About Your Total Pelvic Exenteration Surgery and Wet Colostomy

This guide will help you get ready for your total pelvic exenteration surgery with a wet colostomy at Memorial Sloan Kettering (MSK). It will also help you learn about your wet colostomy and understand what to expect during your recovery.

Read through this guide at least once before your surgery and use it as a reference in the days leading up to your surgery.

Bring this guide with you every time you come to MSK, including the day of your surgery. You and your healthcare team will refer to it throughout your care.

Your Care Team

Doctor: ________________________________________________

Phone number: __________________________________________

Fax number: ____________________________________________

Nurse: ________________________________________________

Your Caregiver

It’s important to choose a person to be your caregiver. They will learn about your surgery with you and help you care for yourself while you’re recovering after surgery. Write down your caregiver’s name below.

Caregiver: _____________________________________________
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About Your Surgery

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.
  - In women, the urethra is very short. It’s located above the vagina.
  - 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 will 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.
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 will need a new place for stool (poop) to leave your body. This will be the fecal (stool) diversion part of your stoma.
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 won't 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 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 will 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 won't 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 will probably be able to have vaginal intercourse once you have healed after surgery. If you have vaginal reconstruction, you may be 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 won’t 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 will 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 will 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 will 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 won’t feel any pain or pressure within your stoma. You also won’t feel heat or cold sensations within your stoma.
About Your Healthcare Team

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

- You will 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 will 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.

Notes

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The information in this section will help you get ready for your surgery. Read through this section when your surgery is scheduled and refer to it as your surgery date gets closer. It has important information about what you need to do before your surgery.

Write down your questions and be sure to ask your doctor or nurse.
Getting Ready for Your Surgery

You and your healthcare team will work together to get ready for your surgery.

About Drinking Alcohol

The amount of alcohol you drink can affect you during and after your surgery. It’s important to talk with your healthcare providers about how much alcohol you drink. This will help us plan your care.

- If you stop drinking alcohol suddenly, it can cause seizures, delirium, and death. If we know you’re at risk for these complications, we can prescribe medications to help keep them from happening.
- If you drink alcohol regularly, you may be at risk for other complications during and after your surgery. These include bleeding, infections, heart problems, and a longer hospital stay.

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. If you develop a headache, nausea (feeling like you’re going to throw up), increased anxiety, or can’t sleep after you stop drinking, tell your healthcare provider right away. These are early signs of alcohol withdrawal and can be treated.
- Tell your healthcare provider if you can’t stop drinking.
- Ask your healthcare provider questions about drinking and surgery. As always, all of your medical information will be kept confidential.

Help us keep you safe during your surgery by telling us if any of the following statements apply to you, even if you aren’t sure.

- I take a blood thinner. Some examples are aspirin, heparin, warfarin (Coumadin®), clopidogrel (Plavix®), enoxaparin (Lovenox®), dabigatran (Pradaxa®), apixaban (Eliquis®), and rivaroxaban (Xarelto®). There are others, so be sure your healthcare provider knows all the medications you’re taking.
- I take prescription medications (medications prescribed by a healthcare provider), including patches and creams.
- I take over-the-counter medications (medications I buy without a prescription), including patches and creams.
- I take dietary supplements, such as herbs, vitamins, minerals, or natural or home remedies.
- I have a pacemaker, automatic implantable cardioverter-defibrillator (AICD), or other heart device.
- I have sleep apnea.
- I have had a problem with anesthesia (medication to make you sleep during surgery) in the past.
- I am allergic to certain medication(s) or materials, including latex.
- I am not willing to receive a blood transfusion.
- I drink alcohol.
- I smoke.
- I use recreational drugs.
About Smoking
If you smoke, you can have breathing problems when you have surgery. Stopping even for a few days before surgery can help. If you smoke, your nurse will refer you to our Tobacco Treatment Program. You can also reach the program by calling 212-610-0507.

About Sleep Apnea
Sleep apnea is a common breathing disorder that causes you to stop breathing for short periods of time while sleeping. The most common type is obstructive sleep apnea (OSA). With OSA, your airway becomes completely blocked during sleep. OSA can cause serious problems during and after surgery.

Please tell us if you have sleep apnea or if you think you might have it. If you use a breathing machine (such as a CPAP machine) for sleep apnea, bring it with you the day of your surgery.

Within 30 Days of Your Surgery

Presurgical Testing (PST)
Before your surgery, you will have an appointment for presurgical testing (PST). The date, time, and location of your PST appointment will be printed on the appointment reminder from your surgeon’s office.

You can eat and take your usual medications the day of your PST appointment.

During your appointment, you will meet with a nurse practitioner (NP) who works closely with anesthesiology staff (doctors and specialized nurses who will give you anesthesia during your surgery). Your NP will review your medical and surgical history with you. You will have tests, including an electrocardiogram (EKG) to check your heart rhythm, a chest x-ray, blood tests, and any other tests needed to plan your care. Your NP may also recommend that you see other healthcare providers.

Your NP will talk with you about which medications you should take the morning of your surgery.

It’s very helpful to bring the following things to your PST appointment:

- A list of all the medications you’re taking, including prescription and over-the-counter medications, patches, and creams.
- Results of any tests done outside of MSK, such as a cardiac stress test, echocardiogram, or carotid doppler study.
- The name(s) and telephone number(s) of your healthcare provider(s).

Identify Your Caregiver
Your caregiver plays an important role in your care. You and your caregiver will learn about your surgery from your doctor and nurse. After your surgery, your caregiver should be with you when you’re given your discharge instructions so they’re able to help you care for yourself at home. Your caregiver will also need to take you home after you’re discharged from (leave) the hospital.
Complete a Health Care Proxy Form

If you haven’t already completed a Health Care Proxy form, we recommend you complete one now. A health care proxy is a legal document that identifies the person who will speak for you if you can’t communicate for yourself. The person you identify is called your health care agent. For more information about health care proxies and other advance directives, read the resource Advance Care Planning. You can find it online at www.mskcc.org/pe/advance_care_planning, or you can ask your nurse.

