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About Your Surgery

This guide will help you prepare for your abdominal perineal resection (APR) surgery at Memorial Sloan Kettering Cancer Center (MSK), and help you understand what to expect during your recovery. Read through this guide at least once before your surgery and then 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, so that you and your healthcare team can refer to it throughout your care.

Your Digestive System

Understanding how your digestive system works can be helpful as you prepare for and recover from your surgery. Your digestive system is made up of organs that break down food, absorb nutrients, and remove waste from your body. They include your mouth, esophagus (food pipe), stomach, small intestine, colon (large intestine), rectum, and anus (see Figure 1).

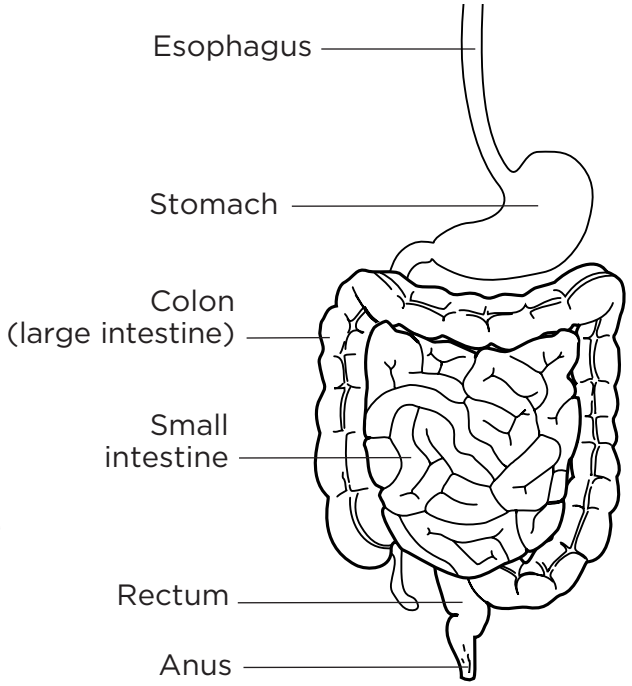


Figure 1: The digestive system

After your food has been chewed and swallowed, it moves into your esophagus. This is a long, muscular tube that serves as a passageway for food as it travels from your mouth into your stomach. Once the food enters your stomach, it mixes with stomach acids. These acids begin to break down or digest the food.

When the food leaves your stomach, it moves into your small intestine. There, it continues to be digested and absorbed. Many nutrients are absorbed in your small intestine. Anything that is not absorbed is called waste. The waste then moves into your colon, where some water is reabsorbed (taken back) into your body. The remaining waste enters the last portion of your colon known as the rectum. Your rectum serves as a holding area for these waste products until they are eliminated through your anus.

Abdominal Perineal Resection (APR)

APR is a surgery that is done to treat cancer of the anus or rectum (see Figure 1). To remove the cancer, your surgeon will remove all of the following:

- The lower part of your colon
- Your rectum
- Your anus

An APR can be done using different techniques. Your surgeon will talk with you about which options are right for you. Depending on what type of surgery you have, your surgeon will make one or more incisions (surgical cuts) in your abdomen (belly). When one long incision is made on the belly, this is called open surgery. When several small incisions are made on the belly, this is called minimally invasive surgery. Small surgical instruments and a video camera are inserted into the incisions to remove the cancer. Some surgeons use a robotic device to assist with the surgery.

Your surgeon will also make one incision in your perineal area. This is the area in between the vagina and anus in women and the scrotum and anus in men.

Colostomy

Because your rectum and anus will be removed, you will need a new exit point for your stool (feces). During your surgery, the lower end of your colon will be brought out through the skin on your abdomen. This is called a colostomy (see Figure 2). You will see the lining of your colon on the outside of your abdomen. This is called a stoma. It will be pink or red, and look shiny and moist.

The stoma is usually placed in the lower left side of the abdomen, about 2 inches away from the belly button. Your stool will now exit from your stoma.

After your surgery, a colostomy pouch will be applied to the skin around your stoma. This pouch will collect your gas and stool. A Certified Wound, Ostomy, Continence Nurse (CWOCN) will teach you how to change the pouch and care for your stoma. No one will know you have a colostomy unless you tell them.

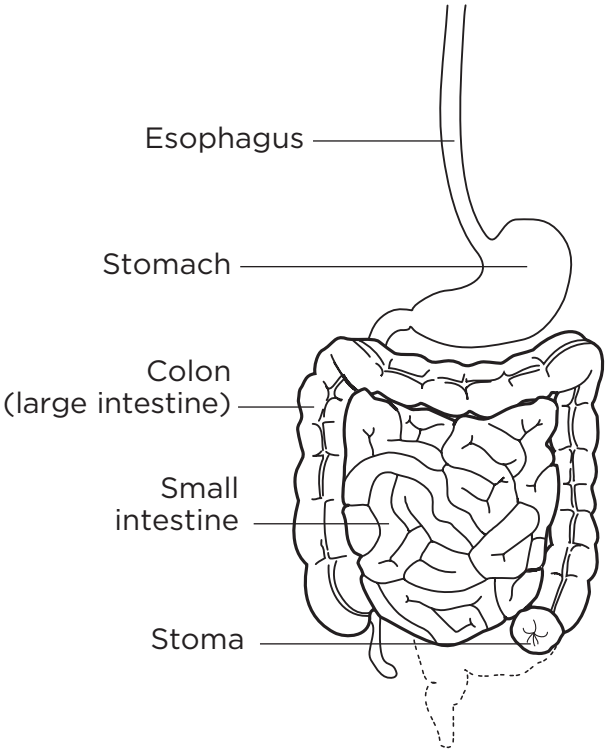


Figure 2: Colostomy

When your surgeon removes your rectum and anus, a large empty space will be left in between your buttocks. The space will be closed by stitches. While the space is healing, there will be restrictions on how you sit, lie down, and carry out some of your usual activities. Your doctor or nurse will discuss these restrictions with you. When the area has healed, it will not feel uncomfortable or be noticeable to other people.

Notes

The information in this section will help you prepare for your surgery. Read through this section when your surgery is scheduled and refer to it as your surgery date gets closer. It contains important information about what you need to do before your surgery. Write down any questions you have and be sure to ask your doctor or nurse.

Preparing for Your Surgery

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

About Drinking Alcohol

The amount of alcohol you drink can affect you during and after your surgery. It is important that you talk with your healthcare providers about your alcohol intake so that we can plan your care.

- Stopping alcohol suddenly can cause seizures, delirium, and death. If we know you are at risk for these complications, we can prescribe medications to help prevent them.
- If you drink alcohol regularly, you may be at risk for other complications during and after your surgery. These include bleeding, infections, heart problems, greater dependence on nursing care, and longer hospital stay.

Here are things you can do to prevent problems before your surgery:

- Be honest with your healthcare provider about how much alcohol you drink.
- Try to stop drinking alcohol once your surgery is planned. If you develop a headache, nausea, increased anxiety, or cannot sleep after you stop drinking, tell your doctor right away. These are early signs of alcohol withdrawal and can be treated.
- Tell your healthcare provider if you cannot stop drinking.
- Ask us any questions you have about drinking and surgery. As always, all of your treatment 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®), and tinzaparin (Innohep®). There are others, so be sure your doctor knows all the medications you're taking.
- I take prescription medications, including patches and creams.
- I take any over-the-counter medications, 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 in the past.
- I have allergies, including latex.
- I am not willing to receive a blood transfusion.
- I drink alcohol.
- I smoke.
- I use recreational drugs.

About Smoking

People who smoke can have breathing problems when they have surgery. Stopping even for a few days before surgery can help. If you want to quit, call our Tobacco Cessation Program at (212) 610-0507. You can also ask your nurse about the program.

About Sleep Apnea

Sleep apnea is a common breathing disorder that causes a person to stop breathing for short periods while sleeping. The most common type is obstructive sleep apnea (OSA). This means that the airway becomes completely blocked during sleep, so no air can get through. OSA can cause serious problems when you have surgery. Please tell us if you have sleep apnea or if you think you may have it. If you use a breathing machine (such as a CPAP) for sleep apnea, bring it with you the day of your surgery.

Within 30 Days of Your Surgery

Presurgical Testing

Before your surgery, you will be given an appointment for presurgical testing (PST). During your PST appointment, you will meet with a nurse practitioner who works closely with anesthesiology staff (doctors and specialized nurses who give you medication to sleep during surgery). You can eat and take your usual medications the day of your PST appointment.

During your appointment, your nurse practitioner 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 necessary to plan your care. Your nurse practitioner may also recommend you see other healthcare providers.

Your nurse practitioner will talk with you about which medications you should take the morning of your surgery. To help you remember, we've left space for you to write these medications down on page 12 of this guide.

It is very helpful if you bring the following with you to your PST appointment:

- ☐ A list of all the medications you are taking, including patches and creams.
- ☐ Results of any tests done outside of MSK, such as a cardiac stress test, echocardiogram (echo), or carotid doppler study.
- ☐ The name(s) and telephone number(s) of your doctor(s).

Use the space below to write in any notes about your PST appointment.

_____

_____

_____

_____

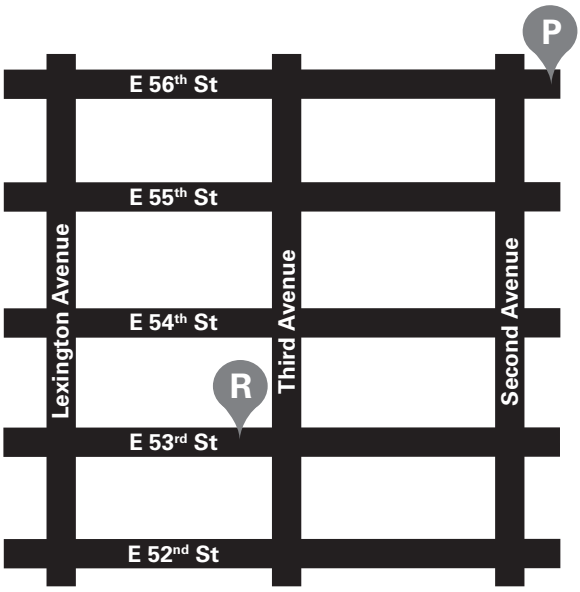
Location and Parking

Your PST appointment will be in the Rockefeller Outpatient Pavilion, also known as MSK 53rd Street.

