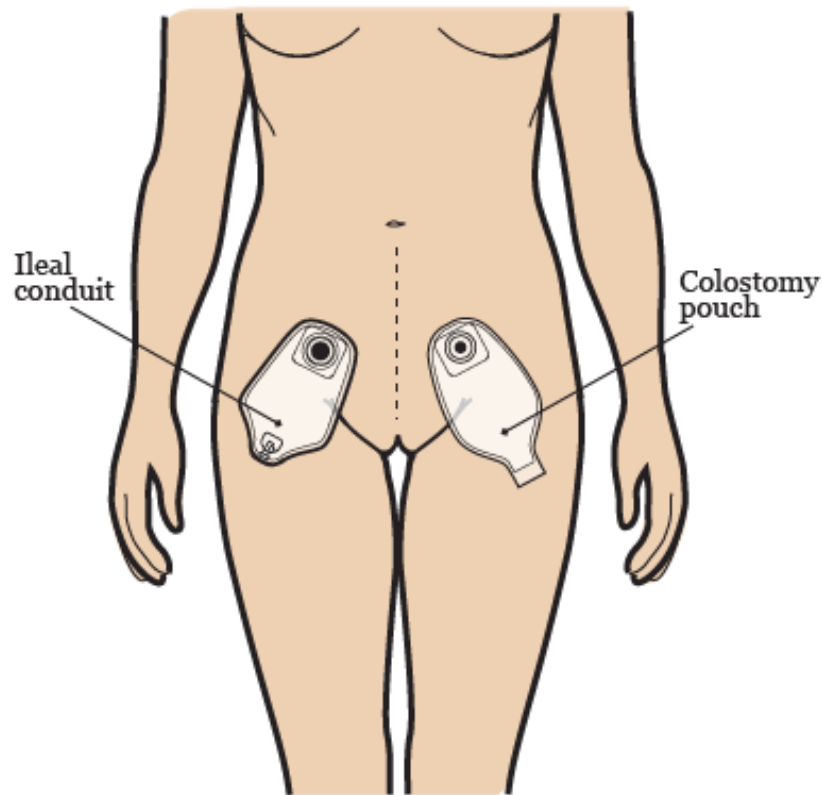


Figure 5. Your urinary and colostomy pouches

## Moving to your hospital room

Most people stay in the PACU overnight. After your stay in the PACU, a staff member will take you to your hospital room.



## 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 about 4 to 7 days.

In your hospital room, you'll meet one of the nurses who will care for you during your stay. Your care team will teach you how to care for yourself while you're healing from your surgery.

You won't be able to sit for 6 to 8 weeks after your surgery. You can lie on your back or side or you can stand. Your healthcare providers will help you with this.

## Managing your pain

You may have pain at your incision sites and your abdomen.

- If you have an epidural catheter, you'll get pain medication into your epidural space. You'll be able to control your medication using a PCA device.
- If you don't have an epidural catheter, you'll get pain medication in your IV line.
- Once you're able to eat normal food, you'll get oral pain medication (medication 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.

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](http://www.msk.org/pe/walking_after_surgery) or ask for a printed copy.

Read *Call! Don't Fall!* to learn what you can do to stay safe and keep from falling while you're in the hospital. You can find it at [www.msk.org/pe/call\\_dont\\_fall](http://www.msk.org/pe/call_dont_fall) or ask for a printed copy.

## 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 will not be able to eat for 1 to 2 days after your surgery. You'll get fluids through an IV line during this time. Then, you'll follow a clear liquid diet. After that, you can start eating normal foods again, as tolerated.

When you're able to eat normal foods again, it's important to eat a balanced diet high in protein to help you heal after surgery. Your diet should include a

healthy protein source at each meal, as well as fruits, vegetables, and whole grains.

For more tips on increasing the calories and protein in your diet, read *Eating Well During Your Cancer Treatment*. You can ask for a printed copy or find it at [www.msk.org/pe/eating\\_cancer\\_treatment](http://www.msk.org/pe/eating_cancer_treatment)

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

## Caring for your drains and incisions

You'll likely have some bleeding from most of your incisions or around your drains. You may also have some discharge and tenderness around your incisions and drains for a few days. Your nurses will show you and tell you what's normal and expected as they care for you. You'll also start to learn how to care for your stoma(s) and incisions.

Some of the tubes and drains may be removed before you're discharged from the hospital. If you go home with the drains, your nurses will teach you how to care for them.

If you have an incision that was closed with staples, the staples are usually taken out before you leave the hospital. Some people will have them removed at their first follow-up visit.

## Showering

You can shower while you're in the hospital. Your healthcare provider will tell you when it's OK to start. Wash your incisions with a 4% CHG solution antiseptic skin cleanser such as Hibiclens until your staples are removed.

## Planning for discharge

Before you go home, one of your healthcare providers will give you the supplies you need to care for yourself for the first month. After that, you can order your supplies from an outside source.

You may still have drains in when you go home. Ask your healthcare provider when they'll be removed. Your discharge nurse case manager will arrange to have a visiting nurse see you at home. Your visiting nurse will help you while you're learning to care for your incision, drains, and stoma.

You'll get a prescription for pain medication. Take your medication as instructed by your healthcare provider and as you need it. Don't drive or drink alcohol while you're taking prescription pain medication.

Read *Gynecology Service: What You Should Know About Going Home* to learn more about getting ready for your discharge. You can find it at [www.msk.org/pe/gyn\\_going\\_home](http://www.msk.org/pe/gyn_going_home) or ask for a printed copy.

## Leaving the hospital

By the time you're ready to leave the hospital, your incisions will have started to heal. Before you leave, look at your incisions with one of your healthcare providers. Knowing what they look like will help you notice any changes later.

On the day of your discharge, plan to leave the hospital around 11 a.m. Before you leave, your healthcare provider will write your discharge order and prescriptions. 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 be discharged, you may be able to wait in the Patient Transition Lounge. A member of your healthcare 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](http://www.msk.org/pe/avoid_falling) or ask for a printed copy.