If you’re interested in completing a Health Care Proxy form, talk with your nurse. If you have completed one already, or if you have any other advance directives, bring them to your next appointment.

Do Breathing and Coughing Exercises

Practice taking deep breaths and coughing before your surgery. You will be given an incentive spirometer to help expand your lungs. For more information, read How to Use Your Incentive Spirometer, located in the “Educational Resources” section of this guide. If you have any questions, ask your nurse or respiratory therapist.

Exercise

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

Follow a Healthy Diet

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

10 Days Before Your Surgery

Stop Taking Vitamin E

If you take vitamin E, stop taking it 10 days before your surgery. Vitamin E can cause bleeding. For more information, read Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), located in the “Educational Resources” section of this guide.

Buy Hibiclens® Skin Cleanser

Hibiclens is a skin cleanser that kills germs for 24 hours after you use it (see figure). Showering with Hibiclens before your surgery will help lower your risk of infection after surgery. You can buy Hibiclens at your local pharmacy without a prescription.
Buy Supplies for Your Bowel Preparation
You will need to do a bowel preparation to clean out your bowels (colon) before your surgery. Your nurse will tell you what medications you will need and how to buy them from your local pharmacy.

Buy Clear Liquids
You will need to follow a clear liquid diet before your surgery. Now is a good time to buy your supplies. For a list of clear liquids you can drink, read the section “Follow a Clear Liquid Diet.”

7 Days Before Your Surgery

Stop Taking Certain Medications
If you take aspirin, ask your doctor if you should keep taking it. Aspirin and medications that contain aspirin can cause bleeding. For more information, read Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), located in the “Educational Resources” section of this guide.

Stop Taking Herbal Remedies and Other Dietary Supplements
Stop taking herbal remedies and other dietary supplements 7 days before your surgery. If you take a multivitamin, ask your doctor or nurse if you should keep taking it. For more information, read Herbal Remedies and Cancer Treatment, located in the “Educational Resources” section of this guide.

Watch a Virtual Tour
This video will give you an idea of what to expect when you come to Memorial Hospital (MSK’s main hospital) on the day of your surgery.

www.mskcc.org/pe/day-your-surgery

2 Days Before Your Surgery

Stop Taking Certain Medications
Stop taking nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Advil®, Motrin®) and naproxen (Aleve®), 2 days before your surgery. These medications can cause bleeding. For more information, read Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), located in the “Educational Resources” section of this guide.
Follow a Clear Liquid Diet

You will need to follow a clear liquid diet the day before your surgery. A clear liquid diet includes only liquids you can see through. Examples are listed in the “Clear Liquid Diet” table.

While you’re following this diet:

- Don’t eat any solid foods.
- Try to drink at least 1 (8-ounce) glass of clear liquid every hour while you’re awake.
- Drink different types of clear liquids. Don’t just drink water, coffee, and tea.
- Don’t drink sugar-free liquids unless you have diabetes and a member of your healthcare team tells you to do so.

For People With Diabetes

If you have diabetes, ask the healthcare provider who manages your diabetes what you should do while you’re following a clear liquid diet.

- If you take insulin or another medication for diabetes, ask if you need to change the dose.
- Ask if you should drink sugar-free clear liquids.

While you’re following a clear liquid diet, make sure to check your blood sugar level often. If you have any questions, talk with your healthcare provider.

### Clear Liquid Diet

<table>
<thead>
<tr>
<th>Drink</th>
<th>Do Not Drink</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Soups</strong></td>
<td>• Clear broth, bouillon, or consommé</td>
</tr>
<tr>
<td><strong>Sweets</strong></td>
<td>• Gelatin (such as Jell-O®)</td>
</tr>
<tr>
<td></td>
<td>• Flavored ices</td>
</tr>
<tr>
<td></td>
<td>• Hard candies (such as Life Savers®)</td>
</tr>
<tr>
<td><strong>Drinks</strong></td>
<td>• Clear fruit juices (such as lemonade, apple, cranberry, and grape juices)</td>
</tr>
<tr>
<td></td>
<td>• Soda (such as ginger ale, 7-Up®, Sprite®, and seltzer)</td>
</tr>
<tr>
<td></td>
<td>• Sports drinks (such as Gatorade®)</td>
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<tr>
<td></td>
<td>• Black coffee</td>
</tr>
<tr>
<td></td>
<td>• Tea</td>
</tr>
<tr>
<td></td>
<td>• Water</td>
</tr>
</tbody>
</table>
Start Your Bowel Preparation

Follow your doctor or nurse’s instructions for starting your bowel preparation.

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 from the Admitting Office will call you after 2:00 PM the day before your surgery. If your surgery is scheduled for a Monday, they will call you on the Friday before. If you don’t get a call by 7:00 PM, please call 212-639-5014.

The staff member will tell you what time to arrive at the hospital for your surgery. Use the area to the right to write down your surgery date and scheduled arrival time.

The staff member will also tell you where to go. This will be the following location:

Presurgical Center (PSC) on the 6th floor
1275 York Avenue (between East 67th and East 68th Streets)
New York, NY 10065
B elevator to 6th floor

Shower With Hibiclens

The night before your surgery, shower using Hibiclens.

1. Use your normal shampoo to wash your hair. Rinse your head well.
2. Use your normal soap to wash your face and genital area. Rinse your body well with warm water.
3. Open the Hibiclens bottle. Pour some solution into your hand or a washcloth.
4. Move away from the shower stream to avoid rinsing off the Hibiclens too soon.
5. Rub the Hibiclens gently over your body from your neck to your feet. Don’t put the Hibiclens on your face or genital area.
6. Move back into the shower stream to rinse off the Hibiclens. Use warm water.
7. Dry yourself off with a clean towel after your shower.
8. Don’t put on any lotion, cream, deodorant, makeup, powder, perfume, or cologne after your shower.

Sleep

Go to bed early and get a full night’s sleep.
Instructions for eating and drinking before your surgery

• Do not eat anything after midnight the night before your surgery. This includes hard candy and gum.