Rockefeller Outpatient Pavilion
160 East 53rd Street (at Third Avenue)
New York, NY 10022

There are several options for parking during your PST appointment. The Bristol Garage offers discounted parking to MSK patients. To receive the discount, have your parking ticket validated at the concierge desk in the Rockefeller Outpatient Pavilion. There is a shuttle that goes from the Bristol Garage to the Rockefeller Outpatient Pavilion every 20 minutes.

The Bristol Garage
300 East 56th Street (between First and Second Avenues)
New York, NY 10022



P = Parking
R = Rockefeller Outpatient Pavilion

There are additional parking garages located at:

East 53rd Street between Second and Third Avenues
East 54th Street between Second and Third Avenues

Meet With a Certified Wound, Ostomy, Continence Nurse (CWOCN)

You will meet with a CWOCN during your PST appointment. A CWOCN is a registered nurse who specializes in wound and ostomy care. He or she will teach you and your family how to care for your new colostomy and help you become more independent. Your CWOCN will also show you a colostomy pouch so that you can become familiar with it.

Before your surgery, your CWOCN will help your surgeon choose the best placement for your stoma. However, your surgeon will select the final location during your surgery.

Your CWOCN will also work with you and your family, doctor, and nurses after your surgery to help with your recovery.

Please be sure to ask your CWOCN any questions you or your family may have about your colostomy.

Health Care Proxy

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 are unable to communicate for yourself. The person you identify is called your health care agent. If you are interested in completing a Health Care Proxy form or to learn more, talk with your nurse. If you have completed one or if you have any other advanced directive, bring it with you to your next appointment.

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, please read *How to Use Your Incentive Spirometer,* located in the "Resources" section of this guide. If you have any questions, ask your nurse.

Exercise

Do some form of exercise every day. If it is cold outside, use stairs in your home or go to a mall or shopping market. Walking will help your body get into its best condition for your surgery and make your recovery faster and easier.

Eat a Healthy Diet

You should eat a well-balanced, healthy diet before your surgery. If you need help with your diet, talk to your doctor or nurse about meeting with a dietitian.

10 Days Before Your Surgery

Review Your Medications

If you take vitamin E, stop taking it 10 days before your surgery. If you take aspirin, ask your surgeon whether you should continue. Medications such as aspirin, medications that contain aspirin, and vitamin E can cause bleeding. For more information, please read *Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs),* located in the "Medications" section of this guide.

Purchase Supplies

You will need to purchase the following supplies for your bowel preparation at your local pharmacy. You do not need a prescription from your doctor.

- ☐ 1 (238-gram) bottle of polyethylene glycol (MiraLAX®)
- ☐ 1 (64-ounce) bottle of a clear liquid (see the clear liquid diet menu on page 10)

This is also a good time to stock up on clear liquids to drink the day before your surgery. For a list of clear liquids that you can drink, please see the table on page 10.

7 Days Before Your Surgery

Stop taking herbal remedies or supplements 7 days before your surgery. If you take a multivitamin, talk with your doctor or nurse about whether you should continue. For more information, please read *Herbal Remedies and Cancer Treatment,* located in the "Medications" section of this guide.

2 Days Before Your Surgery

Stop taking nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (e.g., Advil®, Motrin®) and naproxen (e.g., Aleve®), 2 days before your surgery. These medications can cause bleeding. For more information, please read *Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs),* located in the "Medications" section of this guide.

To reduce your risk of infection, please avoid shaving or waxing your abdominal and perineal areas.

1 Day Before Your Surgery

Start Bowel Preparation

You will need to start your bowel preparation 1 day before your surgery. You will also need to follow a clear liquid diet the day before your surgery. Examples of clear liquids are listed in the table below. During your bowel preparation:

- Do not eat any solid foods.
- Make sure to drink plenty of liquids other than water, decaffeinated black coffee, and decaffeinated tea. Try to drink at least 1 (8-ounce) glass every hour while you're awake.

Food/Beverage	Drink	Do Not Drink
Soups	• Clear broth, bouillon • Clear consommé • Packaged vegetable, chicken, or beef broth mixes	Any products with any particles of dried food or seasoning
Sweets and Desserts	• Gelatin, such as Jell-O® • Flavored ices • Hard candies such as Lifesavers®	All others
Beverages	• Clear fruit juices, such as white cranberry, white grape, apple • Soda, such as 7-Up®, Sprite®, ginger ale, seltzer • Gatorade® • Decaffeinated black coffee • Decaffeinated tea	• Juices with pulp • Nectars • Milk or cream • Alcoholic beverages

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

The MiraLAX® bowel preparation will cause frequent bowel movements, so be sure to be near a bathroom the evening before your surgery.

At 5:00 pm on the day before your surgery, start drinking the MiraLAX® bowel preparation. Drink 1 (8-ounce) glass of the mixture every 15 minutes until the container is empty. When you're finished drinking the MiraLAX®, drink 4 to 6 glasses of clear liquids. You can continue to drink clear liquids until midnight, but it is not required.

Apply zinc oxide ointment or Desitin® to the skin around your anus after every bowel movement. This helps prevent irritation.

Note the Time of Your Surgery

A clerk from the Admitting Office will call you after 2:00 pm the day before your surgery. He or she will tell you what time you should arrive at the hospital for your surgery. If you are scheduled for surgery on a Monday, you will be called on Friday. If you do not receive a call by 7:00 pm the evening before your surgery, please call (212) 639-5014.

Use this area to write in information when the clerk calls:

Date: _____ Time: _____

On the day of your surgery, go to Memorial Hospital at 1275 York Avenue between East 67th and East 68th Streets. Take the B elevator to the 6th Floor to the Presurgical Center (PSC).

Shower With Hibiclens®

Your nurse will give you a bottle of Hibiclens® skin cleanser before your surgery. Hibiclens® contains a strong antiseptic that kills germs and will reduce your risk of infection. The night before your surgery, shower using the Hibiclens®. To use the Hibiclens®, open the bottle and pour some of it into your hand or a clean washcloth. Rub it gently over your body from your neck to your waist and rinse. Do not let the solution get into your eyes, ears, mouth, or genital area. Dry yourself off with a clean towel after your shower.

Sleep

Go to bed early and get a full night's sleep.

! Do not eat or drink anything after midnight the night before your surgery. This includes water, hard candy, and gum.

The Morning of Your Surgery

Shower With Hibiclens®

Shower using Hibiclens® just before you leave for the hospital. Use the Hibiclens® the same way you did the night before. Do not use any other soap. Do not put on any lotion, cream, powder, deodorant, makeup, or perfume after your shower.

Take Your Medications

If your doctor or nurse practitioner instructed 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.

Medication	Dose	Doctor/Nurse
Medication	Dose	Doctor/Nurse
Medication	Dose	Doctor/Nurse
Medication	Dose	Doctor/Nurse

Do not eat or drink anything the morning of your surgery. This includes water, hard candy, and gum. If you were instructed to take any medications, take them with a sip of water.

Things to Remember

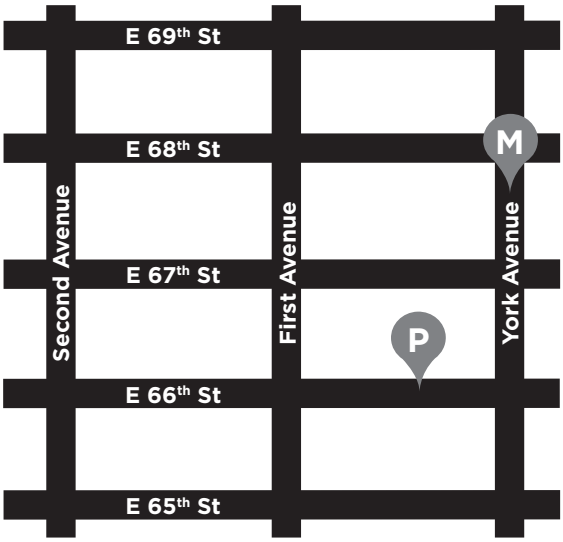
- Do not put on any lotion, cream, deodorant, makeup, powder, or perfume.
- Do not wear any metal objects. Remove all jewlery, including body piercings. The equipment used during your surgery can cause burns if it touches metal.
- Leave valuables, such as credit cards, jewelry, or your checkbook, at home.
- Before you are taken into the operating room, you will need to remove your eyeglasses, hearing aids, dentures, prosthetic device(s), wig, and religious articles, such as a rosary.
- _____
- _____
- _____

What to Bring

- ☐ A pair of loose-fitting pants (sweat pants are a good choice).
- ☐ Brief-style underwear that is 1 to 2 sizes larger than you normally wear.
- ☐ Sneakers that lace up. You may have some swelling in your feet. Lace-up sneakers can accommodate this swelling.
- ☐ A CD player and CDs or an iPod, if you choose. However, someone will need to hold these items for you when you go into surgery.
- ☐ Only the money you may need for a newspaper, bus, taxi, or parking.
- ☐ Your breathing machine for sleep apnea (such as your CPAP), if you have one.
- ☐ Your incentive spirometer, if you have one.
- ☐ If you have a case for your personal items, such as eyeglasses, hearing aid(s), dentures, prosthetic device(s), wig, and religious articles such as a rosary, bring it with you.
- ☐ If you usually wear contact lenses, wear your glasses instead. Remember to bring a case for them.
- ☐ Your Health Care Proxy form, if you have completed one.
- ☐ This guide. Your healthcare team will use this guide to teach you how to care for yourself after your surgery.
- ☐ _____
- ☐ _____
- ☐ _____

Parking When You Arrive

Parking at MSK is available in the garage on East 66th Street between York and First Avenues. To reach the garage, enter 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 is a pedestrian tunnel 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. If you have questions about prices, call (212) 639-2338.



P = Parking
M = Memorial Sloan Kettering

Once You're in the Hospital

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

Get Dressed for Surgery

You will be given a hospital gown, robe, and nonskid socks. Do not bring anything extra with you. Storage space is very limited.

