

PATIENT & CAREGIVER EDUCATION

# About Your Total Pelvic Exenteration and Wet Colostomy Surgery

This guide will help you get ready for your total pelvic exenteration (ek-senter-AY-shun) and wet colostomy (koh-LOS-toh-mee) surgery at MSK. It will also help you know what to expect as you recover.

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

#### Your care team

Doctor:	 	 _
Nurse:		
Phone number:		 _
Fax number:	 	 _



Visit www.msk.org/pe/pelvic-exenteration-wet-colostomy to view this guide online.

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## About your total pelvic exenteration and wet colostomy

During your total pelvic exenteration surgery, organs from your urinary, gastrointestinal, and gynecological systems will be removed and a wet colostomy will be created. You may be having this surgery because you have cancer in your gynecological, urinary, or gastrointestinal systems.

#### About your urinary system

Your urinary system makes urine (pee) and gets it out of your body (see Figure 1).

- Your kidneys clean the toxins out of your blood and make urine.
- Your ureters are tubes that carry urine from your kidneys to your bladder.
- Your bladder stores urine until you feel the need to urinate.
- Your urethra is a tube that carries the urine in your
   bladder out of your body when you urinate.

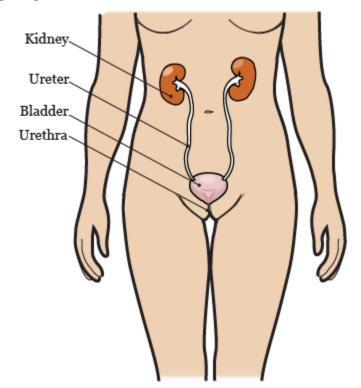


Figure 1. Your urinary system

- o In women, the urethra is very short. It's located above the vagina.
- o In men, the urethra is longer. It passes through the prostate gland and the penis.

During your surgery, your bladder and urethra will be removed. This means you'll need a new place for urine to exit your body. This will be the urinary diversion part of your stoma. For more information about your stoma, read the "About your wet colostomy" section.

#### About your gastrointestinal system

Your gastrointestinal system digests (breaks down) the things you eat and removes solid waste from your body (see Figure 2). It's made up of your mouth, esophagus, stomach, small intestine, large intestine (colon), rectum, and anus.

During your surgery, part of your colon, your rectum, and your anus will be removed. This means you'll need a new place for stool (poop) to leave your body. This will be the fecal (stool) diversion part of your stoma.

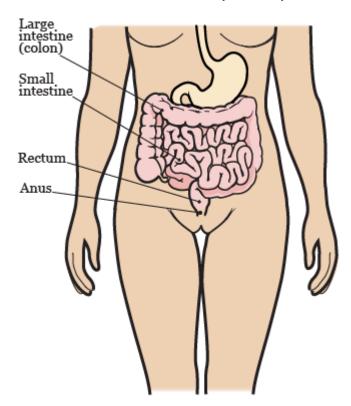


Figure 2. Your gastrointestinal system

#### About your gynecologic system

Your gynecologic system is also called your reproductive system. It's made up of your ovaries, fallopian tubes, uterus, and vagina (see Figure 3).

During your surgery, your ovaries, fallopian tubes, and uterus will be removed. This means that you will not be able to bear children. All or part of your vagina may also be removed.

If all or part of your vagina is being removed, your doctor will give you

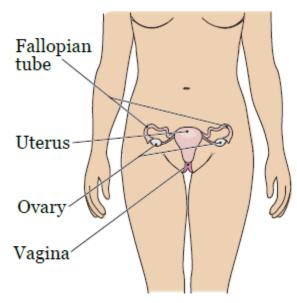


Figure 3. Your gynecologic system

more information. For some people, the vagina can be reconstructed (rebuilt) as part of the surgery. This is called vaginal reconstruction.

- If you're having a vaginal reconstruction, you'll meet with a plastic surgeon to talk about this part of your surgery. If you're having a vaginal reconstruction, your plastic surgeon will create a new vaginal canal using muscles and skin from your abdomen (belly) or inner thighs.
- If you're not having vaginal reconstruction, your vaginal opening will be closed or covered with a flap of skin.

If you have vaginal reconstruction or plastic surgery on your perineum (the area between your legs), you will not be able to sit for 6 to 8 weeks after your surgery. Your nurse will help you find positions that are comfortable for you.

#### Vaginal intercourse after surgery

If no part of your vagina is removed during your surgery, you'll probably be able to have vaginal intercourse once you have healed after surgery. If you have vaginal reconstruction, you may able to have vaginal intercourse when the area heals. Your surgeon will give you more information.

If your vagina is removed and you don't have vaginal reconstruction, you will not be able to have vaginal intercourse (vaginal sex). But, 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 doctor and nurse will tell you what to expect. For example, sensations may not be the same as they were before your surgery. You'll get a referral to our Female Sexual Medicine and Women's Health Program so that you can meet with a therapist and discuss your concerns.

#### About your wet colostomy

An ostomy is an opening made during surgery. To make the ostomy, a piece of your intestine will be pulled to the outside of your abdomen. The part of your intestine that's outside your body is called a stoma.