• Between midnight and up until 2 hours before your scheduled arrival time, you may drink a total of 12 ounces of water (see figure).

• Starting 2 hours before your scheduled arrival time, do not eat or drink anything. This includes water.

The Morning of Your Surgery

Take Your Medications

If your doctor or NP told you to take certain medications the morning of your surgery, take only those medications with a sip of water. Depending on what medications you take and the surgery you’re having, this may be all, some, or none of your usual morning medications.

Shower With Hibiclens

Shower using Hibiclens just before you leave for the hospital. Use the Hibiclens the same way you did the night before.

Don’t 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.

• Don’t wear any metal objects. Remove all jewelry, including body piercings. The equipment used during your surgery can cause burns if it touches metal.

• Don’t put on any lotion, cream, deodorant, makeup, powder, perfume, or cologne.

• Leave valuable items (such as credit cards, jewelry, and your checkbook) at home.

• Before you’re taken into the operating room, you will need to remove your hearing aids, dentures, prosthetic device(s), wig, and religious articles.

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What to Bring

- Your breathing machine 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 portable music player, if you choose. However, someone will need to hold it for you when you go into surgery.
- Your incentive spirometer, if you have one.
- Your Health Care Proxy form and other advance directives, if you have completed them.
- Your cell phone and charger.
- Only the money you may want for small purchases (such as a newspaper).
- A case for your personal items (such as eyeglasses, hearing aid(s), dentures, prosthetic device(s), wig, and religious articles), if you have one.
- A list of the medications you take at home.
- This guide. Your healthcare team will use this guide to teach you how to care for yourself after your surgery.

Where to Park

MSK’s parking garage is located on East 66th Street between York and First Avenues. If you have questions about prices, call 212-639-2338.

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

There are also other garages located on East 69th Street between First and Second Avenues, East 67th Street between York and First Avenues, and East 65th Street between First and Second Avenues.
Once You’re in the Hospital

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

You will be asked to say and spell your name and birth date many times. This is for your safety. People with the same or a similar name may be having surgery on the same day.

Get Dressed for Surgery

When it’s time to change for surgery, you will get a hospital gown, robe, and nonskid socks to wear.

Meet With Your Nurse

You will meet with your nurse before surgery. Tell them the dose of any medications (including patches and creams) you took after midnight and the time you took them.

Your nurse may place an intravenous (IV) line into one of your veins, usually in your arm or hand. If your nurse doesn’t place the IV, your anesthesiologist will do it later once you’re in the operating room.

Meet With Your Anesthesiologist

Your anesthesiologist will:

- Review your medical history with you.
- Ask you if you’ve had any problems with anesthesia in the past, including nausea or pain.
- Talk with you about your comfort and safety during your surgery.
- Talk with you about the kind of anesthesia you will have.
- 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 medication after your surgery.

Get Ready for Your Surgery

Once your nurse has seen you, 1 or 2 visitors can keep you company as you wait for your surgery to start. When it’s time for your surgery, your visitor(s) will be taken to the waiting area. Your visitors should read Information for Family and Friends for the Day of Surgery, located in the “Educational Resources” section of this guide.

You will either walk into the operating room or be taken in on a stretcher. A member of the operating room team will help you onto the operating bed. Compression boots will be placed 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 will fall asleep. You will also get fluids through your IV line during and after your surgery.
During Your Surgery

After you’re fully asleep, a breathing tube will be placed through your mouth and into your windpipe to help you breathe. You will also have a urinary (Foley®) catheter placed to drain urine from your bladder.

Once your surgery is finished, your incision will be closed with staples or sutures (stitches). You may also have Steri-Strips™ (thin pieces of surgical tape) or Dermabond® (surgical glue) over your incisions. Your incisions may be covered with a bandage. Your breathing tube is usually taken out while you’re still in the operating room.
The information in this section will tell you what to expect after your surgery, both during your hospital stay and after you leave the hospital. You will learn how to safely recover from your surgery.

Write down your questions and be sure to ask your doctor or nurse.
In the Post-Anesthesia Care Unit (PACU)

When you wake up after your surgery, you will be in the Post-Anesthesia Care Unit (PACU). A nurse will be monitoring your body temperature, pulse, blood pressure, and oxygen levels. You may be getting oxygen through a thin tube that rests below your nose or a mask that covers your nose and mouth. You will also have compression boots on your lower legs.

Pain Medication

You will get epidural or IV pain medication while you're in the PACU.

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

You will be able to control your pain medication using a button called a patient-controlled analgesia (PCA) device. For more information, read Patient-Controlled Analgesia (PCA), located in the “Educational Resources” section of this guide.

Tubes and Drains

You will have tubes, drains, a pouch, and bandages on your abdomen (see Figure 5). Your nurse will give you information about the exact tubes and drains that 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 will be taken out when your incision stops draining.
- **A pouch on your wet colostomy stoma.** This collects your stool and urine. The specific type of pouch you will have is called a high-output pouch.
If you had vaginal reconstruction, you will also have bandages and drains on the inside of your upper thighs.

When your doctor or nurse changes your pouch, you will 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.
Visitors

Your visitors can see you briefly in the PACU, usually within 90 minutes after you arrive there. A member of the nursing staff will explain the guidelines to them.

Moving to Your Hospital Room

Most people stay in the PACU overnight. After your stay in the PACU, you will be taken to your hospital room.

In Your Hospital Room

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

When you’re taken to your hospital room, you will meet one of the nurses who will care for you and teach you how to care for yourself while you’re recovering from your surgery.

If you had vaginal reconstruction or plastic surgery on your perineum (the area between your legs), you won’t 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.

Read the resource Call! Don’t Fall! to learn about what you can do to stay safe and keep from falling while you’re in the hospital. You can find it online at www.mskcc.org/pe/call_dont_fall, or you can ask your nurse.

Managing Your Pain

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

Your doctor and nurse will ask you about your pain often and give you medication as needed. If your pain isn’t relieved, tell your doctor or nurse. It’s important to control your pain so you can use your incentive spirometer and move around. Controlling your pain will help you recover better.