Meet With Your Nurse

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

Meet With Your Anesthesiologist

He or she will:

- Review your medical history with you.
- Talk to you about your comfort and safety during your surgery.
- Talk to you about the kind of anesthesia (medication to make you sleep) you will receive.
- Answer any questions you may have about your anesthesia.

Prepare for Surgery

Once your nurse has seen you, 1 or 2 visitors can keep you company as you wait for your surgery to begin. When it is time for your surgery, your visitor(s) will be shown to the waiting area. Your visitors should read *Information for Family and Friends for the Day of Surgery* on page 15 of this guide.

You will walk into the operating room or you can 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 circulation in your legs.

Your anesthesiologist will place an intravenous (IV) line into a vein, usually in your arm or hand. The IV line will be used to give you fluids and anesthesia during your surgery.

Your anesthesiologist may also put an epidural catheter (thin, flexible tube) in your spine (back). This will be used to give you pain medication. The medication is delivered into your epidural space, which is the area just outside your spinal cord. It will give you pain relief with fewer side effects, such as nausea, vomiting, and sleepiness. This is similar to what is given to women when they have babies.

Once you are fully asleep, a breathing tube will be placed through your mouth into your windpipe to help you breathe. You will also have a urinary catheter placed to drain urine from your bladder.

Information for Family and Friends for the Day of Surgery

This information explains to your family and friends what will happen on the day of surgery at Memorial Sloan Kettering Cancer Center (MSK).

Before the Surgery

Upon arrival to the hospital, the patient will be asked to provide contact information for the person who wil be speaking to the surgeon after the surgery. If the patient is having an outpatient procedure, he or she will also be asked to provide contact information for the person who will be taking the patient home.

Once the patient is checked in, he or she will go to the Presurgical Center (PSC) to be examined before surgery. One person may come along, but others should wait in the concierge waiting area. If the patient wishes, other people may join him or her when the nurse has finished the examination.

When the operating room (OR) is ready, the surgical team will take the patient there. They will prepare the patient for surgery, which usually takes 30 to 90 minutes, then the surgery will begin.

Please remember the following:

- Do not bring food or drinks to the waiting area or the PSC. Patients are not allowed to eat or drink before their surgery or procedure.
- If the patient brought any valuables, such as a cell phone, iPod, iPad, etc., please keep it safe for them.
- Children under the age of 11 are not allowed to go into the PSC. They must wait in the main lobby on the 1st floor with a responsible adult.

During the Surgery

After the patient is taken to the OR, all visitors should go to the main lobby on the 1st floor.

- Food and drinks are available on the 1st floor in the cafeteria and in the gift shop. You can also bring you own food and eat it in the cafeteria.
- The coat-check room is at the bottom of the escalator on the ground level. It is open Monday through Friday from 11:00 am to 4:00 pm.
- Wireless Internet access is available in most areas of the hospital. You may also use the computers in the rooms off the main lobby.
- Please use the designated cell phone area to accept and make calls. It may be useful to bring your phone charger to the hospital. Please be courteous and mindful of others while using your cell phone.
- The Mary French Rockefeller Chapel, an interfaith chapel near the main lobby on the 1st floor, is open 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 over the age of 11. Arts and crafts, a library, an outdoor terrace, and scheduled entertainment events ar available in this area. To get there, take the M elevators to the 15th floor.

A clinical nurse specialist (CNS) will make rounds in the main lobby about every 2 hours to:

- Give you information about the patient
- Prepare you for your meeting with the surgeon
- Prepare you for visiting the patient in the Post-Anesthesia Care Unit (PACU)

You can contact the CNS between his or her regular visits in the lobby.

- From inside the hospital, use a hospital courtesy phone. Dial 2000 and ask for beeper 9000. Please be patient; this can take up to 2 minutes.
- From outside of the hospital, call (212) 639-2000. Ask for beeper 9000.
- You may also ask the information desk staff to contact the CNS for you.

After the Surgery

When the patient's surgery is done, we will call you to come back to the concierge desk. Please take the B elevator to the 6th floor and check in at the concierge desk. The concierge staff will bring you to a private consultation room to speak with the surgeon.

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

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.

Once the patient is ready for visitors, a nurse will take you to the PACU. Please remember that a limited number of visitors can go into the PACU. This is to keep the area quiet and avoid crowding.

While visiting in the PACU

- Silence your cell phone.
- Apply hand sanitizer before entering.
- Keep noise to a minimum. All patients in the room need to rest.
- Do not wander away from the patient's bedside. It's important to respect each patient's right to privacy.
- Do not bring food or flowers into the PACU.
- Limit the time of your visit so that the patient can rest and recover.
- You may be asked to leave if there is an emergency, x-rays need to be done nearby, or patient care is being interrupted.

The nurse will update you on the patient's condition. He or she will also explain the plan of care for the patient, such as whether the patient is staying overnight and when he or she will be moved to an inpatient room. You should feel assured that you can leave the hospital after your visit. We will give you a card with the PACU phone number. Please appoint one person to call for updates.

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CF-314

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 any questions you have and be sure to ask your doctor or nurse.

What to Expect

When you wake up after your surgery, you will be in the Post Anesthesia Care Unit (PACU). You will stay there until you are awake and your pain is under control. Most patients return to their room after a few hours in the PACU, but some will need to stay in the PACU overnight for observation.

You will receive oxygen through a thin tube called a nasal cannula that rests below your nose. A nurse will be monitoring your body temperature, pulse, blood pressure, and oxygen levels.

You will have a patient-controlled analgesia (PCA) device. PCA uses a computerized pump to deliver pain medication into your IV or epidural space (in your spine). For more information, please read *Patient-Controlled Analgesia (PCA),* located in the "Resources" section of this guide.

You will have a Foley® catheter in your bladder to monitor the amount of urine you are making. You will also have compression boots on your lower legs to help your circulation. They will be taken off when you are able to walk. You will also have 1 or 2 drains in your lower abdomen to drain extra liquid from the area. Most of the time, the drains are removed after a few days. If you will go home with a drain, your nurse will show you how to care for it.

Your visitors can see you briefly in the PACU, usually within 90 minutes after you arrive. A member of the nursing staff will explain the guidelines to them. After your stay in the PACU, you will be taken to your hospital room in the inpatient unit. There, your nurse will tell you how to recover from your surgery. Below are examples of ways you can help yourself recover safely.

- It is important to walk around after surgery. Your nurse will help you get out of bed the day after your surgery. Your activity will be increased until you can walk the halls in the hospital without help. Walking every 2 hours is a good goal. This will help prevent blood clots in your legs and reduce your risk of pneumonia.
- Use your incentive spirometer. This will help your lungs expand, which prevents pneumonia. For more information, please read *How to Use Your Incentive Spirometer*, located in the "Resources" section of this guide.

Your incisions (surgical cuts) will be checked daily. The incision(s) on your abdomen must be kept clean and dry. You may notice small amounts of light pink fluid leaking from your perineal area; this is normal. You can wear Depends® or another type of shield to protect your clothing from stains. Your stoma will also be checked daily. You will have a pouch in place to collect any stool that exits from your stoma.

Notes

Commonly Asked Questions

Will I have pain after my surgery?

You will have some pain from your incisions after your surgery. Your doctor and nurse will ask you about your pain often. You will be given medication to manage your pain as needed. If your pain is not relieved, please tell your doctor or nurse. It is important to control your pain so you can cough, breathe deeply, use your incentive spirometer, and get out of bed and walk.

You will be given pain medication through your PCA pump. For more information, please read *Patient-Controlled Analgesia (PCA),* located in the "Resources" section of this guide. When you can swallow liquids, you will get your pain medication by mouth.

Will I have pain when I am home?

The length of time each patient has pain or discomfort varies. Some patients may have incisional soreness, tightness, or muscle aches for up to 6 months or longer. This does not mean that something is wrong. Follow the guidelines below to manage your pain.

- You will be given a prescription for pain medication before you go home. Call your doctor if the medication prescribed for you doesn't relieve your pain.
- Do not drive or drink alcohol while you are taking prescription pain medication.
- Pain medication should help you as you resume your normal activities. Take enough medication to make sure you can gradually increase your activities. Pain medication is most effective 30 to 45 minutes after taking it.
- Keep track of when you take your pain medication. It will not be as effective if you allow your pain to increase. Taking it when your pain first begins is more effective than waiting for the pain to get worse.

As your incisions heal, you will have less pain and need less pain medication. A mild pain reliever such as acetaminophen (Tylenol®) or ibuprofen (Advil®) will relieve aches and discomfort.

How do I care for my abdominal incision(s)?

Your incision(s) will be closed with stitches, staples, or surgical glue. If you have stitches or staples, they are usually removed the morning you leave the hospital. This is done in your hospital bed and is not painful. If you go home with your staples or stitches in place, you will need to come back to the clinic to have them removed.

Tape strips called Steri-Strips® will be placed across your incision(s) to make sure it stays closed. After about 14 days, these will loosen and you can remove them. Your incision(s) will stay closed.

You will need to check your incision(s) every day for any signs of infection until your doctor tells you it has healed. Call your doctor if you develop any of the following signs of a wound infection:

- Redness
- Swelling
- Increased pain
- Warmth at the incision site
- Foul-smelling or puss-like drainage from your incision
- A temperature of 101° F (38.3° C) or higher

To prevent infection, do not let anyone touch your incision(s). Clean your hands with soap and water or an alcohol-based hand sanitizer before you touch your incision(s).

When you take a shower, gently wash your incision(s) with a fragrance-free, liquid soap. If you have Steri-Strips® or surgical glue on your incision(s), do not scrub it or use a washcloth on it. This could irritate your incision(s) and prevent it from healing. While it is safe to take a shower, do not let your incision(s) be wet for too long. When you are finished with your shower, gently pat your incision(s) with a clean towel. Allow it to air dry completely before getting dressed.

How do I care for my perineal incision?

The stitches in your perineal incision will either dissolve over time or will need to be removed. Your surgeon will tell you if you need to have your stitches removed.

You should check your incision every day for any signs of infection until your doctor tells you it has healed. You can do this by using a hand-held mirror. Call your doctor if you develop any of the following signs of a wound infection:

- Redness
- Swelling
- Increased pain
- Warmth at the incision site
- Foul-smelling or pus-like drainage from the incision
- A temperature of 101° F (38.3° C) or higher

To prevent infection, do not let anyone touch your incision. Clean your hands with soap and water or an alcohol-based hand sanitizer before you touch your incision.