You'll have a type of ostomy called a wet colostomy. This will allow stool, gas, and urine to exit your body from the same opening (see Figure 4). Your wet colostomy is permanent.

You will not feel any pain or pressure within your stoma. You also will not feel heat or cold sensations within your stoma.

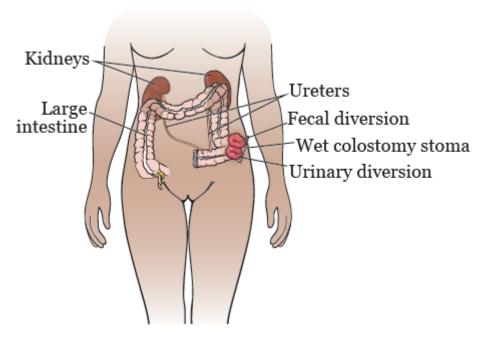


Figure 4. Wet colostomy stoma

#### About your healthcare team

You'll see many doctors and nurses before your surgery. Each one will describe their role in your care and answer your questions.

- You'll see a wound, ostomy, and continence (WOC) nurse, who
  specializes in caring for people with stomas. Your WOC nurse will go
  over the information in this resource with you. They'll also teach you
  about your wet colostomy and how to care for it.
- You may see surgeons from other departments who will work with your doctor to complete your surgery.
- You may see a psychologist who works with people having a total pelvic exenteration surgery.

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

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## Before your total pelvic exenteration and wet colostomy

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



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

Notes	

#### Getting ready for your surgery

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

- I take an anticoagulant (blood thinner), such as:
  - Aspirin
  - Heparin
  - Warfarin (Jantoven®, Coumadin®)
  - Clopidogrel (Plavix®)
  - Enoxaparin (Lovenox®)
  - Dabigatran (Pradaxa®)
  - Apixaban (Eliquis®)
  - Rivaroxaban (Xarelto®)
- I take an SGLT2 inhibitor, such as:
  - Canagliflozin (Invokana®)
  - o 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 ecigarette.
- 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.
  - o Feel nauseous (like you're going to throw up).
  - o Feel more anxious (nervous or worried) than usual.
  - Cannot sleep.

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

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

#### **About smoking**

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

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

#### About sleep apnea

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

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

#### **Using MyMSK**

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

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

Watch How to Enroll in MyMSK: Memorial Sloan Kettering's Patient Portal at www.msk.org/pe/enroll\_mymsk to learn more. You can also contact the MyMSK Help Desk by emailing mymsk@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.

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

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

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

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

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

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

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

#### Identify your caregiver

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

#### For caregivers



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

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

#### Fill out a Health Care Proxy form

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

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

- To learn about health care proxies and other advance directives, read Advance Care Planning. You can ask for a printed copy or find it at www.msk.org/pe/advance\_care\_planning
- To learn about being a health care agent, read How to Be a Health Care
   Agent. You can find it at www.msk.org/pe/health\_care\_agent or ask
   for a printed copy.

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

#### 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.

#### Do physical activity

Doing physical activity will help your body get into its best condition for your surgery. It will also make your recovery faster and easier.

Try to do physical activity every day. Any activity that makes your heart beat faster, such as walking, swimming, or biking, is a good choice. If it's cold outside, use stairs in your home or go to a mall or shopping center.

#### Follow a healthy diet

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

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

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

#### Buy bowel prep supplies

You'll need to do a bowel prep to clean out your bowels (colon) before your surgery. Your nurse will tell you what medicines you'll need and how to buy them from your local pharmacy.

#### **Buy clear liquids**

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

#### 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

You'll 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> <li>Clear broth, bouillon, and consommé.</li> </ul>	Anything with pieces of food or seasoning.
Sweets	<ul> <li>Gelatin, such as Jell-O®.</li> <li>Flavored ices.</li> <li>Hard candies, such as Life Savers®, lemon drops, and peppermints.</li> </ul>	All others.

(Table continued on next page)

	OK to have	Do not have
Drinks	<ul> <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™,</li> </ul>	<ul> <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>
	Pedialyte®, and Diabetishield®.	

#### Start your bowel prep

Follow your healthcare provider's instructions for starting your bowel prep.

Apply zinc oxide ointment (such as Desitin®) to the skin around your anus after every bowel movement (every time you poop). This helps prevent irritation.

#### Note the time of your surgery

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

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

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

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

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

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

  Use warm water.
- 6. Dry yourself off with a clean towel.

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

### Instructions for drinking: 8 hours before your arrival time

**8 hours before your arrival time**, do not eat or drink anything except the clear liquids listed below.

- Water.
- Soda.
- Clear juices, such as lemonade, apple, and cranberry juices. Do not drink orange juice or juices with pulp.
- Black coffee or tea (without any type of milk or creamer).
- Sports drinks, such as Gatorade®.
- ClearFast CF(Preop)® or Ensure® Pre-Surgery clear carbohydrate drink.
- Gelatin, such as Jell-O®.

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

#### The day of your surgery

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

### Instructions for drinking: 2 hours before your arrival time



**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 rescue inhaler (such as albuterol for asthma), 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.
- A list of the medicines you take at home.
- This guide. You'll use it to learn how to care for yourself after surgery.