You will be given a prescription for pain medication before you leave the hospital. Talk with your doctor or nurse about possible side effects and when you should start switching to over-the-counter pain medications.

Moving Around and Walking

Start moving around and walking as soon as you’re able to. Walking every 2 hours is a good goal. Walking helps lower your risk for blood clots and pneumonia. Someone from the nursing staff will help you until you’re able to walk on your own. They will also teach you how to get out of bed without causing pain to your incisions.
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. For more information, read *How to Use Your Incentive Spirometer*, located in the “Educational Resources” section of this guide.

- Do coughing and deep breathing exercises. A member of your care team will teach you how to do these exercises.

Eating and Drinking

You won’t be able to eat or drink for 1 to 2 days after your surgery. Then, you will be on a clear liquid diet. After that, you will start to go back to your regular diet.

Your doctor will give you eating and drinking guidelines to follow after your surgery. You will 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 the resource *Eating Well During and After Your Cancer Treatment*. You can find it online at www.mskcc.org/pe/eating_cancer_treatment, or you can ask your nurse.

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 will 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 will 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 won’t hurt, and you won’t 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 will be removed at your first appointment after surgery.
Your Stoma and Pouch

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

![Wet colostomy pouch](image)

Figure 7. Your wet colostomy pouch

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

Your WOC nurse and other nursing staff will teach you 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.

For more information about your wet colostomy stoma, read the resource *Caring for Your Wet Colostomy*, located in the “Educational Resources” section of this guide.

Planning for Your 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 will need to care for yourself for the first month after your discharge. After the first month, you will order your supplies from an outside source. Your case manager and WOC nurse will give you more information. You can also read the resource *Caring for Your Wet Colostomy*, located in the “Educational Resources” section of this guide.
Leaving the Hospital

By the time you leave the hospital, your incisions will have started to heal. Before you leave the hospital, look at your incisions with your nurse and caregiver. Knowing what your incisions look like will help you notice any changes later.

On the day of your discharge, you should plan to leave the hospital around 11:00 am. Before you leave, your doctor will write your discharge order and prescriptions. Your nurse will also give you written instructions for how to care for your incision, drains, and wet colostomy.

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

At Home

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

Read the resource What You Can Do to Avoid Falling to learn about what you can do to stay safe and keep from falling at home and during your appointments at MSK. You can find it online at www.mskcc.org/pe/avoid_falling, or you can ask your nurse.

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 medication. Some people have soreness, tightness, or muscle aches around their incision for 6 months or longer. This doesn’t mean that something is wrong.

Follow the guidelines below to help manage your pain at home.

- Take your medications as directed and as needed.
- Call your doctor if the medication prescribed for you doesn’t ease your pain.
- Don’t drive or drink alcohol while you’re taking prescription pain medication.
- As your incision heals, you will have less pain and need less pain medication. An over-the-counter pain reliever such as acetaminophen (Tylenol®) or ibuprofen (Advil®) will ease aches and discomfort.
  - Follow your doctor or nurse’s instructions for stopping your prescription pain medication.
  - Don’t take more acetaminophen than the amount directed on the bottle or as instructed by your doctor or nurse. Taking too much acetaminophen can harm your liver.
- Pain medication should help you resume your normal activities. Take enough medication to do your exercises comfortably. However, it’s normal for your pain to increase a little as you start to be more active.
- Keep track of when you take your pain medication. It works best 30 to 45 minutes after you take it. Taking it when your pain first begins is better than waiting for the pain to get worse.
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 go home with Steri-Strips or Dermabond on your incisions, they will loosen and fall or peel off by themselves. If they haven't fallen off within 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 doctor's office if:

• The skin around your incision is very red.
• The skin around your incision is getting more red.
• You see drainage that looks like pus (thick and milky).

Eating and Drinking

Follow the eating and drinking guidelines that your doctor or clinical dietitian nutritionist gives you. You can also read the resource Caring for Your Wet Colostomy, located 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 medication 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 in-person support groups. MSK has a live online support group for people who have ostomies. For more information, go to [www.mskcc.org/vp](http://www.mskcc.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.

**Using MyMSK**

MyMSK (my.mskcc.org) is your MSK patient portal account. You can use MyMSK to send and receive messages from your healthcare team, view your test results, see your appointment dates and times, and more.

If you don’t already have a MyMSK account, you can sign up by going to my.mskcc.org. For more information about signing up for a MyMSK account, watch our video *How to Enroll in the Patient Portal: MyMSK* at [www.mskcc.org/pe/enroll_mymsk](http://www.mskcc.org/pe/enroll_mymsk). You can also contact the MyMSK Help Desk by emailing mymsk@mskcc.org or calling 800-248-0593.
Contact your doctor or nurse if you have:

- A temperature of 100.4 °F (38 °C) or higher.
- Pain that doesn’t get better with pain medication.
- Redness, drainage, swelling, or a smell from your incisions.
- Vaginal bleeding or foul-smelling discharge.
- No urine passing into the pouch.
- No stool passing into the pouch.
- Any questions or concerns.

Monday through Friday from 9:00 AM to 5:00 PM, contact your doctor’s office.

After 5:00 PM, during the weekend, and on holidays, call 212-639-2000 and ask to speak to the doctor on call for your doctor.
This section contains a list of support services that may help you get ready for your surgery and recover safely.

Write down your questions and be sure to ask your doctor or nurse.

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MSK Support Services

**Ostomy Support Groups**

**Online Ostomy Support Group**
Send your email address to virtualprograms@mskcc.org to take part in an online ostomy support group.

**General Support Services**

**Anesthesia**
212-639-6840
Call if you have questions about anesthesia.

**Blood Donor Room**
212-639-7643
Call for more information if you’re interested in donating blood or platelets.

**Bobst International Center**
888-675-7722
MSK welcomes patients from around the world. If you’re an international patient, call for help arranging your care.