When you take a shower, gently wash your incision with a fragrance-free, liquid soap. While it is safe to take a shower, do not let your incision be wet for too long. When you are finished with your shower, gently pat your incision with a clean towel. Allow it to air dry completely before getting dressed.

The time it takes the area to heal is different from patient to patient, but it usually takes about 3 months. Your discomfort will decrease over time.

For several weeks after your surgery, there will be restrictions on how you sit, lie down, and carry out some of your daily activities. You will not be able to sit for long periods of time and you will need to sleep on your side. Your doctor or nurse will go over these restrictions with you.

How do I care for my colostomy?

While you are in the hospital, your CWOCN will teach you how to care for your colostomy. For more information, please read *A Guide for Patients With an Ileostomy or Colostomy,* located in the "Resources" section of the guide.

You will also learn how to irrigate your stoma. Your doctor will tell you when it is okay to start doing this. Irrigation is similar to giving yourself an enema and is not painful. The difference is that the irrigation is done through your stoma instead of your anus. Irrigating your stoma at the same time each day will allow you to empty your bowel and make it possible to wear a small patch over your stoma. Some people can go without wearing a pouch at all. It will take several months to regulate your bowel.

When can I shower?

You will be able to shower in the hospital and after you go home. Do not take tub baths or go swimming until your doctor says it is okay.

Will I need to change my diet after my surgery?

For the first few days after your surgery, you will be given clear liquids. Then, your diet will progress to solid food.

Your doctor will give you dietary guidelines to follow after your surgery. Your dietitian will go over these guidelines with you before you leave the hospital.

What other changes should I expect from my surgery?

The nerves that control sexual function lie within the pelvis. You may worry that they will be damaged. Surgeons at MSK have special training to reduce this risk. Only a small number of patients experience changes in sexual function as a result of this surgery. If you have any concerns about sexual function, talk with your surgeon.

There is a small chance that you may have changes in urinary function. The nerves that control urination also lie in the pelvis. Your surgeon will make every effort to protect these nerves. However, a small number of patients lose urinary control for a short period of time after surgery. If this happens to you, you may need to use a catheter for a longer amount of time after your surgery. Permanent loss of urinary control is uncommon. Your surgeon will discuss this risk with you. You can also speak to your doctor, nurse, and social worker.

When can I resume my normal activities?

Doing your normal activities is an important part of regaining your strength. However, follow the guidelines below:

- Do not lift heavy objects, strain, or do strenuous exercise for at least 6 weeks after your surgery.
- Walking is a good way to increase your endurance. You can climb stairs but try to limit how often you do this for the first week you are home. Do not go out by yourself until you are sure of what you can do.
- Rest as needed, but if you cannot sleep at night, it may be a sign that you are resting too much during the day.

When can I resume sexual activity?

Your surgeon will tell you when you can resume sexual activity.

When is it safe for me to drive?

Do not drive until your surgeon tells you it is okay. This will be some time after your first follow-up appointment after your surgery. If you are still taking your prescribed pain medication, your surgeon may want you to wait longer before driving. The pain medication can slow your reflexes and responses, making it unsafe to drive. Also, braking requires use of the abdominal muscles, so driving may increase your discomfort.

When will I get my test results?

After your surgery, the tumor and the tissue around it will be sent to a pathologist. Your test results will be ready about 5 business days after your surgery. Your surgeon will discuss the results of the tests with you and recommend whether you need any additional treatments.

What type of follow-up care will I receive after I leave the hospital?

Your surgeon will want to see you 1 to 3 weeks after you leave the hospital. If you do not have an appointment before you leave the hospital, please call your surgeon's office to schedule it.

At this visit, your surgeon will check your incisions and overall condition. At other follow-up visits, you may have blood tests or x-rays.

It is important that you go to all of your follow-up visits after your surgery. You can call your doctor or nurse if you have any questions in between these visits.

If you need to have more treatment, it can be done at MSK or at a facility near your home. Your surgeon will plan your care with the doctors in charge of these treatments.

How can I cope with my feelings?

After surgery for a serious illness, you may have new and upsetting feelings. Many patients say they felt sad, worried, nervous, irritable, or angry at one time or another. You may find that you cannot control some of these feelings. If this happens, it's a good idea to seek emotional support.

The first step in coping is to talk about how you feel. Family and friends can help. Your nurse, doctor, and social worker can reassure, support, and guide you. It is always a good idea to let these professionals know how you, your family, and your friends are feeling emotionally. Many resources are available to patients and their families. Whether you are in the hospital or at home, your nurses, doctors, and social workers are here to help you and your family and friends handle the emotional aspects of your illness.

What if I have other questions?

If you have any questions or concerns, please talk with your surgeon or nurse. You can reach them Monday through Friday from 9:00 am to 5:00 pm. Call their offices directly at the numbers listed below.

Surgeon: _____ Telephone: _____

Nurse: _____ Telephone: _____

After 5:00 pm, during the weekend, and on holidays, please call (212) 639-2000 and ask for the doctor on call for your doctor.

! Call Your Doctor or Nurse if You Have:

- **A temperature of 101° F (38.3° C) or higher**
- **Abdominal pain, nausea, and/or vomiting**
- **The following signs of infection in your incision:**
  - **Redness**
  - **Swelling**
  - **Increased pain**
  - **Warmth at the incision site**
  - **Foul smelling or pus-like drainage**
- **Difficulty urinating**
- **Pain at your incisions not relieved by pain medication**
- **Any questions or concerns**

Notes _____

Notes

The information in this section contains important information about what medications, herbal remedies, and other dietary supplements you will need to stop taking before your surgery. Read through this section before your surgery so that you are prepared. Write down any questions you have and be sure to ask your doctor or nurse.

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.

Medications such as aspirin and other NSAIDs, vitamin E, and COX-2 inhibitors can increase your risk of bleeding during cancer treatment. These medications affect your platelets, which are blood cells that clot to prevent bleeding. If you take aspirin or other NSAIDs, vitamin E, or a COX-2 inhibitor such as celecoxib (Celebrex®), tell your doctor or nurse. He or she 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.

If you're having surgery:

- Stop taking medications that contain aspirin or vitamin E 10 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.
- Ask your doctor if you should continue taking a COX-2 inhibitor.

If you're having a procedure in Radiology (including Interventional Radiology, Interventional Mammography, and General Radiology):

- 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. If your doctor instructs you to stop taking aspirin, you should stop 5 days before your procedure or as directed by your doctor.
- Stop taking other NSAIDs 24 hours before your procedure.
- Stop taking medications that contain vitamin E 10 days before your procedure, or as directed by your doctor.

Chemotherapy can decrease your platelet count, which can increase your risk of bleeding. Whether you're just starting chemotherapy or you've been receiving it, talk with your doctor or nurse before taking aspirin or other NSAIDs.

Medications are often called by their brand name, which can make it difficult to know their ingredients. To help you identify medications that contain aspirin, other NSAIDs, and vitamin E, please review the list of common medications in this leaflet. While this list includes the most common products, there are others. Please check with your healthcare provider if you aren't sure. Always be sure your doctor knows all the medications you're taking, both prescription and over-the-counter.

The following common medications contain aspirin:

Alka Seltzer®
Anacin®
Arthritis Pain Formula
Arthritis Foundation Pain Reliever®
ASA Enseals®
ASA Suppositories®
Ascriptin® and Ascriptin A/D®
Aspergum®
Asprimox®
Axotal®
Azdone®
Bayer® (most formulations)
BC® Powder and Cold Formulations
Bufferin® (most formulations)
Buffets II®
Buffex®
Cama® Arthritis Pain Reliever
COPE®
Dasin®
Easprin®
Ecotrin (most formulations)
Empirin® Aspirin (most formulations)
Epromate®
Equagesic Tablets
Equazine®
Excedrin® Extra-Strength Analgesic Tablets and Caplets
Excedrin® Migraine
Fiorgen ®
Fiorinal® (most formulations)
Fiortal®
Gelpirin®
Genprin®
Gensan®
Heartline®
Headrin®
Isollyl®
Lanorinal®
Lortab® ASA Tablets
Magnaprin®
Marnal®
Micrainin®
Momentum®
Norgesic Forte® (most formulations)
Norwich® Aspirin
PAC® Analgesic Tablets
Orphengesic®
Painaid®
Panasal®
Percodan® Tablets
Persistin®
Robaxisal® Tablets
Roxiprin®
Saleto®
Salocol®
Sodol®
Soma® Compound Tablets
Soma® Compound with Codeine Tablets
St. Joseph® Adult Chewable Aspirin
Supac®
Synalgos®-DC Capsules
Tenol-Plus®
Trigesic®
Talwin® Compound
Vanquish® Analgesic Caplets
Wesprin® Buffered
Zee-Seltzer®
ZORprin®

The following common medications are NSAIDs that do not contain aspirin:

Advil®
Advil Migraine®
Aleve®
Anaprox DS®
Ansaid®
Arthrotec®
Bayer® Select Pain Relief Formula Caplets
Celebrex®
Children's Motrin®
Clinoril®
Daypro®
Diclofenac
Etodolac®
Feldene®
Fenoprofen
Flurbiprofen
Genpril®
Ibuprofen
Indomethacin
Indocin®
Ketoprofen
Ketorolac
Lodine®
Meclofenamate
Mefenamic Acid
Meloxicam
Menadol®
Midol®
Mobic®
Motrin®
Nabumetone
Nalfon®
Naproxen
Naprosyn®
Nuprin®
Orudis®
Oxaprozin
PediaCare Fever®
Piroxicam
Ponstel®
Relafen®
Saleto 200®
Sulindac
Toradol®
Voltaren®

Most multivitamins contain vitamin E, so if you take a multivitamin be sure to check the label. The following products contain vitamin E:

Amino-Opt-E	Aquavit	E-400 IU	E complex-600
Aquasol E	D'alpha E	E-1000 IU Softgels	Vita-Plus E

Acetaminophen (Tylenol®) is generally safe to take during your cancer treatment. It doesn't affect platelets, so it will not increase your chance of bleeding. The following common medications contain acetaminophen; those in bold require a prescription:

Acephen®

Aceta® with Codeine

Acetaminophen with Codeine

Aspirin-Free Anacin®

Arthritis Pain Formula® Aspirin-Free

Darvocet-N 100®

Datril®

Di-Gesic®

Esgic®

Excedrin P.M.®

Fiorcet®

Lorcet®

Lortab®

Naldegesic®

Norco®

Panadol®

Percocet®

Repan

Roxicet®

Talacen®

Tempra®

Tylenol®

Tylenol® with Codeine No. 3

Vanquish®

Vicodin®

Wygesic®

Zydone®

! Read the labels on all your medications.