## Filling out your Recovery Tracker

We want to know how you're feeling after you leave the hospital. To help us care for you, we'll send questions to your MyMSK account. We'll send them every day for 10 days after you're discharged. These questions are known as your Recovery Tracker.

Fill out your Recovery Tracker every day before midnight (12 a.m.). It only takes 2 to 3 minutes to complete. Your answers to these questions will help us understand how you're feeling and what you need.

Based on your answers, we may reach out to you for more information. Sometimes, we may ask you to call your surgeon's office. You can always contact your surgeon's office if you have any questions.

To learn more, read *About Your Recovery Tracker*. You can find it at [www.msk.org/pe/recovery\\_tracker](http://www.msk.org/pe/recovery_tracker) or ask for a printed copy.

## 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. Talk with your healthcare provider about how to prevent and manage constipation.

## Caring for your incision

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

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.

## Caring for your colostomy and urinary diversion

Your nurse will teach you how to care for your colostomy and urinary diversion before you leave the hospital. Read *Caring for Your Ileostomy or Colostomy* for more information about caring for your colostomy. You can find it in the “Educational resources” section of this guide. Your WOC nurse will give you information about caring for your urinary diversion.

## Showering

Take a shower every day to clean your incision. If you have staples 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.

It's also important to drink plenty of liquids. Try to drink 8 to 10 (8-ounce) cups of liquids every day. Choose liquids without alcohol. Limit liquids with caffeine.

For more tips on eating and drinking after surgery, read *Eating Well During Your Cancer Treatment*. You can ask for a printed copy or find it at [www.msk.org/pe/eating\\_cancer\\_treatment](http://www.msk.org/pe/eating_cancer_treatment)

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. For the first 6 to 8 weeks after your surgery:

- Do not lift anything heavier than 10 pounds (4.5 kilograms).
- Do not do any high-energy activities, such as jogging and tennis.
- Do not play any contact sports, such as football.

Talk with your healthcare provider before you start doing high-energy activities or lifting heavy objects.

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.

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.

## Sexual activity

If you have a vagina or a reconstructed vagina, don't put anything inside it or have vaginal intercourse until your first appointment after surgery. At this appointment, your healthcare provider will tell you when you can start having vaginal intercourse again.

If your healthcare provider told you it's OK have vaginal intercourse but you feel pain during vaginal intercourse, call them. They can refer you to physical therapy for an evaluation.

## Other activities

Before starting any activities such as driving, traveling, or going back to work, talk with your healthcare provider. They'll help you figure out when you can start doing these again.

## Managing your feelings

This surgery will change your body, and it will probably take time for you to get used to these changes. You may feel scared, angry, or worried. You may have questions or fears about how this surgery will impact your sexuality. These feelings are normal, and many people feel the same way.

Everyone gets used to these changes in their own way. For some people, it can take a few months to get used to their changed body image. For others, it can take longer. As time goes on, you'll get stronger. You'll be more confident in caring for your incisions and pouch. Your appetite and energy will get better. Eventually, you'll be able to resume most of your normal activities.

We have many resources to help you. Your healthcare providers will answer your questions. Our social workers, psychologists, psychiatrists, and WOC nurses have helped many people through this change. You can have one-on-one counseling, or you can join one of our online or in-person support groups. We also have clergy available for spiritual support. You may be able to meet with other people who have had this surgery and who can talk with you and answer your questions. Talk with your healthcare provider if you're interested in this.

To address issues with sexual health and intimacy, you can see someone from our Female Sexual Medicine & Women's Health Program. For more information or to set up an appointment, call 646-888-5076.

# When to call your healthcare provider



Call your healthcare provider if:

- You have a fever of 100.5 °F (38.0 °C) or higher.
- You have chills.
- You're having trouble breathing.
- The skin around your incision is warmer than usual.
- The skin around your incision is getting redder.
- The area around your incision is starting to swell.
- The area around your incision is getting more swollen.
- You have discharge coming from your incisions.
- You have a bad smell coming from your incisions.
- You have pain that doesn't get better with pain medication.
- You have vaginal bleeding or bad-smelling vaginal discharge.
- You have burning when passing stool or urine.
- You can't pass stool or urine into your stoma or pouch.
- 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.





## Gynecologic surgery support services

United Ostomy Associations of America, Inc (UOAA)

800-826-0826

[www.ostomy.org](http://www.ostomy.org)

Volunteer group who supports people who have or will have an ostomy and provides educational resources.

Women's Cancer Network: Gynecological Cancer Foundation (GCF)

312-578-1439

[www.foundationforwomenscancer.org](http://www.foundationforwomenscancer.org)

Nonprofit organization that provides education and supports research on gynecologic cancers.

Wound, Ostomy, Contenance Nurses Society

888-224-WOCN (9626)

[www.wocn.org](http://www.wocn.org)

Provides patient resource from nursing members who have special training in the care of people with wounds, ostomies, and continence problems.

## 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](http://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](http://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](http://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](http://libguides.mskcc.org/patienteducation)

## Nutrition Services

[www.msk.org/nutrition](http://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](http://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](http://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](http://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](http://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](http://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](http://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.

Notes \_\_\_\_\_  
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# 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.