**Chaplaincy Service**
212-639-5982
At MSK, our chaplains are available to listen, help support family members, pray, contact community clergy or faith groups, or simply be a comforting companion and a spiritual presence. Anyone can request spiritual support, regardless of formal religious affiliation. The interfaith chapel is located near Memorial Hospital’s main lobby and is open 24 hours a day. If you have an emergency, please call the hospital operator and ask for the chaplain on call.

**Counseling Center**
646-888-0200
Many people find that counseling helps them. We provide counseling for individuals, couples, families, and groups, as well as medications to help if you feel anxious or depressed. To make an appointment, ask your healthcare provider for a referral or call the number above.

**Food Pantry Program**
646-888-8055
The food pantry program provides food to people in need during their cancer treatment. For more information, talk with your healthcare provider or call the number above.

**Integrative Medicine Service**
646-888-0800
Integrative Medicine Service offers patients many services to complement traditional medical care, including music therapy, mind/body therapies, dance and movement therapy, yoga, and touch therapy.
Look Good Feel Better Program  
www.lookgoodfeelbetter.org  
800-395-LOOK (800-395-5665)  
This program offers workshops to learn things you can do to help you feel better about your appearance. For more information or to sign up for a workshop, call the number above or visit the program’s website.

MSK Library  
library.mskcc.org  
212-639-7439  
You can visit our library website or speak with the library reference staff to find more information about your specific cancer type. You can also visit LibGuides on MSK’s library website at libguides.mskcc.org.

Patient and Caregiver Support Program  
212-639-5007  
You may find it comforting to speak with a cancer survivor or caregiver who has been through a similar treatment. Through our Patient and Caregiver Support Program, you’re able to speak with former patients and caregivers. These conversations may take place in person, over the phone, or through email.

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 if you have 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 Nursing Office  
212-639-6892  
You may request private nurses or companions. Call for more information.

Resources for Life After Cancer (RLAC) Program  
646-888-8106  
At MSK, care doesn’t end after active treatment. The RLAC Program is for patients and their families who have finished treatment. This program has many services, including seminars, workshops, support groups, counseling on life after treatment, and help with insurance and employment issues.

Sexual Health Programs  
Cancer and cancer treatments can have an impact on your sexual health. MSK’s Sexual Health Programs can help you take action and address sexual health issues before, during, or after your treatment.

• Our Female Sexual Medicine and Women’s Health Program helps women who are dealing with cancer-related sexual health challenges, including premature menopause and fertility issues. For more information, or to make an appointment, call 646-888-5076.

• Our Male Sexual and Reproductive Medicine Program helps men who are dealing with cancer-related sexual health challenges, including erectile dysfunction. For more information, or to make an appointment, call 646-888-6024.
Social Work  
212-639-7020  
Social workers help patients, family, and friends deal with issues that are common for people with cancer. They provide individual counseling and support groups throughout the course of treatment and can help you communicate with children and other family members. Our social workers can also help refer you to community agencies and programs, as well as financial resources if you're eligible.

Tobacco Treatment Program  
212-610-0507  
If you want to quit smoking, MSK has specialists who can help. Call for more information.

For more online information, visit the “Cancer Types” section of www.mskcc.org.

External Support Services

Ostomy and Gynecological Cancer Support Services

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.

General Support Services

Access-A-Ride  
web.mta.info/nyct/paratran/guide.htm  
877-337-2017  
In New York City, the MTA offers a shared ride, door-to-door service for people with disabilities who aren’t able to take the public bus or subway.

Air Charity Network  
www.aircharitynetwork.org  
877-621-7177  
Provides travel to treatment centers.
American Cancer Society (ACS)
www.cancer.org
800-ACS-2345 (800-227-2345)
Offers a variety of information and services, including Hope Lodge, a free place for patients and caregivers to stay during cancer treatment.

Cancer and Careers
www.cancerandcareers.org
A resource for education, tools, and events for employees with cancer.

CancerCare
www.cancercare.org
800-813-4673
275 Seventh Avenue (Between West 25th & 26th Streets)
New York, NY 10001
Provides counseling, support groups, educational workshops, publications, and financial assistance.

Cancer Support Community
www.cancersupportcommunity.org
Provides support and education to people affected by cancer.

Caregiver Action Network
www.caregiveraction.org
800-896-3650
Provides education and support for those who care for loved ones with a chronic illness or disability.

Corporate Angel Network
www.corpangelnetwork.org
866-328-1313
Offers free travel to treatment across the country using empty seats on corporate jets.

Gilda’s Club
www.gildasclubnyc.org
212-647-9700
A place where men, women, and children living with cancer find social and emotional support through networking, workshops, lectures, and social activities.

Good Days
www.mygooddays.org
877-968-7233
Offers financial assistance to pay for copayments during treatment. Patients must have medical insurance, meet the income criteria, and be prescribed medication that is part of the Good Days formulary.

Healthwell Foundation
www.healthwellfoundation.org
800-675-8416
Provides financial assistance to cover copayments, health care premiums, and deductibles for certain medications and therapies.

Joe’s House
www.joeshouse.org
877-563-7468
Provides a list of places to stay near treatment centers for people with cancer and their families.
LGBT Cancer Project
www.lgbtcancer.org
Provides support and advocacy for the LGBT community, including online support groups and a database of LGBT-friendly clinical trials.

LIVESTRONG Fertility
www.livestrong.org/we-can-help/fertility-services
855-744-7777
Provides reproductive information and support to cancer patients and survivors whose medical treatments have risks associated with infertility.

National Cancer Institute
www.cancer.gov
800-4-CANCER (800-422-6237)

National Cancer Legal Services Network
www.nclsn.org
Free cancer legal advocacy program.

National LGBT Cancer Network
www.cancer-network.org
Provides education, training, and advocacy for LGBT cancer survivors and those at risk.

Needy Meds
www.needymeds.org
Lists Patient Assistance Programs for brand and generic name medications.

NYRx
www.nyrxplan.com
Provides prescription benefits to eligible employees and retirees of public sector employers in New York State.