Acetaminophen (Tylenol®) 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 is not always written out, so look for these common abbreviations, especially on prescription pain relievers: APAP, AC, Acetaminoph, Acetaminop, Acetamin, and Acetam.

Acetaminophen is safe when used as directed, but there is a limit to how much you can take in one day. It's possible to take too much acetaminophen without knowing because it's in so many different medications. Taking more acetaminophen than directed can lead to liver damage. You should never take more than 3,250 mg of acetaminophen in one day.

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Herbal Remedies and 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 because they can:

- Interact with other drugs
- Increase or lower blood pressure
- Thin the blood and increase the risk of bleeding
- Make radiation therapy less effective
- Lower the effects of medications that suppress the immune system
- Increase the effects of sedation or anesthesia

Below are examples of common herbs and a description of their effects.

Echinacea

- Can cause an allergic reaction such as a rash or difficulty breathing
- Can lower the effect of drugs used to suppress the immune system

Garlic

- Can lower blood pressure, fat, and cholesterol levels
- Can prevent platelets (the blood cells that help stop bleeding) from sticking together, which increases the risk of bleeding

Gingko (also known as gingko biloba)

- Can change how platelets function, which can increase the risk of bleeding

Ginseng

- Can act as a stimulant, which can decrease the effects of anesthesia or sedation
- Can interfere with platelet function, which can increase the risk of bleeding
- Can lower blood glucose (sugar) level

Turmeric

- Can reduce the antitumor action of chemotherapy drugs

St. John's Wort

- Can interact with medications given during surgery
- Can make the skin more sensitive to laser treatment

Valerian

- Can have a sedative effect, which can increase the effects of anesthesia or sedation

Herbal formulas

- Many herbal formulas contain different herbs. We don't know their side effects. You must also stop taking these products 1 week before and during treatment

For more information about herbs and botanicals, visit: http://www.mskcc.org/aboutherbs.
You can also download the Memorial Sloan Kettering About Herbs app from the App Store at:
https://itunes.apple.com/us/app/about-herbs/id554267162?mt=8

This information does not cover all possible side effects. Please share any questions or concerns with your doctor or nurse.

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This section contains a list of MSK support services, as well as the resources that were referred to throughout this guide. These resources will help you prepare for your surgery and recover safely. Write down any questions you have and be sure to ask your doctor or nurse.

MSK Resources

Admitting
(212) 639-5014
Call to discuss private room or luxury suite options. If you want to change your room choice after your presurgical testing visit, call (212) 639-7873 or 7874.

Anesthesia
(212) 639-6840
Call with questions about anesthesia.

Blood Donor Room
(212) 639-7643
Call for more information if you are interested in donating blood or platelets.

Bobst International Center
(888) 675-7722
MSK welcomes patients from around the world. If you are an international patient, call for help.

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 the main lobby of Memorial Hospital, 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 counseling helpful. We provide counseling for individuals, couples, families, and groups, as well as medications to help if you feel anxious or depressed.

Integrative Medicine Service
(800) 525-2225
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
(212) 639-5665
Learn beauty techniques to help you feel better about your appearance. This program is for both women and men. To register for a workshop at MSK, call (212) 639-LOOK. To find out if a group program is available in your area, check the www.lookgoodfeelbetter.org, or call 1-800-395-LOOK.

Patient-to-Patient 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-to-Patient Support Program, we are able to offer you a chance to speak with former patients and caregivers.

Patient Financial Services
(212) 639-8242
Call with any questions about preauthorization from your insurance company. This is also called preapproval. Patient Financial Services can also help you with your billing or other insurance questions.

Patient Representative Office
(212) 639-7202
Call if you have any questions about the Health Care Proxy form or if you have any concerns about your care.

Perioperative Clinical Nurse Specialist
(212) 639-5935
Call if you have any questions about MSK releasing any information while you are having surgery.

Private Nursing Options
(212) 639-6892
Patients may request private nurses or companions. Call for more information.

Resources for Life After Cancer (RLAC) Program
(646) 888-4740
At MSK, care doesn't end after active treatment. The RLAC Program is for patients and their families who have finished treatment. This program has many services, including seminars, workshops, support groups, counseling on life after treatment, and help with insurance and employment issues.

Social Work
(646) 888-5271 or (646) 888-5203
Social workers help patients, family, and friends deal with issues that are common for cancer patients. They provide individual counseling and support groups throughout the course of treatment, and can help you communicate with children and other family members. Our social workers can also refer you to community agencies and programs, as well as financial resources if you're eligible.

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

For additional online information, visit LIBGUIDES on MSK's library website at http://library. mskcc.org. You can also contact the library reference staff at (212) 639-7439 for help.

External Resources

The following are resources outside of MSK that you may find helpful:

Access-A-Ride
www.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 are unable 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) 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 comprehensive resource for education, tools, and events for employees with cancer.

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

Cancer Support Community
http://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.

Chronic Disease Fund
www.cdfund.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 CDF formulary.

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

fertileHOPE
www.fertilehope.org
(855) 220-7777
Provides reproductive information and support to cancer patients and survivors whose medical treatments have risks associated with infertility.

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.

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

Hospital Hosts
www.hospitalhosts.com
National resource to help reduce costs related to medical travel needs such as air, car, and lodging near hospitals.

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
http://lgbtcancer.com
Provides support and advocacy for the LGBT community, including a online support groups and a database of LGBT friendly clinical trials.

National Cancer Institute
www.cancer.gov

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.com
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 obtain medications that they have trouble affording.

The Ostomy Association
www.uoaa.org

Wound Ostomy Continence Organization
www.wocn.org
Go to this website to find a CWOCN in your area. The website also has information on resources, suppliers of ostomy products, and support groups.

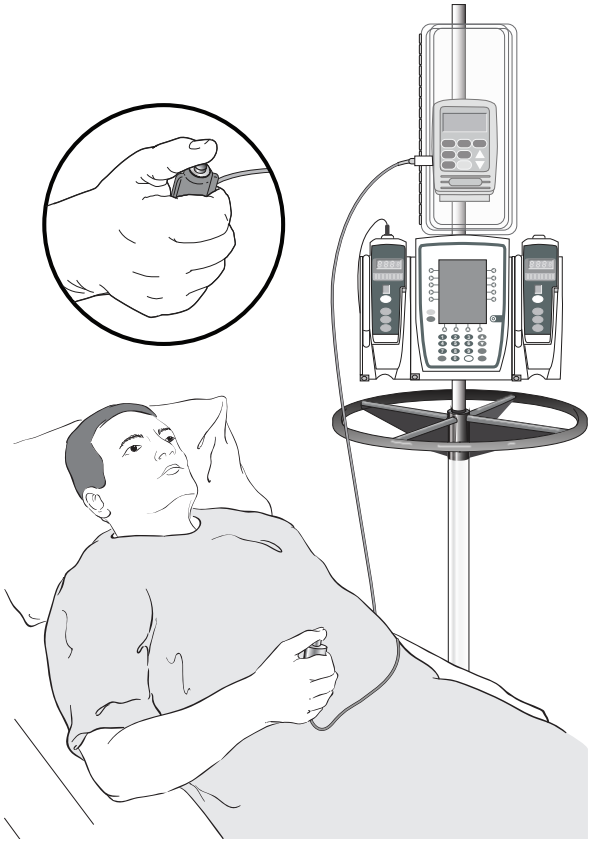
Patient-Controlled Analgesia (PCA)

Patient-controlled analgesia helps you control your pain by administering your pain medicine. It is often called "PCA". PCA uses a computerized pump to deliver pain medicine into a vein (intravenous, or IV) or epidural space (in your spine). Whether you have an IV PCA or epidural PCA depends on what you and your doctor decided was right for you. When you have pain, you simply press the button attached to the pump. 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.

How It Is Given:

The pump can be programmed to deliver your medicine in 2 ways:

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



Possible Side Effects:

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

- Constipation
- Nausea, vomiting
- Dry mouth
- Itching
- Changes in vision, such as seeing things that are not there
- Drowsiness, dizziness, or confusion
- Weakness, numbness, or tingling in your arms or legs
- Difficulty urinating

Special Instructions:

PCA is not right for everyone.

- Patients who are confused or cannot follow these instructions should not use PCA.
- If you have been told you have sleep apnea, tell your doctor. This may affect the way we prescribe your PCA.
- If you have weakness in your hands and may have trouble pushing the PCA button, talk with your doctor or nurse.

When using PCA, tell your doctor or nurse if:

- The medicine is not controlling your pain.
- Your pain changes. For example, tell them if:
  - It gets worse
  - You feel it in a new place
  - Feels different than before

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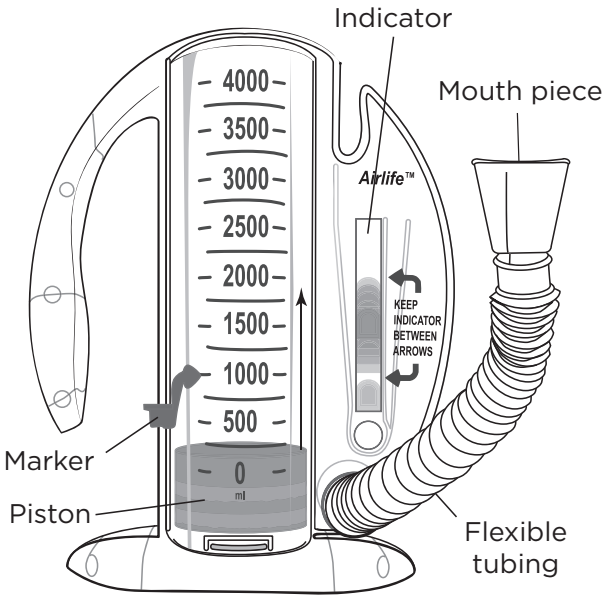
How to Use Your Incentive Spirometer

An incentive spirometer will help you expand your lungs by encouraging you to breathe more deeply and fully. Using your incentive spirometer along with deep breathing and coughing exercises will help prevent complications such as pneumonia.