These are the educational resources 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](http://www.msk.org/pe/guide_caregivers))
- *About Your Recovery Tracker* ([www.msk.org/pe/recovery\\_tracker](http://www.msk.org/pe/recovery_tracker))
- *Advance Care Planning for Cancer Patients and Their Loved Ones* ([www.msk.org/pe/advance\\_care\\_planning](http://www.msk.org/pe/advance_care_planning))
- *Call! Don't Fall!* ([www.msk.org/pe/call\\_dont\\_fall](http://www.msk.org/pe/call_dont_fall))
- *Caring for Your Ileostomy or Colostomy* ([www.msk.org/pe/caring\\_ileostomy\\_colostomy](http://www.msk.org/pe/caring_ileostomy_colostomy))
- *Eating Well During Your Cancer Treatment.* ([www.msk.org/pe/eating\\_cancer\\_treatment](http://www.msk.org/pe/eating_cancer_treatment))
- *Fertility Preservation Before Cancer Treatment: Options for People Born with Ovaries and a Uterus* ([www.msk.org/pe/fertility\\_starting\\_treatment](http://www.msk.org/pe/fertility_starting_treatment))
- *Frequently Asked Questions About the MyMSK Goals to Discharge Checklist* ([www.msk.org/pe/goals\\_discharge\\_checklist](http://www.msk.org/pe/goals_discharge_checklist))

- *Frequently Asked Questions About Walking After Your Surgery*  
([www.msk.org/pe/walking\\_after\\_surgery](http://www.msk.org/pe/walking_after_surgery))
- *Gynecology Service: What You Should Know About Going Home*  
([www.msk.org/pe/gyn\\_going\\_home](http://www.msk.org/pe/gyn_going_home))
- *Herbal Remedies and Cancer Treatment*  
([www.msk.org/pe/herbal\\_remedies](http://www.msk.org/pe/herbal_remedies))
- *How to Be a Health Care Agent*  
([www.msk.org/pe/health\\_care\\_agent](http://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](http://www.msk.org/pe/check-med-supplement))
- *How to Enroll in MyMSK: Memorial Sloan Kettering's Patient Portal*  
([www.msk.org/pe/enroll\\_mymask](http://www.msk.org/pe/enroll_mymask))
- *How to Use Your Incentive Spirometer*  
([www.msk.org/pe/incentive\\_spirometer](http://www.msk.org/pe/incentive_spirometer))
- *Information for Family and Friends for the Day of Surgery*  
([www.msk.org/pe/info\\_family\\_friends](http://www.msk.org/pe/info_family_friends))
- *Patient-Controlled Analgesia (PCA)* ([www.msk.org/pe/pca](http://www.msk.org/pe/pca))
- *What You Can Do to Avoid Falling* ([www.msk.org/pe/avoid\\_falling](http://www.msk.org/pe/avoid_falling))



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PATIENT & CAREGIVER EDUCATION

# Caring for Your Ileostomy or Colostomy

This information will help you care for your ileostomy or colostomy.

An ostomy is an opening created during surgery. A piece of your intestine is brought to the outside of your abdomen (belly) so that bowel movements (stool) and gas can exit your body. The part of your intestine that's on the outside of your body is called a stoma. Your stoma will look red and moist, like the inside of your mouth. Your stoma will be swollen right after surgery, but the size will decrease in 6 to 8 weeks. You usually don't feel pain or pressure within your stoma. Your stoma does not have the nerve endings and cannot feel sensations of heat or cold.

Having an ostomy is a big change for most people. We have written this resource with the help of people who have an ostomy. We hope it will help prevent problems and give you tips that can make your daily life easier. Your wound, ostomy, continence (WOC) nurse will go over most of this information with you.

## Types of Ostomies

An ostomy can be made out of the small intestine or colon (large intestine). When a piece of the small intestine is used to create an ostomy, it's called an ileostomy. When a piece of the colon is used to create an ostomy, it's called a colostomy.

The consistency of your bowel movements from your ostomy will depend on the part of your intestine that's used to create the ostomy. Your bowel movements may be liquid, soft, or solid.

The most common types of ostomies are:

## **Ileostomy**

- Created from the part of the small intestine called the ileum.
- Bowel movements are loose, pasty, or watery.
- Stoma is usually located on the right lower side of the abdomen.

## **Ascending colostomy**

- Created out of the ascending colon.
- Bowel movements are loose, pasty, or watery.
- Stoma is usually located on the right side of the abdomen.

## **Descending colostomy**

- Created out of the descending colon.
- Bowel movements are usually soft.
- Stoma is usually located on the left side of the abdomen.

## **Sigmoid colostomy**

- Created out of the last part of the colon.
- Bowel movements can be soft or firm.
- Stoma is usually located on the left side of the abdomen.

## **Loop ostomy**

- Created out of any part of the small intestine or colon.
- There are 2 openings in the stoma instead of 1. Many times, only 1 opening can be seen. This type of ostomy is often temporary.

In some surgeries, a second opening is created on the abdomen called a mucous fistula. It drains left over stool (poop) or a mucus-like fluid and leads



to the rectum. If you have a mucous fistula, your WOC nurse will teach you how to care for it while you're in the hospital. Usually, a small pouch (bag) or dressing is placed over the mucous fistula. The pouch may need to be emptied throughout the day. Once the drainage decreases, the mucus fistula can be covered with gauze and tape, band aid, or a special mucus fistula bandage.

## **Learning to Care for Your Ostomy**

Your WOC nurse and nursing staff will teach you how to care for your stoma and ostomy while you're in the hospital. When you're discharged from the hospital, you'll be given the basic supplies you need to care for your ostomy. During your post-operative appointment, a WOC nurse will re-evaluate your ostomy supplies and will show you how to order them. There's a list of medical suppliers at the end of this resource.

Your case manager in the hospital will also arrange for a visiting nurse to come to your home after you're discharged from the hospital. They will reinforce the information on how to care for your stoma and adjust to being home. If you have any questions or problems once you're home, call your healthcare provider to contact your WOC nurse.

### **Pouching (bag) systems**

After your surgery, you'll wear a pouching (bag) system over your ostomy. All pouching systems are waterproof and odor-proof. The pouching system is made up of a skin barrier (wafer) and a collection pouch. There are many different sizes and styles of pouching systems. Most pouching systems are either a 1-piece system in which the pouch is attached to the skin barrier, or a 2-piece system in which the pouch can be taken off of the skin barrier. With both types, the pouch attaches to your abdomen by the skin barrier and is fitted over and around your stoma to collect your stool and gas. The skin barrier protects the skin around your stoma from possible stool leakage.

Your WOC nurse will help you find the best pouching (bag) system for your stoma. As the size of your stoma changes, you may need to change your

pouching system.

Some people find it helpful to buy a fitted waterproof mattress cover or waterproof bed pads to place over the mattress and bed sheets to use after surgery at home. This protects the bed in case the pouch accidentally leaks during the night.