Partnership for Prescription Assistance
www.pparx.org
888-477-2669
Helps qualifying patients without prescription drug coverage get free or low-cost medications.

Patient Access Network Foundation
www.panfoundation.org
866-316-7263
Provides assistance with copayments for patients with insurance.

Patient Advocate Foundation
www.patientadvocate.org
800-532-5274
Provides access to care, financial assistance, insurance assistance, job retention assistance, and access to the national underinsured resource directory.

RxHope
www.rxhope.com
877-267-0517
Provides assistance to help people get medications that they have trouble affording.
This section contains the educational resources that were referred to throughout this guide. These resources will help you get ready for your surgery and recover safely after surgery.

Write down your questions and be sure to ask your doctor or nurse.
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.

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
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 ⅓ to ½ 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.

**Byram Healthcare**
877-902-9726
www.byramhealthcare.com

**Liberator Medical**
877-649-7359
www.liberatormedical.com

**CCS Medical**
800-722-2604
www.ccsmed.com

**McKesson Medical-Surgical**
800-453-5180
www.mckesson.com

**Edgepark Medical Supplies**
888-394-5375
www.edgepark.com

**180 Medical**
(ConvaTec supplies only)
877-688-2729
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.

**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**
888-726-7872  
www.coloplast.us

**Hollister**
888-740-8999  
www.hollister.com

**ConvaTec**
800-422-8811  
www.convatec.com

**Marlen**
216-292-7060  
www.marlenmfg.com

**Cymed**
800-582-0707  
www.cymed-ostomy.com

**Nu-Hope Laboratories, Inc.**
800-899-5017  
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.
Traveling

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 www.ostomyinternational.org.

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 ⅓ to ½ 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.
Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs)

This information will help you identify medications that contain aspirin and other nonsteroidal anti-inflammatory drugs (NSAIDs). It’s important to stop these medications before many cancer treatments.

Aspirin, other NSAIDs (such as ibuprofen), and vitamin E can increase your risk of bleeding during cancer treatment. These medications affect your platelets, which are blood cells that clot to prevent bleeding.

Read the section “Examples of Medications” to see if your medications contain aspirin, other NSAIDs, or vitamin E.

If you take aspirin, medications that contain aspirin, other NSAIDs, or vitamin E, tell your doctor or nurse. They will tell you if you need to stop taking these medications before your treatment. You will also find instructions in the information about the treatment you’re having.

Before Your Surgery

If you’re having surgery, follow the instructions below.

- Stop taking medications that contain vitamin E 10 days before your surgery, or as directed by your doctor.

- Stop taking medications that contain aspirin 7 days before your surgery, or as directed by your doctor. If you take aspirin because you’ve had a problem with your heart or you’ve had a stroke, be sure to talk with your doctor.
before you stop taking it.

- Stop taking NSAIDs 48 hours before your surgery, or as directed by your doctor.

Examples of Medications

Medications are often called by their brand name, which can make it hard to know their ingredients. To help you identify medications that contain aspirin, other NSAIDs, and vitamin E, please review the lists below.

These lists include the most common products, but there are others. Check with your healthcare provider if you aren’t sure. **Always be sure your doctor knows all of the medications you’re taking, both prescription and over-the-counter (not prescription).**

<table>
<thead>
<tr>
<th>Common Medications that Contain Aspirin</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggrenox®</td>
</tr>
<tr>
<td>Alka Seltzer®</td>
</tr>
<tr>
<td>Anacin®</td>
</tr>
<tr>
<td>Arthritis Pain Formula</td>
</tr>
<tr>
<td>Arthritis Foundation Pain Reliever®</td>
</tr>
<tr>
<td>ASA Enseals®</td>
</tr>
<tr>
<td>ASA Suppositories®</td>
</tr>
<tr>
<td>Ascriptin® and Ascriptin A/D®</td>
</tr>
<tr>
<td>Aspergum®</td>
</tr>
<tr>
<td>Common Medications that are NSAIDs that Don’t Contain Aspirin</td>
</tr>
<tr>
<td>-------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Advil®</strong></td>
</tr>
<tr>
<td><strong>Advil Migraine®</strong></td>
</tr>
<tr>
<td><strong>Aleve®</strong></td>
</tr>
<tr>
<td><strong>Anaprox DS®</strong></td>
</tr>
<tr>
<td><strong>Ansaid®</strong></td>
</tr>
<tr>
<td><strong>Arthrotec®</strong></td>
</tr>
<tr>
<td><strong>Bayer® Select Pain Relief Formula Caplets</strong></td>
</tr>
<tr>
<td><strong>Celebrex®</strong></td>
</tr>
<tr>
<td><strong>Celecoxib</strong></td>
</tr>
<tr>
<td><strong>Children’s Motrin®</strong></td>
</tr>
</tbody>
</table>
Products that Contain Vitamin E

<table>
<thead>
<tr>
<th>Product</th>
<th>Vitamin Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amino-Opt-E</td>
<td>Aquavit E-400 IU E complex-600</td>
</tr>
<tr>
<td>Aquasol E</td>
<td>D’alpha E E-1000 IU Softgels Vita-Plus E</td>
</tr>
</tbody>
</table>

Most multivitamins contain vitamin E. If you take a multivitamin, be sure to check the label.

About Acetaminophen

Acetaminophen (Tylenol®) is generally safe to take during your cancer treatment. It doesn’t affect platelets, so it won’t increase your chance of bleeding. However, talk with your doctor before taking acetaminophen if you’re getting chemotherapy.

Medications that Contain Acetaminophen

| Acetaminophen with Codeine       | Excedrin P.M.®          | Percocet®          | Vanquish®          |
| Aceta® with Codeine              | Esgic®                  | Panadol®           | Tylenol® with Codeine No. 3 |
| Aspirin-Free Anacin®             | Fiorcet®                | Repan              | Vicodin®           |
| Arthritis Pain Formula® Aspirin-Free | Lorcet®               | Roxiset®           | Wygesic®           |
| Darvocet-N 100®                  | Lortab®                 | Talacen®           | Zydone®            |
| Datril®                         | Naldegesic®             | Tempra®            |                    |

Read the labels on all your medications

Acetaminophen is safe when used as directed, but there’s a limit to how much you can take in 1 day. It’s possible to take too much acetaminophen without knowing because it’s in many different medications.
Make sure to always read and follow the label on the product you’re taking. Acetaminophen is a very common ingredient found in over-the-counter and prescription medications. It’s often an ingredient in pain relievers, fever reducers, sleep aids, and cough, cold, and allergy medications.