#### Where to park

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

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

There are other parking garages on:

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

#### Once you're in the hospital

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

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

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

#### For caregivers, family, and friends



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

#### Meet with a nurse

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

Your nurse may place an intravenous (IV) line in one of your veins, usually in your arm or hand. If your nurse does not place the IV, your anesthesiologist (A-nes-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.

Your surgeon will close your incisions with staples or stitches once they finish your surgery. They may also place Steri-Strips $^{\text{TM}}$  (thin pieces of surgical tape) or Dermabond $^{\text{R}}$  (surgical glue) over your incisions. They may cover your incisions with a bandage.

## After your total pelvic exenteration and wet colostomy

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 or ask for a print copy.

#### Tubes, drains, pouch (bag), and bandages

You'll have tubes, drains, a pouch (bag), and bandages on your abdomen (see Figure 5).

Your nurse will give you information about the exact tubes and drains you have. They may include:

• A wound VAC covering your incision. This is a special dressing that lessens the pressure on your incision, which can help it heal.

- Jackson-Pratt (JP) drains near your incision. These also drain fluid from around your incision. They'll be taken out when your incision stops draining.
- A pouch (bag) on your wet colostomy stoma. This collects your stool
  and urine. The specific type of pouch you'll have is called a highoutput pouch.

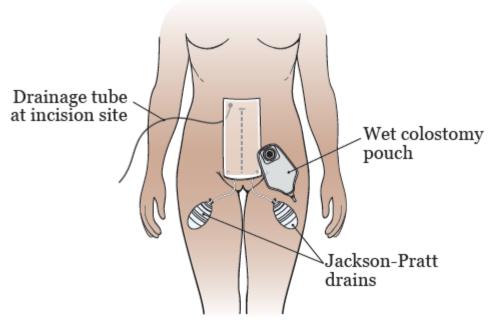


Figure 5. Drains, pouch, and bandages after your surgery

If you had vaginal reconstruction, you'll also have bandages and drains on the inside of your upper thighs.

When your healthcare provider changes your pouch, you'll see several tubes coming out of your stoma (see Figure 6). These include:

- A urinary catheter. This drains urine from the urinary diversion part of your wet colostomy.
- Stents (drainage tubes). These drain urine from your kidneys.
- A tube to support your stoma. This is called a rod or bridge.

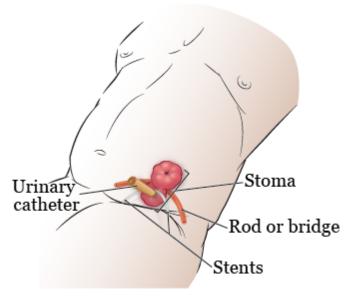


Figure 6. Tubes in your stoma

#### Moving to your hospital room

Most people stay in the PACU overnight. A staff member will bring you to your hospital room after your stay in the PACU.

#### In your hospital room

The length of time you're in the hospital after your surgery depends on your recovery. Most people stay in the hospital for 7 to 10 days after a total pelvic exenteration.

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.

If you had vaginal reconstruction or plastic surgery on your perineum (the area between your legs), you will not be able to sit for 6 to 8 weeks. You can lie on your back or side, or you can stand. Your nurse will help you with this.

#### Managing your pain

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

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

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

#### Moving around and walking

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

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

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

#### **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 or drink for 1 to 2 days after your surgery. Then, you'll be on a clear liquid diet. After that, you'll start to go back to your regular diet.

Your doctor will give you eating and drinking guidelines to follow after your surgery. You'll also meet with a dietitian while you're in the hospital to review these guidelines.

Eating a balanced diet high in protein will 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 find it at www.msk.org/pe/eating\_cancer\_treatment or ask for a printed copy.

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

#### **Showering**

Your doctor will tell you when you can shower.

#### Your drains, tubes, and incisions

You'll probably have some discharge and tenderness around most of your incisions or around your drains. You may also have some bleeding for a few days after surgery. Your nurses will show and tell you what's normal and expected. They'll also help you start learning how to care for your drains, tubes, and incisions.

Your drains and tubes will be removed over the next days to weeks. Removing them will not hurt, and you will not need anesthesia. If you go home with any tubes or drains, your nurses will teach you how to care for them before you leave the hospital.

If you have staples in any of your incisions, they may be taken out before you leave the hospital. If you go home with staples in your incisions, they'll be removed at your first appointment after surgery.

#### Your stoma and pouch (bag)

Your wet colostomy stoma will be covered with a pouch (bag) to collect stool and urine (see Figure 7).

At first, there will be tubes coming out of your stoma. They'll be removed as you heal. After the tubes are removed, you'll have 2 openings in your stoma: 1 for urine and 1 for stool.

Your WOC nurse and other nursing staff will teach you

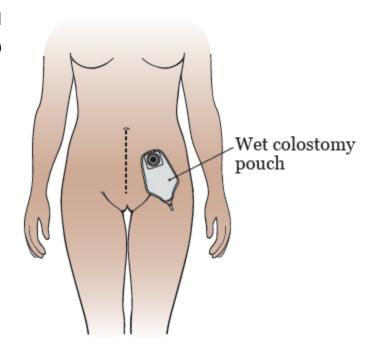


Figure 7. Your wet colostomy pouch

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

To learn more about your wet colostomy stoma, read *Caring for Your Wet Colostomy*. You can find it in the "Educational resources" section of this guide.