## **Emptying your pouch (bag)**

Empty your pouch (bag) when it's  $\frac{1}{3}$  to  $\frac{1}{2}$  full. The pouch shouldn't become overly full. A full pouch will be more difficult to empty and could cause leakage. Your WOC nurse and the staff nurse will teach you how to empty your pouch.

Liquid stool empties easily out from the bottom of the pouch (bag). Pasty or thick stool may not drop to the bottom of the pouch as easily. You may squeeze the stool out from the pouch or add water to make it more liquid, and then empty the stool into the toilet. When emptying your pouch, do not squeeze all the air out of the pouch because the sides will stick together, and this could slow stool from dropping to the bottom. There are lubricants to help keep this from happening. This is more of an issue if your stool is thicker. If your stool is thinner, you can use a thickening product in the pouch to help thicken them. Your WOC nurse will help you determine which product you should use.

## **Changing your pouching (bag) system**

Your WOC nurse will teach you how to change your pouching (bag) system. Generally, you should change your pouching system every 3 to 5 days. If you have leakage, change it immediately. This is to protect the skin around your stoma from getting irritated from stool leakage. If you have any leakage or irritation that has lasted for a few days, call your healthcare provider's office to get in touch with your WOC nurse.

# Lifestyle Issues

## Body image and depression

After people learn that they have cancer, they often view their bodies in a different way. Surgery, chemotherapy, and radiation therapy can change the way a body looks and works. This may be especially true when someone has a new ostomy. Some people feel disgust. This is normal given the shame in many cultures of talking about bowel movements. Other people feel sadness at the loss or change in their bodies. They view their ostomy with negative thoughts and feelings. However, others view their ostomy more positively and see it as an answer to difficult symptoms, such as bowel incontinence (trouble controlling your bowel movements), or as the path to better health. You may have both positive and negative feelings. As you adjust to living with an ostomy and get used to how it looks and works, you'll feel better about your body. It may help you cope better if you:

- Look at your stoma to help you get comfortable with it.
- Remind yourself about the positive aspects of your ostomy.
- Talk with other people with ostomies. You may learn new ostomy techniques and this may help you regain a sense of normalcy.
- Get counseling to help you improve your body image, feelings, and quality of life. At Memorial Sloan Kettering (MSK), counseling is available from social workers and at the Counseling Center. You can reach the Social Work Department at 212-639-7020 and the Counseling Center at 646-888-0200.

## Nutrition

Your healthcare provider will give you dietary guidelines to follow after your surgery. You'll also meet with a dietitian while you're in the hospital to review these guidelines.

Below are some recommended guidelines if you have an ileostomy:

- Stay hydrated

- Drink at least 8 to 10 (8-ounce) glasses of liquids a day.
- Limit your intake of caffeine and alcohol. They can dehydrate you.
- Limit foods high in fiber and high in simple sugars (such as glucose, sucrose, fructose), as they can dehydrate you.
- Contact your healthcare provider if you're experiencing abdominal pain or symptoms of dehydration. Symptoms include:
  - Increased thirst
  - Dry mouth
  - Loss of appetite
  - Weakness
  - Decreased urine output
  - Dark amber colored urine
  - Muscle, abdominal, or leg cramps
  - Feeling faint
  - More bowel movements than usual or changes in consistency
  - Increased frequency of emptying pouch
- Foods that upset your stomach before your surgery may have the same effect after your surgery. If you feel bloating and pain after eating a certain food, remove it from your diet. Try eating it again in a few weeks. If you're still having pain and bloating after eating this food, avoid it.
- Some people with ostomies choose to limit gas by regulating their diet. The following can increase gas:
  - Foods such as cabbage and broccoli
  - Carbonated beverages
  - Drinking through a straw
  - Chewing gum
- If you have tried limiting gas and still have a problem, talk with your WOC nurse. They may suggest using pouches with charcoal filters. The

filter can help prevent the buildup of gas and avoid inflation of the pouch.

- Don't prick your pouch to release built-up gas because this will destroy the pouch's odor proof system.
- Don't scrub your pouch with water. This will deactivate the filter.
- Make sure you cover your filter with the provided waterproof sticker when showering or bathing, if suggested by the manufacturer.
- If you're constipated (having fewer bowel movements than what's normal for you):
  - Drink more liquids.
  - Eat foods that are high in fiber, such as fruits, vegetables, and bran.
  - Walk around.
  - Contact your healthcare provider's office to discuss options for stool softeners.

**If you have an ileostomy, don't take any kind of laxative.** It can cause severe dehydration and other problems.

## Medication

If you have an ileostomy, your body may not be able to completely absorb some medications. This happens because your bowel is shortened and some medications are absorbed slowly or in a lower portion of the intestines. This happens most often with:

- Pills with enteric coating (a special coating that prevents pills from being absorbed until they reach the small intestine)
- Sustained-release or extended release medications (designed to release a medication in the body slowly over an extended period of time)

Ask your healthcare provider if you're taking these types of medications. If you see a tablet in your pouch (bag) that isn't absorbed, call your healthcare provider.

Don't crush pills unless your healthcare provider or pharmacist says you can do so. Taking crushed pills change the absorption of the medication and can cause problems with digestion.

## **Exercise**

Talk with your healthcare provider about what exercise is right for you. For most people, walking and light stretching are good exercises to do while recovering from surgery. You should avoid lifting or pushing anything heavier than 10 pounds for 6 to 8 weeks after your surgery. This includes housework such as vacuuming or mowing the lawn. If this will be a problem for you, talk with your healthcare provider.

Don't do sit-ups, pushups, or any strenuous exercise for 2 to 3 months after your surgery. This will help prevent a hernia (bulging of an organ or tissue) through your incision or around your ostomy. Speak with your WOC nurse after your surgery and during your postop visit to learn more about how to prevent a hernia around your stoma.