A video demonstrating how to use your incentive spirometer can be found on MSK's website at: http://www.mskcc.org/videos/how-use-your-incentive-spirometer.

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

1. Sit upright in a chair or in bed. Hold the incentive spirometer upright at eye level.
2. Breathe out (exhale) once slowly. Put the mouthpiece in your mouth and close your lips tightly around it.
3. Take a slow, deep breath in through your mouth. As you take a deep breath, you will see the piston rise on the left side of the device. While the piston rises, the indicator on the right should move upwards. It should stay in between the 2 arrows (see figure). If the indicator does not stay between the arrows, you are breathing either too fast or too slowly.
4. Try to get the piston as high as you can, while keeping the indicator between the arrows.
5. When you get it as high as you can, try to keep it at that level for as long as possible.
6. Exhale normally, allowing the piston to fall all the way back to the bottom. Rest for a few seconds. Take 10 to 12 breaths every hour with your incentive spirometer while you are awake. Try to get the piston to the same level with each breath.
7. After each set of breaths, cough 3 times. This will help loosen or clear any secretions in your lungs.

Special Points

- If you feel dizzy at any time, stop and rest. Try again at a later time.
- Hug or hold a pillow to help splint your incision if you had surgery on your chest or abdomen. This will help decrease pain at your incision.
- 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.
- Keep the incentive spirometer clean by covering the mouthpiece when it is not in use.

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A Guide for Patients with an Ileostomy or Colostomy

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An ostomy is an opening created during surgery that brings a piece of the bowel to the outside of the abdomen. It is created so stool can exit the body. A colostomy is made with the colon or large bowel. An ileostomy is made with the small bowel. Having an ostomy is a big adjustment for most people. You may have many questions. We have written this booklet with the help of patients. Some have recently had an ostomy and others have had one for a long time. It covers topics related to both colostomy and ileostomy. We hope it will help prevent problems and give you tips that can make your daily life easier.

Before Surgery

Your Disgestive System

Your digestive system is made up of organs responsible for the:

- Breakdown of food.
- Absorption of nutrients.
- Elimination of waste from your body.

These organs include the:

- Mouth.
- Esophagus.
- Stomach.
- Small intestine.
- Colon or large intestine.

(See Figure 1)

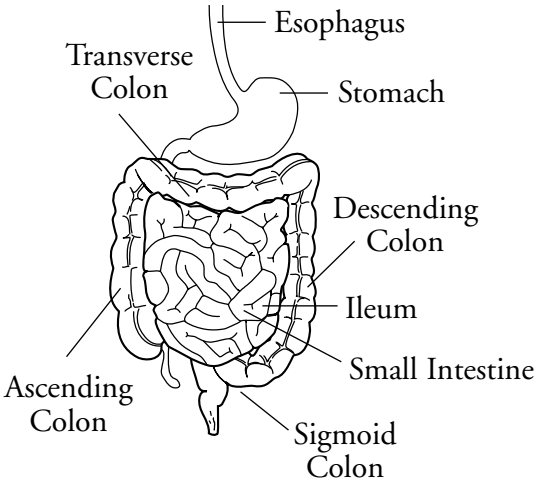

Figure 1

After food has been chewed and swallowed, it moves into the esophagus. This is the passageway for food as it travels from the mouth into the stomach. Once the food enters the stomach, it mixes with stomach juices. These juices change the form and appearance of the food.

When the food leaves the stomach, it moves into the small intestine. There it is digested further and broken down. Nutrients are absorbed into the bloodstream. What is not absorbed into the bloodstream is called waste. The waste is pushed along the small intestine through the large intestine until it reaches the rectum. The waste is then expelled from the anus as a bowel movement or stool.

Creation of an Ostomy

To remove a tumor or a blockage in the intestine, a new exit for the stool may need to be created. To do this, the intestine is cut and brought out through the skin on the abdomen. The new opening is called a stoma or an ostomy. The name of the ostomy tells you where it is located.

Types of Ostomies

An ostomy can be made in any part of the small or large intestine. The stool will differ depending on the part of the intestine used to create the ostomy. The stool may be liquid, soft, or solid. Listed below are the most common types of ostomies.

- *Ileostomy.* It is created in a portion of the small intestine called the ileum. The stool is liquid or semi-liquid. The stoma is usually on the right lower side of the abdomen.
- *Ascending colostomy.* It is created in the ascending colon. The stool is liquid or semiliquid. The stoma is usually on the right side of the abdomen.
- *Transverse colostomy.* It is created in the transverse colon (across the upper abdomen). The stool can be thick, liquid, pasty, or semisolid.

- *Descending colostomy.* It is created in the descending colon. The stool is usually soft. The stoma is usually on the left side of the abdomen.
- *Sigmoid colostomy.* It is created in the last portion of the colon. The stool can be soft or firm. It can vary with each patient. The stoma is usually on the left side of the abdomen.
- *Loop ostomy.* This type of ostomy can be placed in any portion of the intestine. There are two openings in the stoma instead of one. Many times only one opening can be seen. This ostomy is often temporary.

Your surgeon will tell you whether your ostomy is permanent or temporary. The stoma will look red and moist similar to the inside of your mouth. Because there are no nerve endings you will not feel pain or light pressure within your stoma. You will also not feel a sensation of heat or cold.

In some procedures a second opening is created on the abdomen. This is in addition to the ostomy. It is called a mucous fistula. It is not connected to the flow of stool. It secretes mucus (a saliva-like fluid) and leads to the rectum. Patients will be taught how to care for a mucus fistula while in the hospital. Generally a small pouch or dressing is placed over the mucus fistula.

How to Prepare Before Surgery

Your nurse will give you the booklet Getting Ready for Surgery. Tests will be done to make sure that you are ready to undergo the surgery. These tests include:

- Blood tests.
- An electrocardiogram (EKG).
- A chest x-ray.
- Other tests that your doctor may believe are necessary.

The nurse will also give you bowel prep instructions for the day before surgery. Your nurse will go over what you can expect right before and after surgery. The CWOCN (certified wound, ostomy, continence nurse) will show you the ostomy pouches. This is so you can become familiar with the equipment. The CWOCN will answer any questions you or your family have regarding ostomy care and management.

Your surgeon may ask the CWOCN to mark the spot where your stoma may be formed. Some patients may not be marked by the CWOCN if their surgery needs to be done in an emergency.

After Surgery

Surgery can last a couple of hours. The length will depend on the type of operation you are having. When you wake up you will be in the Post-Anesthesia Care Unit (PACU). You may have one of the following tubes in place:

- A gastrostomy tube (GT). This is a tube in your abdomen.
- A nasogastric (NG) tube. This tube goes through your nose into your stomach.

These tubes drain the stomach contents that pass through the intestine. Some patients will not have either tube.

You will not be able to eat or drink for a few days after the surgery. Your doctor will first allow you to drink clear liquids such as tea, broth, and Jell-O®. Your diet will slowly be advanced to solid food. If you have a GT, it will be removed just before your discharge from the hospital.

You may also have a Foley® catheter in place. This is a tube that drains urine from the bladder into an external collection bag. It is inserted during your surgery. It will stay in place for two to seven days.

The period after surgery can be a difficult time for you and your family. As you recover, you will slowly return to your normal level of function. The tubes will be removed. You will gradually begin eating a normal diet. Your abdominal

incision will heal. Your ostomy will start to function and stool will pass through your stoma. The MSKCC staff is here to help you in whatever way they can. The staff can provide you with the care and support you need. You and your family should not hesitate to ask questions or discuss your concerns. The inpatient CWOCN will likely see you after surgery to review ostomy care and further discuss your equipment for your ostomy.

There is a basic ostomy class held twice a week in the hospital. Patients and family are encouraged to attend. You will get additional instruction from your nurses. You will also be set up with a visiting nurse. This nurse will come to you in your home after you are discharged from the hospital.

Learning to Care for your Stoma

After the surgery, you will have an odor proof ostomy appliance/pouch over your ostomy. It will be applied to the skin around your stoma to collect the exiting stool. If you have a mucous fistula, it will drain small amounts of mucus. It will need to be cleaned with soap and water and covered with a small gauze pad or smaller pouch.

The CWOCN and nursing staff will help you to learn to care for your ostomy.

Changing your Ostomy Appliance (Wafer and Pouch)

Generally, the ostomy appliance/pouch is changed every four to five days. If you have leakage, you may need to change it sooner. This is to protect the skin around the stoma from getting irritated. The skin can get irritated from stool leakage or wafer breakdown. There are two main types of appliances on the market: one piece appliance and two piece appliances. After surgery, the CWOCN nurse will guide you to the best system for your stoma. Insurance allows only a certain amount of appliances/pouches per month. Discuss which pouch may be best for you with your CWOCN.

Discharge from the Hospital

When you are discharged from the hospital, you will be given basic supplies you need to care for your ostomy. Then you will order supplies from a surgical supplier. Some patients find it helpful to buy a fitted waterproof mattress cover for their bed. This protects the bed in case the pouch leaks during the night.

A visiting nurse can help you care for your stoma and adjust to being home. If you have any questions or problems once you are home, you can call your CWOCN or your social worker. He or she can answer questions about other resources.

Follow Up Care

You will have an appointment to see your doctor about two weeks after you are discharged. Call your doctor, CWOCN, or nurse if you have questions before this visit. At this follow-up visit, your doctor will check your health. He or she will also decide when you should come back for other follow-up visits.