#### Planning for discharge

Your case manager will arrange for a home care nurse to visit you at home. The home care nurse will help you care for your incisions, drains, and stoma.

Your nurses will give you the supplies you'll need to care for yourself for the first month after your discharge. After the first month, you'll order your supplies from an outside source. Your case manager and WOC nurse will give you more information. You can also read *Caring for Your Wet Colostomy*. You can find it in the "Educational resources" section of this guide.

#### Leaving the hospital

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

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

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

# At home

You may still have tubes and drains when you go home. Ask your nurse or doctor when they'll be removed. Your home care nurse will help you learn how to care for your incisions and wet colostomy.

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

#### 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.

#### Caring for your incisions

Change your bandages at least once a day, or more often if they become wet with drainage. If there's more than a small amount of drainage on any of your bandages, contact your doctor's office to tell them.

You can stop using bandages when there's no longer any drainage coming from your incisions.

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

It's normal for the skin below your incisions to feel numb. This happens because some of the nerves were cut. 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.

### **Eating and drinking**

Follow the eating and drinking guidelines your doctor or clinical dietitian nutritionist gives you. You can also read *Caring for Your Wet Colostomy*. You can find it in the "Educational resources" section of this guide.

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

#### **Driving**

Your doctor will tell you when you can start driving again. Don't drive while you're taking prescription pain medicine that may make you drowsy

#### Physical activity and exercise

Doing gentle aerobic exercise, such as walking or stair climbing, will help you gain strength and feel better. Gradually increase the distance you walk.

Climb stairs slowly, resting or stopping as needed.

Don't do any demanding activities (such as running) for 2 to 3 months after surgery. Don't lift anything heavier than 10 pounds (4.5 kilograms) for 2 to 3

months after your surgery. Talk with your doctor before you begin doing demanding exercise or lifting heavy objects.

# Sexual activity

Talk with your doctor before starting sexual activity again. Ask them when it's safe for you to start and what kinds of sexual activities you can do. This will depend on the specific surgery you had, such as if you had vaginal reconstruction.

- Don't place anything inside your vagina or reconstructed vagina until your doctor tells you it's okay.
- Don't use your stoma for sexual activities.
- Before starting any sexual activity, check to see if your pouching system is secure and that there's no odor (smell). You may also want to empty your pouch.

Some people with ostomies prefer to cover their pouch with a cloth band or wrap, shirt, or lingerie during sexual activity. You can buy ready-made pouch covers or undergarments to help cover your pouching system.

Sexual health and intimacy is an important part of your recovery. If you have vaginal dryness, pain, or other issues, you may want to talk with someone from our Female Sexual Medicine & Women's Health Program. To reach the program, call 646-888-5076.

### **Emotional support**

Having a total pelvic exenteration will change your body. It will probably take time for you to adjust to these changes. You may feel frightened, angry, embarrassed, or worried. You may have questions or fears about how this surgery will impact your life and sexuality. These feelings are normal, and most people have them.

Everybody adjusts in their own way. For some people, it will take a few months to adjust to a changed body image. For other people, it may take longer. As time goes on, you should get stronger and become more confident in caring for your pouch.

We have many resources to help you. Your doctors and nurses will answer your questions. We also have social workers, psychologists, psychiatrists, and WOC nurses who have helped many people through this change. We also have clergy available for spiritual support.

You can have one-on-one counseling or you can join one of our online or inperson support groups. MSK has a live online support group for people who have ostomies. To learn more, go to www. msk.org/vp or send an email to virtualprograms@mskcc.org. You can also join a support group in your neighborhood.

Every new situation requires time to adjust. We are here to help you through this transition.

# When to call your healthcare provider



Call your healthcare provider if:

- You have a fever of 100.5 °F (38 °C) or higher.
- You have pain that does not get better after taking pain medicine.
- You have redness, drainage, swelling, or a smell from your incisions.
- You have vaginal bleeding or foul-smelling discharge.
- No urine is passing into your pouch (bag).
- You stool is passing into your pouch (bag).
- 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.

# **Support services**

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



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

Notes	 	 

# Ostomy and gynecological cancer support services

#### **Online Ostomy Support Group**

Visit www.msk.org/event/ostomy-support-group for information or to register.

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

800-826-0826

www.ostomy.org

Volunteer group that supports people who have or will have intestinal or urinary diversions or ostomies.

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

312-578-1439

www.wcn.org

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

#### Wound, Ostomy, Continence Nurses Society

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

www.wocn.org

This is a professional nursing society. Nursing members have special training in the care of people with wounds, ostomies, and incontinence.