## **Odor control**

Pouching (bag) systems are designed to be odor proof. Unless you're leaking bowel movements underneath the wafer, there should be no odor while the pouching system is attached. However, if odor is a problem for you, there are deodorants that you can put into the pouch to help. Some examples are drops, charcoal tablets, or lubricating gel. You may need to experiment to find one that works best for you. There are also deodorants you can take orally (by mouth) to decrease your bowel movement's odor. Check with your healthcare provider before using any of these.

Many pouches have a built-in charcoal filter. This vents the gas and filters it at the same time to prevent odor. There are also filters that can be bought separately and attached to the pouch, or you can apply a small plastic vent on each pouch. This vent allows gas to be released without opening the pouch.

Some people find it useful to empty the pouch at bedtime. This is done because gas could continue to build overnight and fill the pouch.

## **Sexuality**

Sexuality is a part of relationships and life. After ostomy surgery it's common to feel insecure or concerned about your sexuality with a new stoma. Most people with new ostomies experience changes in how they feel about their bodies and worry about sexual activities. Talk with your healthcare provider about difficulties or fears that you may have.

## **Sexual activity**

Talk with your healthcare provider about when it's safe to resume sexual activity. Generally, this is after your incision is healed, about 2 months after your surgery. As long as excessive pressure isn't placed on your stoma, there should be no harm done to it. Do not use your stoma as a sexual orifice (opening).

For many people, returning to a normal sex life will come naturally. This happens as your concerns decrease and your feelings about your body become more positive. Try to stay intimate with your partner as much as possible. Use kind words, meaningful touch, and hugs.

Check to see if your pouching (bag) system fits well and if there's any odor. Some people prefer to cover their pouching system with a cloth band or wrap, shirt, or lingerie during sexual activity. You can buy ready-made covers from many ostomy supply companies.

You may also plan your sexual activity for times when you're less likely to have a bowel movement. Some people with a permanent colostomy, irrigate (give themselves an enema through the stoma) to try to control their bowel movements. For more information about irrigation, see the section titled "Frequently Asked Questions About Ostomy Care".

Talk with your healthcare provider if surgery or radiation therapy caused changes that make it hard to have sex. Examples are erectile dysfunction (difficulty getting or keeping an erection) or vaginal dryness, pain, or tightness. If these problems don't get better, you can talk with a sexual health specialist. MSK has a Sexual Health Program to help people address the impact of their disease and treatment on sexuality. You can contact our

Sexual Health Programs at the numbers listed below or have your healthcare provider's office place a referral.

Female Sexual Medicine and Women's Health Program: 646-888-5076

Male Sexual and Reproductive Medicine Program: 646-888-6024

The United Ostomy Associations of America, Inc. ([www.ostomy.org](http://www.ostomy.org) or 800-826-0826) has information on sex for people with ostomies.

Other good sources of information are the following resources published by the American Cancer Society. You can get these resources by calling 800-ACS-2345 (800-227-2345) or by going to the links below.

- *Sex and the Adult Male With Cancer:*  
[www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-men-with-cancer.html](http://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-men-with-cancer.html)
- *Sex and the Adult Female With Cancer:*  
[www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-women-with-cancer.html](http://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-women-with-cancer.html)

## **Showering, bathing, and swimming**

You can shower with your pouching (bag) system on or off. However, if you have an ileostomy, you may want to keep the pouch on during the shower due to possible drainage of bowel movements while showering. You can also use waterproof tape or strips around the edges of the wafer to keep it from getting wet.

When you take a bath or swim, keep your pouching system on. Most people can wear the same swimsuit they wore before their surgery. However, it may not be possible to wear hip-high swimsuits or two-piece swimsuits.



## Work

You can go back to work as soon as you feel ready and your healthcare provider approves. Unless you tell them, people won't know that you have an ostomy. It's highly unlikely that the pouching system will be visible. You'll probably be able to wear most of the same clothes you wore before your surgery.

## Travel

Bring extra pouching (bag) systems with you wherever you go, even if it's only a short trip or a healthcare provider's appointment. If you're going to be away from home for several hours, think about where you're going and mentally prepare yourself. Some people feel anxiety the first few times they travel. If you feel anxious, you may be able to lower your stress by thinking ahead. First, think about where the bathroom is located and what you may need. Second, get the supplies you plan to take with you. Place 2 of every item in a travel bag. This way, if you have an emergency or are away from home longer than you expect, you'll be prepared. Remember to bring:

- Pouches
- Wafers
- Clamps (if you have a pouching system with a clamp closure)
- Paper towels

When you're traveling by air:

- Pack your ostomy supplies in at least 2 places, such as in your carry-on and checked luggage.
- Take extra supplies in case you're stranded where supplies may not be available.
- You may want to bring a letter from your healthcare provider stating your need for ostomy supplies, as well as a private area be used in case of an extended search by TSA agents.
- If you're traveling to a foreign country, it's a good idea to have ostomy

information written in that language. One of the 70 member associations of the International Ostomy Association may be able to help with this translation, as well as with locating supplies while visiting their country. For more information, visit [www.ostomyinternational.org](http://www.ostomyinternational.org).

- You may want to carry photocopies of the catalogue pages displaying and explaining your equipment for TSA agents.
- The United Ostomy Association of America web site, ([www.uoaa.org](http://www.uoaa.org)) has information and helpful 'travel tips' that can be printed and used.

## **Call Your Healthcare Provider if You:**

- Vomit
- Have a colostomy and haven't had a bowel movement for 3 days
- Have an ileostomy and haven't had a bowel movement for 3 to 6 hours
- Develop abdominal pain or symptoms of dehydration (this is more common for those with an ileostomy), including:
  - Increased thirst
  - Dry mouth
  - Loss of appetite
  - Weakness
  - Decreased urine output
  - Dark amber colored urine
  - Muscle, abdominal, or leg cramps
  - Feeling faint
  - More bowel movements than usual or changes in consistency
  - Increased frequency of emptying pouch

# Frequently Asked Questions About Ostomy Care

## What is irrigation and will I be able to do it?

A colostomy irrigation is a type of enema that helps control when you have bowel movements. This means you wouldn't have any bowel movements between the irrigations. Irrigating may also reduce gas. Some people who irrigate their stoma are able to wear a stoma cap over their stoma instead of using a pouching system. Irrigation is done every day or every other day. People who have a sigmoid colostomy may be able to irrigate. Most people who have had an abdominal perineal resection have a sigmoid colostomy. **People with an ileostomy should never irrigate because it can cause dehydration.**

You also can't irrigate:

- If you have a stomal hernia (bulge around the stoma).
- While you're getting chemotherapy.
- While you're getting radiation therapy.