Lifestyle Issues

Body Image and Depression

After people learn that they have cancer, they often view their bodies in a different way. Surgery, chemotherapy, and radiation can change the way a body looks and works. This may be especially true when someone has a new ostomy. Some people feel disgust. This is normal given the shame in our culture of talking about bowel functions. Other people feel sadness at the loss or change in their bodies. They view their ostomies with negative thoughts and feelings. However, others view the ostomy more positively. These people see it as an answer to troublesome symptoms (such as bowel incontinence) or as the path to survival. You may have both positive and negative feelings. Body image usually gets better with time. This will happen as you adjust to living with an ostomy and get used to how it looks and works. It may help you cope better if you:

- Learn about the reason for the stoma, its normal function and self-care.
- Look at your stoma to help you get comfortable with how it looks.
- Remind yourself about the positive aspects of the stoma, such as its role in possibly prolonging your life.
- Talk to other people with ostomies. You may learn good coping techniques and this may help you regain a sense of normalcy.
- Get counseling to help you improve your body image, mood, and quality of life. At MSKCC, counseling is available from social workers and at the Counseling Center. You can call the social workers at 212-639-7020 and the Counseling Center at 646-888-0100.

Nutrition

The first four weeks after surgery you will be on a low-fat, low-fiber diet. A dietitian will see you while you are in the hospital to review the diet with you. You may also refer to the "Low-Fat, Low-Fiber" booklet for a list of foods to eat. Below are some recommended guidelines:

- Drink eight to ten 8-ounce glasses of fluids a day. Limit caffeine and alcohol. These beverages will dehydrate you.
- Keep in mind that the foods that disagreed with you before surgery will have the same effect.
- Some people with ostomies choose to control the amount of gas they expel. They do this by regulating their diet. The following can increase gas:
  - Eating foods such as cabbage and broccoli.
  - Drinking through a straw.
  - Chewing gum.
  - Drinking beer or carbonated beverages.
- If you have tried limiting gas and still have a problem, talk to your CWOCN nurse. He or she may suggest using charcoal filters. Some patients find it useful to use an appliance with a filter for airplane travel. The filter can help prevent the buildup of gas in the appliance to avoid inflation of the pouch. Do not prick your pouch to release built-up gas because this will destroy the pouch's odor proof system.
- If you are constipated:
  - Increase your fluid intake.
  - Eat foods that are high in bulk such as fruits, vegetables, and bran.
- Call your doctor if you:
  - Vomit.
  - Have a colostomy and have not passed any stool for three days.
  - Have an ileostomy and have not passed any stool for four to six hours.
  - Develop abdominal pain or symptoms of dehydration (more common with an ileostomy) including:
    - Thirst.
    - Dry mouth.
    - Loss of appetite.
    - Weakness.
    - Decreased urine output or dark amber urine.
    - Muscle/abdominal cramps.
    - Feeling faint.

  - Increased stool output or stool consistency changes.
  - Increased frequency of emptying pouch.

- Patients with ileostomies should not take any kind of laxative. It could cause severe dehydration and other problems.

After three to four weeks, you can add raw fruits and vegetables into your diet one at a time. If you feel bloating and pain after eating a certain food, remove this food from your diet. You can try it again in a few weeks. If you notice pain and bloating after eating such foods, then avoid them.

- "Diet is important. I had trouble with carrots. They were painful to eliminate from my stoma.
- I avoided gassy foods like broccoli. You need to experiment to see what works for you."
- "I stuck to diets of rice and potatoes. I didn't eat fruits unless they were peeled. Fiber creates a lot of wind."
- "You see corn, carrots, and mushrooms in the bag."
- "People have individual issues with foods. Try foods gradually and eat small amounts as you add to your diet to see what happens. Hot liquids stimulate the bowel more than cold liquids.
- Eliminate foods or reduce amounts if gas bothers you. Ask about medicines for gas. There are many products on the market."

Medication

Patients with ileostomies should note that some pills might not be totally absorbed. This can happen because of the decrease in your bowel length and transit time. This happens most often with:

- Large pills.
- Enteric-coated pills.
- Capsules.
- Sustained-release medications.

You can test a pill by placing it in a glass of water and see how long it takes to dissolve completely. If the pill dissolves in 30 minutes, most patients may take it. Most liquid or chewable forms of medications are more likely to be absorbed. Do not crush tablets unless your pharmacist says it is okay. Taking crushed pills can cause irritation or interfere with the acids in your stomach. **It is important to tell all your healthcare providers, including dentists and pharmacists, that you have an ostomy.** Your pharmacist is a great resource for medication but this does not take the place of your doctor's orders.

Exercise

Please talk to your doctor about what exercise is right for you. For most patients, walking and light stretching are good exercises for this period. You should avoid lifting or pushing anything over ten pounds for two to three months after surgery. This includes housework such as vacuuming or mowing the lawn. If this will be a problem, talk to your doctor. Do not do sit-ups, pushups, and any hard exercise for two to three months after surgery. This will help prevent a hernia or weakening of a muscle near the stoma. It will also help prevent a bulging out of the stoma (stomal prolapse).

- "I go swimming now and lift weights."
- "It was reassuring when I met someone who had an ostomy for years. She skis and does whatever she wants."

Odor Control

The pouches are designed so that they are odor proof. Unless you are leaking stool underneath the wafer, there should be no odor while the bag and wafer are attached. However, if odor is a problem for you, deodorants can be put into the pouch to help. Some examples are drops, charcoal tablets, or lubricating gel. You may need to experiment to find one that works for you.

There are also oral deodorants to decrease fecal odor. Check with your doctor or nurse before using any of these.

- "Sometimes, other issues get put on to the ostomy. Some people have gas that can be heard, even though they no longer have a rectum."
- "I learned to cough every time the gas was coming to mask the sounds."
- "Odor was never a problem."

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

Some patients suggest that the bag be emptied at bedtime. This is done because gas could continue to build overnight and fill the bag. If gas is a problem, you can get a filter or vent.

- "Chewing gum creates gas."
- "Air flights have not created a gas problem for me."
- "You may have more gas if you go a long time without eating. Regular, frequent meals may be a way to control gas for some people."
- "Problems with gas are more common in the beginning. It takes awhile for the bowel to adjust to food again."

Sexual activity

Talk to your doctor about when it is safe to have sex. Generally, after your incision is healed you may resume normal sexual activity. This usually takes about two months. As long as excessive pressure is not placed on the stoma, there should be no harm to it. The stoma should not be used as a sexual orifice.

For many people, returning to a normal sex life will come naturally. This happens as concerns lessen and body image gets better. Try to stay intimate with your partner as much as possible. Use kind words, meaningful touch, and hugs. As time passes, you may become more interested in sex. Take steps to make you and your partner as comfortable as possible. Check to see if your appliance fits well and if there is any odor. Some people prefer to cover the stoma with a cloth band. You can also wear a shirt or lingerie that covers the stoma and appliance. Ready-made covers can be bought from many ostomy supply companies. Some companies make a pouch with a cotton cover attached to it. You might also be able to time your sexual activity for times when you are less likely to be actively draining. This would be after an irrigation.

Talk to your doctor or nurse if surgery or radiation caused changes that make it hard to have sex. This would be impotence in men or vaginal dryness or tightness in women. If these problems do not get better, you can talk to a sexual health specialist. There are often many solutions to such problems and the specialist can help.

MSKCC has a *Sexual Health Program* to help patients address the sexual impact of their disease and treatment. You can meet with a specialist before, during, or after your treatment.

- Female Sexual Health Program. Call 646-888-5076 for an appointment.
- Male Sexual Health Program. Call 646-422-4359 for an appointment.

The United Ostomy Associations of America, Inc. (www.uoaa.org or 800-826-0826) has information on sex for both males and females. Other good sources of information are the free booklets:

- *Sexuality and Cancer: For the Man Who Has Cancer and His Partner*
- *Sexuality and Cancer: For the Woman Who Has Cancer and Her Partner.*

You can get these resources by calling 800-ACS-2345.

- "My husband had no problems if I leaked; he was far less upset than I was."
- "Sex was sort of a problem. I was afraid of the pressure with lying on top, but we found other ways."
- "When we have sex, I cover it up. I used a towel or blanket. It didn't interfere with our sex life at all. My husband had no issues."

Showering, bathing and swimming

The ostomy products are called the "wafer," "appliance," or "pouch." They are designed so you can shower with the appliance on or off. You can also use waterproof tape around the edges of the wafer. Depending on your skin type or the adherence of the appliance, you can place a piece of plastic over the whole appliance. This will prevent it from getting wet.

- "Showers were wonderful. When I was changing the wafer, I'd stand in the shower and let water run over it [the stoma]."
- "Showering is not a problem, but some products are more vulnerable to breaking down in the heat. It's not necessary to take it off during showering. It gets cleaned when we change the pouch."
- You can take a bath or swim. Start off with bathing or swimming for 15 minutes to see how the appliance holds up. Many companies say that you can soak or swim for up to two hours. However, how well the appliance sticks to the skin varies from person to person. Most people can wear the same swimsuit they wore before the surgery. Hip high one-piece swimsuits for men or hip high two-piece swimsuits for women may not be possible.
- "I could do just about everything I could before. I admit I didn't swim, but think I could have."

Travel/Work Concerns

You can go back to work as soon as you feel ready and your doctor approves. Unless you tell them, people will not know that you have an ostomy. It is highly unlikely that the pouch would be visible. You will probably be able to wear all of the clothes you wore before. However, some people do change their wardrobes slightly. They often start wearing a size larger, to make themselves feel more comfortable.

- "Women ask me what I wear. I bought one size larger briefs. They held the bag and didn't press too hard. I would wear a tee shirt and those panties to bed."
- "I wear a lot of slacks with pleats."
- "I had to wear looser clothes, but I never really had a problem. I could tell when it was time to empty the pouch—it simply inflated."
- "People are afraid of having the pouch fall off and being embarrassed in front of other people. Those concerns can be reinforced if some special circumstance makes the fit of the pouch not be ideal. It's important for patients to meet with the CWOCN. Some experimentation may be needed to find the optimal pouching system. The CWOCN will have suggestions."

It is best to have spare pouches with you wherever you go, even if it is only a brief trip or a doctor's appointment. If you are going to be away from home for several hours, think about where you are going and mentally prepare yourself. Some people feel anxiety the first few times they venture outside their homes. If you feel anxious, your stress will be reduced by thinking ahead. First, think about where the bathroom is located and what you might need. Second, get the supplies you plan to take with you. Place two of every item in a travel bag. This way, if you have an emergency or are away longer than you expect, you will be prepared. Remember to bring:

- Bags.
- Wafers.
- Clamps.
- Paper towels.