# 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**

888-675-7722

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

#### **Counseling Center**

www.msk.org/counseling

646-888-0200

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

#### **Food Pantry Program**

646-888-8055

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

#### Integrative Medicine Service

www.msk.org/integrativemedicine

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

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

#### **MSK Library**

library.mskcc.org

212-639-7439

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

#### **Nutrition Services**

www.msk.org/nutrition

212-639-7312

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

#### **Patient and Community Education**

www.msk.org/pe

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

#### **Patient Billing**

646-227-3378

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

#### **Patient Representative Office**

212-639-7202

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

#### Perioperative Nurse Liaison

212-639-5935

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

#### **Private Duty Nurses and Companions**

917-862-6373

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

#### Rehabilitation Services

www.msk.org/rehabilitation

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

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

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

646-888-8106

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

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

#### **Sexual Health Programs**

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

- Our Female Sexual Medicine and Women's Health Program can help with sexual health problems such as premature menopause or fertility issues. Ask a member of your MSK care team for a referral or call 646-888-5076 to learn more.
- Our Male Sexual and Reproductive Medicine Program can help with sexual health problems such as erectile dysfunction (ED). Ask a member of your care team for a referral or call 646-888-6024 to learn more.

#### **Social Work**

www.msk.org/socialwork

212-639-7020

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

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

#### **Spiritual Care**

212-639-5982

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

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

#### **Tobacco Treatment Program**

www.msk.org/tobacco

212-610-0507

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

#### **Virtual Programs**

www.msk.org/vp

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

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

# **External support services**

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

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

Notes	

# **Educational resources**

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



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

Notes

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

- A Guide for Caregivers (www.msk.org/pe/guide\_caregivers)
- Advance Care Planning (www.msk.org/pe/advance\_care\_planning)
- Caring for Your Wet Colostomy
   (www.msk.org/pe/caring\_wet\_colostomy)
- Call! Don't Fall! (www.msk.org/pe/call\_dont\_fall)
- Eating Well During Your Cancer Treatment
   (www.msk.org/pe/eating\_cancer\_treatment)
- Frequently Asked Questions About Walking After Your Surgery
   (www.msk.org/pe/walking\_after\_surgery)
- Herbal Remedies and Cancer Treatment
   (www.msk.org/pe/herbal\_remedies)
- How to Be a Health Care Agent
   (www.msk.org/pe/health\_care\_agent)
- How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil (www.msk.org/pe/check-medsupplement)
- How to Enroll in MyMSK: Memorial Sloan Kettering's Patient Portal (www.msk.org/pe/enroll\_mymsk)
- How to Use Your Incentive Spirometer
   (www.msk.org/pe/incentive\_spirometer)
- Patient-Controlled Analgesia (PCA) (www.msk.org/pe/pca)
- What You Can Do to Avoid Falling (www.msk.org/pe/avoid\_falling)



PATIENT & CAREGIVER EDUCATION

# Caring for Your Wet Colostomy

This information will help you care for your wet colostomy.

# **About Your Wet Colostomy**

After your surgery, your urine (pee) and stool (poop) will leave your body through your wet colostomy stoma. Your stoma will have 2 parts (see Figure 1):

- A urinary diversion. Your urine will flow from your kidneys, through your ureters, and out of your body through your urinary diversion.
- A fecal diversion. Your stool will move through your large intestine (colon) and out of your body through your fecal diversion.

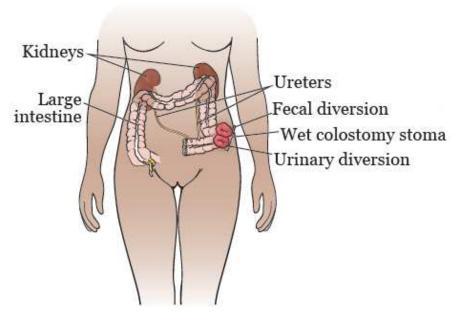


Figure 1. Wet colostomy

Your stoma should be a deep pink or red color at all times. While it's contracting and expanding to move stool out of your body, it may look slightly paler in color

(change from red to pink). This should only last for a few seconds to minutes. If your stoma looks dark maroon, grey, brown, or black, call your doctor right away.

Your stoma will slowly get smaller as it heals. This usually takes about 6 to 8 weeks after your surgery.

#### Learning about your wet colostomy

While you're in the hospital, your wound, ostomy, and continence (WOC) nurse and nursing staff will teach you how to care for your wet colostomy. Your case manager will arrange for a home care nurse to visit you at home after you're discharged from (leave) the hospital. They will also make sure you leave the hospital with enough supplies to care for your wet colostomy for the first month you're home.

After you're discharged, a home care nurse will help you care for your wet colostomy. At your first appointment after surgery, a WOC nurse will teach you more about caring for your wet colostomy. They will review how to:

- Empty your pouch
- Change your pouching system
- Care for your skin around your stoma
- Order supplies

If you have any questions or problems once you're home, call your doctor's office.

# **About your Pouching System**

After your surgery, you will wear an odor-proof pouching system over your wet colostomy. The pouching system will probably be a 2-piece system made up of a skin barrier (wafer) and a high-output collection pouch.

- The wafer sticks to your skin and is sized to fit around your stoma. It protects the skin from getting irritated by your urine and stool.
- The high-output pouch attaches to the wafer and collects your urine and stool. You will need to empty the pouch multiple times each day.