Ask your healthcare provider or WOC nurse for more information about irrigation.

## What color should my stoma be?

Your stoma should be a deep pink or red color at all times. While it's working to move bowel movements out of your body, you may notice a slight change in its color. This should only be for a few seconds to a minute. If your stoma looks dark red, grey, brown, or black, call your healthcare provider immediately.

## **Is it normal for my stoma to bleed when I touch it or change my pouching (bag) system?**

Your stoma has many blood vessels, so it may bleed easily with touch or irrigation. It's common to have a small amount of blood on the tissue when cleaning your stoma. The bleeding should stop on its own within a few minutes. If you're on a blood thinner or aspirin, you may bleed more easily and for a longer period of time. If you bleed a lot or if the bleeding doesn't stop after 5 to 10 minutes, apply pressure to the area and call your healthcare provider. If you notice blood in your bowel movements or coming from the inside of your stoma, call your healthcare provider immediately.

## **The area around my stoma seems to bulge. Is this normal?**

If you have a change in the curve around your stoma, tell your healthcare provider or WOC nurse. You may have a stomal hernia (parastomal hernia). This happens because the abdominal wall muscle may be weak and the intestines bulge through the weak area. Your healthcare provider or WOC nurse will examine you to see if you have a stomal hernia.

People with a stomal hernia don't initially feel any symptoms. Surgery isn't needed unless you have a complication, including a blockage or twisting of the herniated bowel.

If you have any of the following symptoms, call your healthcare provider:

- Nausea
- Vomiting
- Pain
- Abdominal bloating, and lack of gas and bowel movements in your pouch

If you have a stomal hernia, your WOC nurse can measure you for a custom-made hernia support belt. These belts don't cure the hernia, but they can try to prevent it from getting bigger by giving it support. A light panty girdle or biking shorts with a hole cut out for your pouch may also work well as an alternative to the custom-fitted hernia belt.

## **How do I wear a belt over my stoma?**

Try to wear the belt above or below your stoma. If the belt is worn directly over your stoma, it can cause:

- Irritation
- Bleeding
- An overgrowth of tissue

While you're wearing the belt, position your pouch downward or to the side. You can also fold it, depending on your preference.

## **What do I do if I have leakage of bowel movements under my wafer?**

If you're having leakage, tell your WOC nurse. You may need a different pouching (bag) system that fits better to avoid this problem.

## **Is there anything I should do to prepare for tests, such as scans with contrast dye?**

Always take an extra set of supplies when going to the healthcare provider for tests because you may have to remove your pouching system.

If you live 1 hour or longer away from the hospital, be ready to change or empty your bag during the trip home. The contrast dye may empty into your pouch in 1 or 2 hours, but it can take longer.

## **Do I need to wear gloves when I change my pouching (bag) system?**

This is a personal choice. There is no risk of infection from changing your pouching (bag) system. However, some people prefer to wear gloves because some bowel movements could come in contact with your fingers.

## If I have an ileostomy, is it normal to still pass bowel movements or mucous from my rectum?

Depending on the type of surgery you had, you may pass left over bowel movements or mucous from your rectum. This should decrease over time, but it may be useful to wear a pad and apply a zinc ointment product (such as Desitin®) around your anus to prevent irritation.

## What should I do if I am admitted to the hospital?

If you're admitted to the hospital, you may want to bring 1 or 2 extra sets of supplies with you, just in case they stock a different product or they have run out of the product you use.

## Video Resources

This video will teach you how to change your ostomy appliance.



Please visit [www.mskcc.org/pe/caring\\_ileostomy\\_colostomy](http://www.mskcc.org/pe/caring_ileostomy_colostomy) to watch this video.

This video will teach you how to empty your velcro end closure pouch.



Please visit [www.mskcc.org/pe/caring\\_ileostomy\\_colostomy](http://www.mskcc.org/pe/caring_ileostomy_colostomy) to watch this video.

This video will teach you how to care for irritated skin around your stoma.



Please visit [www.mskcc.org/pe/caring\\_ileostomy\\_colostomy](http://www.mskcc.org/pe/caring_ileostomy_colostomy) to watch this video.

## Support Groups

You may find it helpful to join our ostomy group for patients with different types of ostomies. This is a live, confidential, online support group in which people can share their experiences and provide practical and emotional

support for one another. Discussions are guided by a social worker and nurse. The group is open to everyone, including non-MSK patients. The group is held monthly on the 3<sup>rd</sup> Thursday of the month from 4:00 p.m. to 5:00 p.m. Visit [www.mskcc.org/event/ostomy-support-group](http://www.mskcc.org/event/ostomy-support-group) to learn more or register.

On the United Ostomy Associations of America (UOAA) website, you can search for UOAA-affiliated online and in-person support groups for people with ostomies. To find a group, go to [www.ostomy.org/supportgroups.html](http://www.ostomy.org/supportgroups.html).

Local hospitals may also offer ostomy support groups.

## Ordering Supplies

Speak with your WOC nurse about ordering supplies. They are familiar with the latest products on the market. You can also call companies to ask for samples of their products.

### Mail order medical supply companies

Listed below are some mail order medical supply companies. Most of the supply companies accept Medicare and other types of insurance. Call the company directly to ask if they take your insurance. If they don't accept your insurance, call your insurance company to get a list of suppliers that do. These companies will mail the supplies to you every month. After you reach out to the company for your supplies, they will work with your healthcare provider's office to get an order for the supplies. The supply companies are familiar with the insurance companies' coverage and can let you know the amount of supplies covered by your insurance company, and if you have a co-pay.