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

<table>
<thead>
<tr>
<th>Common Abbreviations for Acetaminophen</th>
</tr>
</thead>
<tbody>
<tr>
<td>APAP</td>
</tr>
<tr>
<td>Acetamin</td>
</tr>
</tbody>
</table>

Don’t take more than 1 medication that contains acetaminophen at a time without talking with a member of your healthcare team.
Herbal Remedies and Cancer Treatment

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

One week before you have surgery or start chemotherapy or radiation therapy, you must stop taking any herbal or botanical home remedies or other dietary supplements. This is because they can:

- Interact with your other medications.
- Increase or lower your blood pressure.
- Thin your blood and increase your risk of bleeding.
- Make radiation therapy less effective.
- Increase the effects of sedation or anesthesia (medications to make you sleepy).

You can continue to use herbs in your food and drinks, such as using spices in cooking and drinking tea. However, you must stop taking herbal supplements before your treatment. Herbal supplements are stronger than the herbs you would use in cooking.

**Common Herbal Supplements and Their Effects**

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

**Echinacea**

- Can cause an allergic reaction, such as a rash or difficulty breathing.
• Can lower the effects of medications used to weaken the immune system.

**Garlic**

• Can lower your blood pressure, fat, and cholesterol levels.
• Can increase your risk of bleeding.

**Gingko (also known as *Gingko biloba*)**

• Can increase your risk of bleeding.

**Ginseng**

• Can lower the effects of sedation or anesthesia.
• Can increase your risk of bleeding.
• Can lower your blood glucose (sugar) level.

**Turmeric**

• Can make chemotherapy less effective.

**St. John’s Wort**

• Can interact with medications given during surgery.
• Can make your skin more sensitive to radiation or laser treatment.

**Valerian**

• Can increase the effects of anesthesia or sedation.

**Herbal formulas**

• Herbal formulas contain different herbs. We don’t know their side effects. You must also stop taking these products 1 week before treatment. Do not start taking herbal formulas again until your doctor tells you it’s safe.

This information does not cover all herbal remedies or possible side effects. Speak with your healthcare provider if you have any questions or concerns.
For more information about herbs and botanicals, visit the Memorial Sloan Kettering (MSK) Integrative Medicine Service website at www.aboutherbs.com.
How to Use Your Incentive Spirometer

This information will help you learn how to use your incentive spirometer.

About Your Incentive Spirometer

An incentive spirometer is a device that will expand your lungs by helping you to breathe more deeply and fully. The parts of your incentive spirometer are labeled in Figure 1.

![Figure 1. Incentive Spirometer](image)

Use your incentive spirometer after your surgery and do your deep breathing and coughing exercises. This will help keep your lungs active throughout your
recovery and prevent complications such as pneumonia.

How To Use Your Incentive Spirometer

Here is a video demonstrating how to use your incentive spirometer:

Please visit mskcc.org/pe/incentive_spirometer to watch this video.

Setting up your incentive spirometer

The first time you use your incentive spirometer, you will need to take the flexible tubing with the mouthpiece out of the bag. Stretch out the tubing and connect it to the outlet on the right side of the base (see Figure 1). The mouthpiece will be attached to the other end of the tubing.

Using your incentive spirometer

When you are using your incentive spirometer, make sure to breathe through your mouth. If you breathe through your nose the incentive spirometer will not work properly. You can plug your nose if you have trouble.

If you feel dizzy at any time, stop and rest. Try again at a later time.

To use your incentive spirometer, follow the steps below.

1. Sit upright in a chair or in bed. Hold the incentive spirometer at eye level.
   - If you had surgery on your chest or abdomen (belly), hug or hold a pillow to help splint or brace your incision (surgical cut) while you’re using the incentive spirometer. This will help decrease pain at your incision.

2. Put the mouthpiece in your mouth and close your lips tightly around it. Slowly breathe out (exhale) completely.

3. Breathe in (inhale) slowly through your mouth as deeply as you can. As you take the breath, you will see the piston rise inside the large column. While the piston rises, the indicator on the right should move upwards. It should stay in between the 2 arrows (see Figure 1).

4. Try to get the piston as high as you can, while keeping the indicator
between the arrows.

- If the indicator does not stay between the arrows, you are breathing either too fast or too slow.

5. When you get it as high as you can, hold your breath for 10 seconds, or as long as possible. While you’re holding your breath, the piston will slowly fall to the base of the spirometer.

6. Once the piston reaches the bottom of the spirometer, breathe out slowly through your mouth. Rest for a few seconds.

7. Repeat 10 times. Try to get the piston to the same level with each breath.

8. After each set of 10 breaths, try to cough, holding a pillow over your incision, as needed. Coughing will help loosen or clear any mucus in your lungs.

9. Put the marker at the level the piston reached on your incentive spirometer. This will be your goal next time.

Repeat these steps every hour that you are awake.

Cover the mouthpiece of the incentive spirometer when you are not using it.
Information for Family and Friends for the Day of Surgery

This information explains what to expect on the day your friend or family member is having surgery at Memorial Sloan Kettering’s (MSK) main hospital.

Before the Surgery

After arriving at the hospital, the patient will be asked to provide contact information for the person who will be meeting with the surgeon after the surgery. This is the same person who will get updates from the nurse liaison during the surgery. If the patient is having an outpatient procedure, they will also be asked to provide contact information for the person who will be taking them home.

Once the patient is checked in, they will go to the Presurgical Center (PSC) to be examined before surgery. Sometimes, they may need to wait before they are admitted to the PSC.