For the first 6 to 8 weeks after your surgery, you may need to change the size of your pouching system as your stoma gets smaller. Your WOC nurse and home care nurse will help you measure your stoma and find the pouching system that fits best.

While you're getting used to your wet colostomy and pouching system, you may find it helpful to buy a waterproof mattress cover. The cover will protect your bedding and mattress if the pouching system leaks.

#### **Emptying your pouch**

While you're in the hospital, your nurse and WOC nurse will teach you how to empty your pouch. After you leave the hospital, your home care nurse will help you get more comfortable with changing it.

Empty your pouch when it's  $\frac{1}{3}$  to  $\frac{1}{2}$  full. Don't let your pouch get too full.

You will also need to empty your pouch every night before bed. You can use a night drainage bag so you don't need to empty your pouch during the night. A night drainage bag connects to your pouching system and rests on the floor.

#### Changing your pouching system

Your WOC nurse will teach you how to change your pouching system. You should change your pouching system every 3 to 5 days. **If your pouching system is leaking, change it right away.** This is to keep urine or stool from irritating the skin around your stoma.

If you're having leakage or irritation, call your doctor's office to make an appointment with your WOC nurse. You may need a different pouching system that fits your stoma better.

#### About wearing gloves

You can decide if you want to wear gloves when you change your pouching system. Just as you didn't wear gloves when using the bathroom before your wet colostomy, you don't need to wear them now. You can wear gloves if you will feel more comfortable, but there's no risk of infection if you don't wear them.

Wash your hands before and after caring for your pouching system.

#### What to do if you see blood on your stoma

Your stoma has many blood vessels and may bleed easily. It's normal to see a small amount of blood on the gauze when you're cleaning your stoma.

If your stoma starts bleeding, apply pressure to the area that's bleeding. It should stop on its own within a few minutes. If you take a blood thinner or aspirin, you may bleed more easily and for a longer time. Call your doctor if you bleed a lot or if the bleeding doesn't stop after 5 to 10 minutes.



If there's blood in your stool or coming from the inside of your stoma, call your doctor right away.

#### Odor control

Pouching systems are designed to be odor-proof. You shouldn't smell anything while your pouching system is in place. If you do notice an odor, this means there's urine or stool leaking underneath the wafer or that the outside of the pouching system is dirty.

There will be some odor when you're emptying your pouch or changing your pouching system. There are deodorants that you can put into your pouch to help lessen the odor. The deodorants come as drops, charcoal tablets, or lubricating gels. You may need to try a few different types to find one that works best for you. Check with your doctor or nurse before using any deodorants in your pouch. You can also buy a deodorant spray to help freshen the air after you empty your pouch.

# **Ordering Ostomy Supplies**

Talk with your WOC nurse about ordering supplies. Your WOC nurse is familiar with the latest products on the market. You can also call companies and ask for samples of their products. You may want to wait to do this until you're comfortable with caring for your stoma. Too many options may get overwhelming.

#### Mail-order medical supply companies

Mail-order supply companies will mail your supplies to you every month. Choose a company that accepts your insurance. You can call the company directly to find out. If they don't accept your insurance, call your insurance company to get a list of suppliers that do.

The company you're ordering from will contact your doctor's office to get a prescription for your supplies. It's important for you to give your doctor's office a clear and complete list of the supplies you need, including the product numbers, so they can send a correct prescription to the supply company.

Below is a list of some mail-order medical supply companies. These companies offer many different products. You can call and ask them to send you a catalog, or you can view one online.

#### **Liberator Medical** Byram Healthcare

877-902-9726 877-649-7359

www.byramhealthcare.com www.liberatormedical.com

#### **CCS Medical McKesson Medical-Surgical**

800-722-2604 800-453-5180

www.ccsmed.com www.mckesson.com

#### 180 Medical **Edgepark Medical Supplies** (ConvaTec supplies only)

888-394-5375

www.edgepark.com www.180medical.com

You can also buy ostomy supplies at your local pharmacy or medical supply store. However, the prices may be higher, or they may not take your insurance. Also, they may not be able to get the exact product you need.

877-688-2729

#### Ostomy product manufacturers

If you have questions about your supplies, you can call an ostomy product manufacturer. Many of these companies have a WOC nurse on staff to answer questions. You can also call to ask for samples of products.

Below is a list of some companies that make ostomy products (such as wafers and pouches) and other ostomy accessories (such as barrier strips, powders, and rings).

Coloplast Hollister

888-726-7872 888-740-8999

www.coloplast.us www.hollister.com

ConvaTec Marlen

800-422-8811 216-292-7060

www.convatec.com www.marlenmfg.com

Cymed Nu-Hope Laboratories, Inc.

800-582-0707 800-899-5017

www.cymed-ostomy.com www.nu-hope.com

# Lifestyle Issues

#### Staying hydrated

It's important to drink 8 to 10 (8-ounce) glasses of liquids every day. This will help you stay hydrated, keep your kidneys healthy, and keep urine flowing. Limit the amount of caffeine and alcohol you drink, because these things can make you dehydrated.

If you get diarrhea (loose or watery bowel movements), call your doctor's office. Make sure to drink extra liquids so you don't get dehydrated. You should also call your doctor's office if you feel nauseous (like you're going to throw up) or weak.