#### **Byram Healthcare**

877-902-9726

[www.byramhealthcare.com](http://www.byramhealthcare.com)

#### **CCS Medical**

800-260-8193

[www.ccsmed.com](http://www.ccsmed.com)

## **Edgepark Medical Supplies**

888-394-5375

[www.edgepark.com](http://www.edgepark.com)

## **Landauer Metropolitan**

800-631-3031

[www.landmetro.com](http://www.landmetro.com)

(Accepts Medicaid in New York State)

You can also buy ostomy supplies at local pharmacies and medical supply stores. However, the prices may be higher due to a low volume of supplies or because they may not take your insurance.

## **Ostomy product manufacturers**

Listed below are companies that make ostomy products such as skin barriers, pouches, and other ostomy accessories (such as pastes, powder, and rings). Many of these companies also have a WOC nurse on staff to answer questions. Feel free to call and ask for samples of products.

### **Coloplast Corporation**

800-533-0464

[www.coloplast.us](http://www.coloplast.us)

### **ConvaTec Professional Services**

800-422-8811

[www.convatec.com](http://www.convatec.com)

### **Cymed**

800-582-0707

[www.cymed-ostomy.com](http://www.cymed-ostomy.com)

### **Hollister, Inc.**

888-740-8999

[www.hollister.com](http://www.hollister.com)

### **Marlen Manufacturing & Development Company**



216-292-7060

[www.marlenmfg.com](http://www.marlenmfg.com)

**Nu-Hope Laboratories, Inc.**

800-899-5017

[www.nu-hope.com](http://www.nu-hope.com)

## **MSK Support Services**

### **Resources for Life After Cancer (RLAC) Program**

646-888-8106

At MSK, care doesn't end after active treatment. The RLAC Program is for patients and their families who have finished treatment. This program has many services, including seminars, workshops, support groups, counseling on life after treatment, and help with insurance and employment issues.

### **Social Work Department**

212-639-7020

Social workers help patients and their families and friends deal with issues that are common for cancer patients. They provide individual counseling and support groups throughout the course of treatment, and can help you communicate with children and other family members. Our social workers can also refer you to community agencies and programs, as well as financial resources if you're eligible.

### **Sexual Health Programs**

Female Sexual Medicine and Women's Health Program: 646-888-5076

Male Sexual and Reproductive Medicine Program: 646-422-4359

MSK's Sexual Health Programs help people address the sexual impact of their disease and treatment. You can meet with a specialist before, during, or after your treatment.

# Resources

## Books

*100 Questions & Answers about Colorectal Cancer*

Authors: David Bub, Susannah L. Rose, and W. Douglas Wong

Boston, MA: Jones and Bartlett Publishers; 2003

*The Ostomy Book: Living Comfortably with Colostomies, Ileostomies, and Urostomies*

Authors: Barbara Dorr Mullen and Kerry Anne McGinn

Boulder, CO: Bull Publishing; 2008

*The Complete Financial, Legal, and Practical Guide for Living With Cancer, HIV, and Other Life-Challenging Conditions*

Author: David Landay

New York, NY: St. Martin's Press; 1998

*Positive Options for Living with Your Ostomy: Self-Help and Treatment*

Authors: Craig A. White and Robert W. Beart Jr.

Alameda, CA: Hunter House; 2002

*The Human Side of Cancer: Living With Hope, Coping With Uncertainty*

Authors: Jimmie Holland and Sheldon Lewis

New York, NY: Harper Collins Publishers; 2000

## Organizations

### **Cancer***care*

800-813-HOPE (800-813-4673)

[www.cancer.org](http://www.cancer.org)

National nonprofit organization that provides free help to people with all cancers. Services include counseling, education, information, and financial assistance.

### **Caregiver Action Network**

[caregiveraction.org](http://caregiveraction.org)

Provides support to caregivers of those who are ill, elderly, or disabled.

Works to provide caregivers with support, empowerment, education, and advocacy.

### **Colon Cancer Alliance (CCA)**

877-422-2030 (toll-free helpline)

[www.ccalliance.org](http://www.ccalliance.org)

National nonprofit patient advocacy organization dedicated to screening, access, awareness, advocacy, and research related to colon cancer.

### **Crohn's and Colitis Foundation of America**

800-932-2423

[www.ccfa.org](http://www.ccfa.org)

Works to find a cure for and prevent Crohn's disease and ulcerative colitis. Aims to improve the quality of life for people living with these diseases through research, education, and support.

### **C3Life.com**

[www.c3life.com](http://www.c3life.com)

Website dedicated to helping people with ostomies live their lives to the fullest. Online community includes a discussion forum, recipes, blogs, hints, and tips.

### **Red Door Community**

195 West Houston St.

New York, NY 10014

212-647-9700

[www.reddoorcommunity.org](http://www.reddoorcommunity.org)

Provides meeting places for people living with cancer and their family and friends. Gives people a place where they can meet others to build support systems. Offers free support and networking groups, lectures, workshops, and social events. Red Door Community used to be called Gilda's Club.

### **International Ostomy Association (IOA)**

[www.ostomyinternational.org](http://www.ostomyinternational.org)

Works to improve the quality of life for people who have ostomies or related surgeries.

## **National Ovarian Cancer Coalition (NOCC)**

888-682-7426

[www.ovarian.org](http://www.ovarian.org)

Works to increase awareness of ovarian cancer and to improve the survival rate and quality of life for people with ovarian cancer.

## **NCI's Cancer Information Service**

800-4 CANCER (800-422-6237)

[www.cancer.gov/aboutnci/cis](http://www.cancer.gov/aboutnci/cis)

A federally funded cancer education program that provide accurate, up-to-date, and reliable information on cancer that is easy to understand.

## **Ovarian Cancer National Alliance (OCNA)**

866-399-6262 (toll free)

[www.ovariancancer.org](http://www.ovariancancer.org)

Works to put ovarian cancer on the agenda of policy makers and women's health leaders.

## **United Ostomy Associations of America, Inc. (UOAA)**

800-826-0826

[www.ostomy.org](http://www.ostomy.org)

A volunteer-based health organization that supports people who have had or will have intestinal or urinary diversions. This includes providing education, information, support, and advocacy.