In the PSC, the nurse will do an exam. One person can come along to the PSC, but other visitors should wait in the waiting area. If the patient wants, other visitors may join them when the nurse has finished the exam.

When the operating room (OR) is ready, a member of the surgical team will come to escort the patient into the OR. They will prepare the patient for surgery, which can take 15 to 90 minutes. Then, the surgery will begin.

Please remember the following:

- **Do not bring food or drinks to the waiting area.** Patients are not allowed to eat or drink before their surgery or procedure.

- Our patients are at high risk for infection. Please do not visit if you have any cold or flu symptoms (fever, sneezing, sniffling, or a cough). We may ask you
to wear a mask if there are any concerns about your health.

- If the patient brought any valuables, such as a cell phone, iPod, or iPad, please keep them safe for them during surgery.

- Sometimes, surgeries may be delayed. We make every effort to tell you when this happens.

**During the Surgery**

After the patient is taken to the OR, please wait in the main lobby on the 1st floor, where you will be updated by the nurse liaison. While you’re waiting, here are some things you can do:

- Food and drinks are available in the cafeteria and gift shop. You can also bring your own food and eat it in the cafeteria.

- The coat-check room is located at the bottom of the escalator on the ground level. It’s open Monday through Friday from 11:00 am to 4:00 pm.

- Wireless Internet access is available in most areas of the hospital. The wifi network name is MSK_guest. You can also use the computers in the room off the main lobby.

- Please be courteous and mindful of others while using your cell phone. Use the designated area to accept and make calls on your cell phone. It may be useful to bring your phone charger to the hospital.

- The Mary French Rockefeller All Faith Chapel is an interfaith chapel located in room M106 near the main lobby on the 1st floor. It’s open at all times for meditation and prayer.

- The Patient Recreation Pavilion is open daily from 9:00 am to 8:00 pm for patients and their visitors. Children are allowed in the pavilion as long as they are supervised by an adult. The pavilion has arts and crafts, a library, an outdoor terrace, and scheduled entertainment events. To get to the pavilion, take the M elevators to the 15th floor.

**Surgery updates**

A nurse liaison will keep you updated on the progress of surgery. They will:

- Give you information about the patient.
• Prepare you for your meeting with the surgeon.
• Arrange for you to visit the patient in the Post Anesthesia Care Unit (PACU).

To contact the nurse liaison:

• From inside the hospital, use a hospital courtesy phone. Dial 2000 and ask for beeper 9000. Please be patient, as this can take up to 2 minutes.
• Ask the information desk staff to contact the nurse liaison for you.

After the Surgery

Meeting with the surgeon
When the patient’s surgery is completed, we will call you and ask you to return to the concierge desk to tell you where to go to meet with the surgeon.

After you have met with the surgeon, return to the concierge desk and tell them that you have finished your consultation.

Visiting the patient in the PACU
After surgery, the patient will be taken to the PACU. It can take up to 90 minutes before the patient is ready to have visitors. You can use this time to take a walk or just relax in the waiting area until the patient is ready to see you.

When the patient is able to have visitors, a staff member will take you to the PACU for one brief visit. No one is allowed to stay overnight with the patient in the PACU, except for caregivers of pediatric patients.

Please follow these guidelines before your visit:

• Silence your cell phone.
• Apply an alcohol-based hand sanitizer (such as Purell®) before entering. There are hand sanitizer stations located throughout the hospital.
• Do not bring food or flowers into the PACU.

Please remember that only a limited number of visitors can go into the PACU. This is to keep the area quiet and allow the patients to rest and receive care.
While visiting in the PACU

- Speak quietly.
- Respect other patients’ privacy by staying at the bedside of your friend or family member.
- If any PACU patient needs special nursing attention, we may ask you to leave or to delay your visit.

The nurse will update you with the plan of care for the patient, such as whether the patient is staying overnight and when they will be moved to an inpatient room. If the patient is staying overnight, you may visit them again in the PACU. If the patient is going home the same day, a caregiver must take them home.

After your visit, a staff member will escort you back from the PACU.

We will give you a card with the PACU phone number. Please choose one person to call for updates.
Patient-Controlled Analgesia (PCA)

This information will help you understand what patient-controlled analgesia (PCA) is and how to use your PCA pump.

PCA helps you control your pain by letting you give yourself pain medication. It uses a computerized pump to deliver pain medication into your vein (intravenous, or IV PCA) or into your epidural space, which is in your spine (see Figure 1). Whether you have an IV PCA or an epidural PCA depends on what you and your doctor decide is right for you.

PCA is not right for everyone. Some people may not be able to use PCA. Tell your doctor if you have weakness in your hands and think you may have trouble pushing the PCA button. Also, before you get PCA, tell your doctor if you have sleep apnea. This may affect the way we prescribe your medication. People who are confused or cannot follow these instructions should not use PCA.

Using the PCA

To give yourself pain medication, press the button attached to the pump when you have pain. The pump will deliver a safe dose that your doctor has prescribed.

Only you should push the PCA button. Family and friends should never push the button.
The pump can be programmed to deliver your medication in 2 ways:

- **As needed.** You get your pain medication only when you press the button. It will not allow you to get more medication than prescribed. The pump is set to allow only a certain number of doses per hour.

- **Continuous.** You get your pain medication at a constant rate all the time. This can be combined with the “as needed” mode. That allows you to take extra doses safely if you’re having pain.

Tell your doctor if your PCA is not helping with your pain. Also, tell your doctor if your pain changes, such as if it gets worse, feels different than before, or you feel pain in a new place. Your doctor may be able to change the medication to one that may work better for you.

## Side Effects

Pain medication delivered by the PCA can have side effects. Tell your doctor or nurse if you have any of these problems:

- Constipation
- Nausea or vomiting
- Dry mouth
- Itching
- Changes in your vision, such as seeing things that aren’t there
- Drowsiness, dizziness, or confusion
- Weakness, numbness, or tingling in your arms or legs
- Difficulty urinating
- Any other side effects or problems

Your doctor may be able to give you a different medication that has fewer side effects.