#### **Nutrition**

Your appetite may be smaller than it was before your surgery. You will probably be able to eat the same foods you did before your surgery. Foods that upset your stomach before your surgery may still upset your stomach 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 discomfort and bloating after eating this food, avoid it.

Now that you have a wet colostomy, you won't be able to control when you pass gas. You may want to avoid things that increase gas, such as:

- Cruciferous vegetables (such as cabbage and broccoli)
- Carbonated drinks
- Drinking through a straw
- Chewing gum

If you have tried avoiding these things but have a problem with gas, talk with your WOC nurse or a clinical dietitian nutritionist.

If you're having problems with gas building up inside your pouch, talk with your WOC nurse. They may suggest using pouches with charcoal filters. The filter can help keep gas from building up and inflating your pouch. You may also find it useful to use a pouch with a filter when you travel on an airplane, because the altitude changes may cause air pressure to build up inside your pouch.

If you're constipated (having fewer bowel movements than usual):

- Drink more liquids.
- Eat foods that are high in fiber, such as fruits, vegetables, and bran.
- Exercise, if you can. Walking is an excellent form of exercise.

#### **Exercise**

Talk with your doctor about what exercise is right for you. For most people, walking and light stretching are good exercises to do while recovering from surgery. Avoid lifting or pushing anything heavier than 10 pounds (4.5 kilograms) for 2 to 3 months after your surgery. This includes housework such as vacuuming or mowing the lawn. If this will be a problem for you, talk with your doctor.

Don't do sit-ups, push-ups, or any strenuous exercise for 2 to 3 months after your

surgery. This will help prevent a hernia (bulging of your intestines through a weakened abdominal muscle) near or around your stoma.

Your WOC nurse can measure you for a hernia belt to wear while you exercise. Your nurse will also tell you how you can order one.

#### Showering, bathing, and swimming

Your colostomy pouching system is waterproof. Always wear your pouching system when you take a bath or swim. You can use waterproof tape around the edges of the wafer or adhesive strips to help keep a tight seal around your pouching system, if needed. Most people can wear the same swimsuit they wore before their surgery. Some companies sell swim wraps or bathing suits to cover the pouching system.

You can shower with or without your pouching system. If you shower without your pouching system, urine, stool, or both may leak out of your stoma and you will need to clean the shower area afterward.

#### Positioning your pouch

You can position your pouch downward or to the side. You can also fold it, if you prefer.

## Wearing a belt

Try to wear the belt above or below your stoma. If the belt is worn directly on your stoma, it can cause irritation, bleeding, or an overgrowth of tissue. There are stoma guards that help protect your stoma from being injured by your belt. If you'd like to order a stoma guard, ask your WOC nurse for more information.

#### Going back to work

You can go back to work when you and your doctor feel you have recovered and are able to work.

You may feel uncomfortable going back to work. This is okay. Your pouching system probably won't be visible. You will probably be able to wear most of the same clothes you wore before your surgery.

You can choose if you want to tell your coworkers, friends, or family about your wet colostomy. Usually, people won't know you have a wet colostomy unless you tell them.

### T maeling

Some people are nervous the first few times they travel. If you feel anxious, it may help to look up the locations of some bathrooms on your route.

Always carry 2 sets of extra supplies with you wherever you go, even if it's only a short trip or a doctor's appointment. This way, you will be prepared in case you have an accident while away from home. Remember to bring:

- Pouches
- Wafers
- Clamps (if you have a pouching system with a clamp closure)
- Cleaning items such as paper towels, gauze, or wipes
- Adhesive remover wipes and skin prep wipes
- A trash bag for dirty items

If you're going to be away from home for several hours, think about where you're going and prepare yourself in case you need to empty your pouch while you're out of the house.

When you're traveling on an airplane:

- 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 aren't available.
- You may want to precut your pouches at home and pack them already cut into your travel bag.

You may want to bring a letter from your doctor that says that you have an ostomy and need ostomy supplies. The letter should also ask transportation security

administration (TSA) staff members to use a private area if they need to do an extended search. You may also want to carry copies of the catalog pages that show and explain your equipment.

If you're traveling to a foreign country, it's a good idea to have important ostomy information written in that language. One of the 70 members of the International Ostomy Association may be able to help with this translation and with finding supplies while visiting their country. For more information, visit <a href="https://www.ostomyinternational.org">www.ostomyinternational.org</a>.

The United Ostomy Association of America web site (www.uoaa.org) has more information and travel tips that you can print and use.

# **About Parastomal Hernias**

If the area around your stoma seems to bulge, you may have a hernia. A hernia is when a loop of bowel (intestine) pokes through a weak area of muscle. This causes a bulge to form. A hernia that's near a stoma is called a parastomal hernia. If you see a bulge around your stoma, contact your doctor or WOC nurse.

Hernias can feel tender, uncomfortable, like pressure, or like something is hanging. Sometimes, hernias can become twisted or blocked and need to be treated.