## **Women's Cancer Network**

312-578-1439

[www.wcn.org](http://www.wcn.org)

Works to inform people around the world about gynecologic cancers. Provides a personalized risk assessment tool to assess risk for gynecologic and breast cancers.

## **Wound, Ostomy, Contenance Nurses Society**

888-224-WOCN (888-224-9626)

[www.wocn.org](http://www.wocn.org)

Members are experts in the care of people with wounds, ostomies, and

continence disorders.

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit [www.mskcc.org/pe](http://www.mskcc.org/pe) to search our virtual library.

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Caring for Your Ileostomy or Colostomy - Last updated on August 15, 2022  
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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.aboutherbs.com](http://www.aboutherbs.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.

## **Gingko (also known as Gingko 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](http://www.mskcc.org/IntegrativeMedicine) or read *Integrative Medicine Therapies and Your Cancer Treatment* ([www.mskcc.org/pe/integrative\\_therapies](http://www.mskcc.org/pe/integrative_therapies)).

For more resources, visit [www.mskcc.org/pe](http://www.mskcc.org/pe) to search our virtual library.

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

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## 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](http://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.

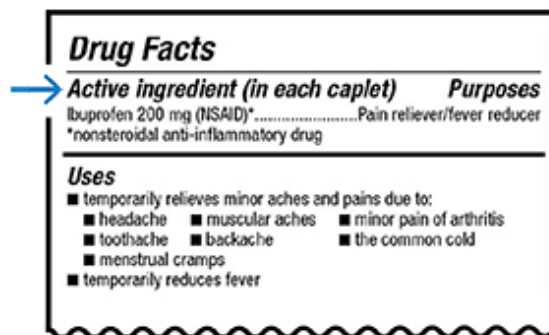


Figure 1. Active ingredients on an over-the-counter medicine label

# 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).

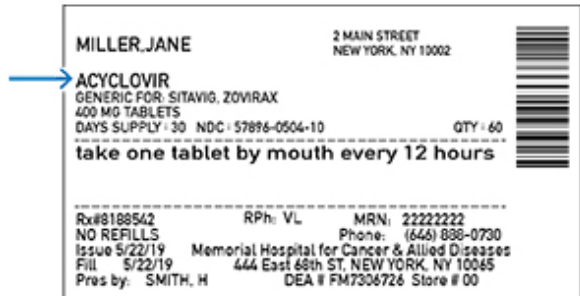


Figure 2. Active ingredients on a prescription medicine label

# 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.

	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)	90 IU	100%
Thiamin (as thiamin mononitrate)	1.5 mg	100%
Riboflavin	1.7 mg	100%
Niacin (as niacinamide)	20 mg	100%
Vitamin B <sub>6</sub> (as pyridoxine hydrochloride)	2.0 mg	100%
Folate (as folic acid)	400 mcg	100%
Vitamin B <sub>12</sub> (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"><li>• Acetylsalicylic acid</li><li>• Alpha-linolenic acid (ALA)</li><li>• Aspirin</li><li>• Acetaminophen*</li><li>• Celecoxib</li><li>• Diclofenac</li><li>• Diflunisal</li><li>• Docosahexaenoic acid (DHA)</li><li>• Eicosapentaenoic acid (EPA)</li></ul>	<ul style="list-style-type: none"><li>• Etodolac</li><li>• Fish oil</li><li>• Fenoprofen Flurbiprofen</li><li>• Ibuprofen</li><li>• Indomethacin</li><li>• Ketoprofen</li><li>• Ketorolac</li><li>• Meclofenamate</li><li>• Mefenamic acid</li><li>• Meloxicam</li></ul>	<ul style="list-style-type: none"><li>• Nabumetone</li><li>• Naproxen</li><li>• Omega-3 fatty acids</li><li>• Omega-6 fatty acids</li><li>• Oxaprozin</li><li>• Piroxicam</li><li>• Sulindac</li><li>• Tolmetin</li><li>• Vitamin E</li></ul>

\* 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"><li>• APAP</li><li>• Acetamin</li></ul>	<ul style="list-style-type: none"><li>• AC</li><li>• Acetam</li></ul>	<ul style="list-style-type: none"><li>• Acetaminop</li><li>• Acetaminoph</li></ul>

## 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](http://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

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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.

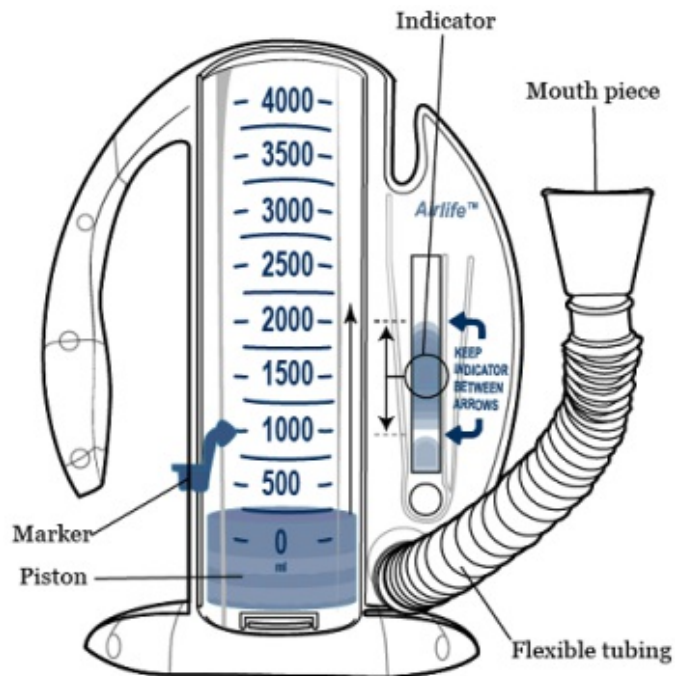


Figure 1. Parts of an incentive spirometer



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](http://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](http://www.mskcc.org/pe) to search our virtual library.

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

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