If your hernia is causing pain or any other symptoms, call your doctor's office. You should also call your doctor's office if you have:

- Nausea (feeling like you're going to throw up) or vomiting (throwing up)
- Pain in your abdomen (belly)
- Bloating in your abdomen and no gas or stool in your pouch

If you have a parastomal hernia, your WOC nurse can suggest a hernia support belt. You can also use a girdle, specially made spandex clothes, or biking shorts to support the hernia. If you use biking shorts, you will need to cut out a hole for your pouch. Talk with your WOC nurse about what will work best for your needs.

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

# **About Urinary Tract Infections (UTIs)**

The signs and symptoms of a UTI are:

- Cloudy urine
- Back pain
- Nausea and vomiting
- Loss of appetite
- Fever of 100.4 °F (38 °C) or higher

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

To keep from getting a UTI:

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

## What to do Before Medical Tests

Always bring an extra set of supplies when going to the doctor for tests. You may need to remove your pouching system for the test.

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

#### Imaging scan with contrast

If you're having a scan with contrast, bring an extra pouch and wafer, including an extra leg bag or night bag (if you use one). For the scan, you will need to drink more liquids than usual. This will help the contrast leave your body, but it will also increase your urine output. You may need the extra pouch and wafer if you have a leak because of increased urine output.

## Chemotherapy

If you're having chemotherapy, bring an extra pouch and wafer, including an extra leg bag or night bag. Chemotherapy may cause your body to make more urine. Using a leg bag or night drainage bag during treatment may help prevent leakage due to increased urine output.

Chemotherapy may also make your skin more sensitive or change the way the wafer sticks to your skin. Schedule an appointment with your WOC nurse if you notice changes to the skin around your stoma or have issues with your pouching system while you're getting chemotherapy.

# What to Do Before Being 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. The hospital may have a different product than the one you use, or they may not have any supplies at all.

# **Contact Your Doctor or Nurse if:**

- Your stoma looks dark maroon, grey, brown, or black.
- Your stoma bleeds for longer than 5 to 10 minutes.
- There's blood coming from the inside of your stoma.
- There's blood in your stool.
- You're having problems with your pouching system leaking.
- The skin around your stoma is irritated.

- You have diarrhea.
- You feel nauseous or weak.

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

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

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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 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 or read Integrative Medicine Therapies and Your Cancer Treatment (www.mskcc.org/pe/integrative\_therapies).

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

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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) 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.

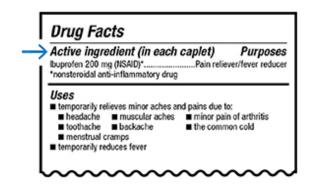


Figure 1. Active ingredients on an over-the-counter medicine label

# **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).

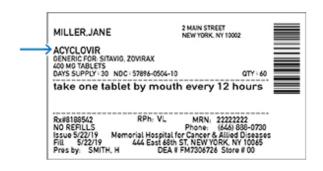


Figure 2. Active ingredients on a prescription medicine label

## **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
itamin A (as retinyl acetate and 50% as beta-carotene)	5000 IU	100%
itamin C (as ascorbic acid)	60 mg	100%
itamin D (as cholecalciferol)	400 IU	100%
itamin E (as di-alpha tocopheryl acetate)	30 IU	100%
hiamin (as thiamin monoitrate)	1.5 mg	100%
iboflavin	1.7 mg	100%
liacin (as niacinamide)	20 mg	100%
tamin B <sub>e</sub> (as pyridoxine hydrocholride)	2.0 mg	100%
olate (as folic acid)	400 mcg	100%
itamin B <sub>12</sub> (as cyanocobalamin)	6 mcg	100%
iotin	30 mog	10%
antothenic Acid (as calcium pantothenate)	10 mg	100%

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> <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> <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> <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>	

<sup>\*</sup> 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			
• APAP	• AC	Acetaminop	
Acetamin	Acetam	Acetaminoph	

#### **About acetaminophen (Tylenol)**

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

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

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

# **Instructions before your cancer treatment**

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

# **Before your surgery**

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

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

# Before your radiology procedure

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

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

# Before and during your chemotherapy

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

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

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

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

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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.

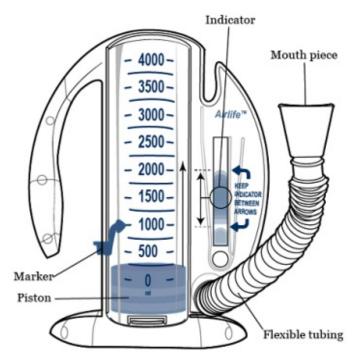


Figure 1. Parts of an incentive spirometer

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 to watch this video.

# Setting up your incentive spirometer

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

# Knowing what number to aim for on your incentive spirometer

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

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

incentive spirometer" section.

## Using your incentive spirometer

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

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

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

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

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

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

# Tips for using your incentive spirometer

Follow these tips when using your incentive spirometer:

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

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

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

# Common questions about your incentive spirometer

### How often should I use my incentive spirometer?

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

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

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

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

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

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

# How do I clean my incentive spirometer?

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

# What do the numbers on my incentive spirometer measure?

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

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

## What number I should aim for?

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

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

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

# What does the coaching indicator on my incentive spirometer measure?

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

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

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

# When to call your healthcare provider

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

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

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

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

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