General Stoma Information/Common Questions

What is irrigation and am I a candidate for it?

Patients who have a sigmoid colostomy may be able to irrigate (give themselves an enema). Patients with an ileostomy should never irrigate. It can cause dehydration. This would eliminate the need for wearing a pouching system over the stoma. This type of enema may mean you would not have any stool between the irrigations. It is done every day or every other day.

Most patients who have had an abdominal perineal resection have a sigmoid colostomy. You cannot irrigate:

- If you have a stomal prolapse or a hernia.
- While you are on chemotherapy.
- While you are having radiation.

Ask your doctor or CWOCN for more information about it.

What color should my stoma be?

Your stoma should be a deep pink/red color all the time. It contracts and expands continually to move the stool through the bowel and out of the body. During these movements you may notice a slight change in its color. This should only be for a few seconds to a minute. If your stoma looks grey, brown, or black, call your doctor right away.

- "The stoma is swollen right after surgery. It's helpful to know that the size will change over time. It looks angry and swollen in the beginning, but that will decrease."
- "It's a turn-off when a surgeon says 'Oh, that's a beautiful stoma.' You can't expect a new patient to think that way."

Is it normal for my stoma to bleed when I touch it or change my appliance?

The stoma has many blood vessels. It may bleed easily with touch or irritation. It is common to have a small amount of blood on the tissue when cleaning the stoma. The bleeding should stop on its own within a few minutes. If you are on a blood thinner or aspirin, you may bleed more easily and for a longer period of time. Contact your doctor if you bleed a lot or if the bleeding does not stop after 5 to 10 minutes. If you notice blood in your stool or coming from the inside of your stoma, call your doctor right away.

The area around my stoma seems to bulge, is this normal?

If you have a change in the curve around your stoma, you should talk to your doctor or ostomy nurse. You may have a hernia. Often, this may happen because the abdominal wall muscle is weak. This causes a bulge to form in the area of your stoma. They will confirm that it is a hernia.

There are often no symptoms with a hernia. Surgery is not needed unless you have a complication. These can be a blockage or twisting of the herniated bowel. If a complication occurs, you will feel one or more of the following symptoms:

- Nausea.
- Vomiting.
- Pain.
- Abdominal bloating and lack of gas and stool in the ostomy pouch.

Your ostomy nurse can measure you for a custom made hernia support belt. These belts do not cure the hernia but they can help. They may keep the hernia from getting worse by giving support to the hernia. A girdle or biking shorts with a hole cut out for the ostomy pouch may also work. This would be an alternative to the custom fitted hernia belt.

What do I do when I must use a public restroom?

There are different ways to handle this depending on the type of pouch that you use. What is most important is that you empty your pouch when it is one-third to one-half full. The pouch should not become overly full. You should empty your pouch before you leave home. If you use a pouch with a clamp closure while sitting on or standing over the toilet, hold the bottom of the pouch up and then unclamp it. Roll the opening of the pouch back to avoid soiling the tail of the pouch. Empty the contents into the toilet bowl. Dry the bottom of the pouch with toilet paper and clamp it. Some people choose to clean the bottom of the pouch with a wet wipe. Some people choose to rinse the bottom of the pouch with water using a squirt top plastic water bottle. This is optional.

Some new systems have a Velcro closure. Empty as described above and refasten the Velcro closure. Some patients have an option of a closed end pouch that you do not empty. Closed end pouches should just be thrown away. You should always carry an extra pouch with you just in case you need it. Some people are concerned about odor while emptying. There is spray, liquid, and other types of deodorants that can help you with this.

- "One of the nicest things [of having an ileostomy] was knowing I'd never have to put my 'tushie' on a public toilet again."
- "I have more success sitting on the toilet. I undo the clip, empty the bag, put water into the bag, slosh it around, and empty it. I like bags with clips."
- "I always carried a little bottle of perfume to offset any whiff of gas."

Can I wear a belt over my stoma and how do I position the pouch?

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

- Irritation.
- Bleeding.
- An overgrowth of tissue.

The pouch may point directly downward or to the side. It can also be folded depending on your preference.

What do I do if I develop leakage of stool under my wafer?

If you have leakage, see your CWOCN for an assessment of your appliance. You may need a different system that fits better to avoid this problem.

- "I had a lot of leakage. My skin broke down; I had pain, irritating pain. It was awful. I tried different appliances. I finally found a wafer with deep convexity that worked and then I could go 6-7 days."
- "It's important to work with CWOCN to get the best pouch for anatomical differences or with other health issues such as arthritis, peripheral neuropathy, etc."

Is there anything I should do to prepare for tests such as a scans with contrast?

If you live an hour or more away from the hospital, be ready to change or empty your bag during the trip home. The contrast may empty into your bag in an hour or two but it can take longer. Always take a change of appliance when going to the doctor for a test, as you may have to remove it.

Do I need to wear gloves when I change the pouch?

That is a personal choice. Gloves are not needed because there is no risk of infection. However, some people prefer to wear gloves because some stool could come into contact with your fingers.

Are there any other tips you can give me?

Depending on the type of surgery you had, you may pass left over stool or mucous from your rectum. This should decrease over time, but it may be useful to wear a pad.

- "You might want to bring an extra set or two of supplies with you if you are admitted to the hospital, on the off chance that they stock a different product or that they have run out of the product you use."
- "If you squeeze every bit of air out of the pouch, the sides are likely to stick together and make it more difficult to evacuate stool. There are lubricants to make the sides of the pouch not stick together. This is more of an issue if the output is thicker. It's the reverse for people with thinner output; you can put something in pouch to thicken it."

Ordering Supplies

Consult with your CWOCN. He or she should be familiar with the latest products on the market. You may also call companies and ask for samples of their latest products. Additionally, the United Ostomy Associations of America, Inc., (www.uoaa.org or 800-826-0826) has information that you can get on its website or by mail. You can also do a search on the web for ostomy products or join an online chat room. Another option is to join a local support group for ostomy patients. Often, other patients may know of products that might meet your needs.

- "Supplies are important. Tiny bags made a huge difference for me."
- "The benefit of belonging to a group or association is that you know that everyone in the room has been through the same thing and has overlapping issues. You get the benefit of other people's experiences. You can take and adapt other people's solutions."
- "I didn't get involved with a group until I was about to go on a safari."
- "I was youngish and not very social. Our [support] group tries to match people with same age, same procedure, etc."

Medical Supplies Mail Order Companies

Listed below are some mail order medical suppliers. Some may accept Medicare and some types of medical insurance. Please call the supply company to ask if they take your insurance. If they do not, call your insurance company for a list of suppliers that do. These companies will mail the supplies to you every month. You do not usually need a prescription to order products. The company will work with your doctor's office and the insurance company. These companies offer a wide variety of products. Call and ask for their catalog.

Byram Healthcare
(877) 902-9726
www.byramhealthcare.com

CCS Medical
2105 Newpoint Place Suite 600
Lawrenceville Georgia 30043
888-724-4357
www.ccsmed.com

Edgepark Surgical Inc.
(800) 321-0591
www.edgepark.com

Fox Healthcare LLL
(877) Fox-Foxx

Landauer Metropolitan
(800) 631-3031 (outside New York)
www.landmetro.com
Accepts Medicaid in NY

Liberty Medical
P.O. Box 20005
Fort Pierce FL 34979-0005
1-888-844-2651
www.libertyMedical.com

Sterling Medical Services
2 Twosome Drive
Moorestown, NJ 08057
1-888-896-0759
www.sterlingmedical.com

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

Major Ostomy Product Manufacturers

Listed below are major manufacturers of ostomy products. These companies make products such as:

- Wafers.
- Pouches.
- Pastes.

The web sites have information about the products and other information that is helpful for people with ostomies. These companies also have ostomy nurses on staff to answer questions. Feel free to call and ask for samples of products.

Coloplast Corporation
1601 West River Road
Minneapolis, Minnesota 55411
(800) 788-0293 extension 7800
www.us.coloplast.com

Product line includes: AC Assura – two piece, Assura, and Coloplast as one and two piece systems.

Convatec Professional Services
100 Headquarters Park Drive
Skillman, NJ 08558
(800) 422-8811

www.convatec.com
Product line includes: Esteem Synergy, Sur Fit Natura and Sur Fit Autolock – two piece, Active Life – one piece system.

Cymed Ostomy Company
1440C Fourth Street
Berkeley, CA 94710
(800) 582-0707
www.cymed-ostomy.com

Product line includes Microskin Pouching system – one and two piece systems.

Hollister, Inc.
2000 Hollister Drive
Libertyville, IL 60048-3746
(800) 323-4060
www.hollister.com

Product line includes: New Image and CenterPointLock – two piece, Premier and FirstChoice – one piece system.

Marlen Manufacturing & Development Co.
5150 Richmond Road
Bedford, OH 44146-1331
(216) 292-7060
www.marlenmfg.com

Product line includes: Ultra-Duet – two piece, Ultralite – one piece system.

Nu-Hope Laboratories, Inc.
P.O.Box 331150
Pacoima, CA 91333-1150
(800) 899-5017
www.nu-hope.com

Product line includes: Nu-Hope one piece systems and custom made hernia and prolapse support belts. (Must be measured for the belt)

Conclusion

Most patients with a new ostomy have a period of adjustment. We hope that this information will make your adjustment period easier. If you have any questions, call your doctor, nurse, or social worker.

Resources

Books

Bub, D., Rose, S., Wong, W. D. *100 Questions & Answers about Colorectal Cancer.* Boston, MA: Jones and Bartlett Publishers; 2003.

Mullen, B., McGinn, K. *The Ostomy Book.* Coulder, CO: Bull Publishing; 1992.

Landay, D. *Be Prepared: The Complete Financial, Legal, and Practical Guide for Living with a Life-challenging Condition.* New York, NY: St. Martin's Press; 1998.

White, C. *Positive Options for Living with Your Ostomy: Self-Help and Treatment.* Alameda, CA: Hunter House; 2002.

Holland, J.C., Lewis, S. *The Human Side of Cancer: Living with Hope, Coping with Uncertainty.* New York, NY: Harper Collins Publishers; 1999.

Resources at Memorial Sloan-Kettering Cancer Center

Department of Social Work
(212) 639-7020

Services are focused on giving support and information to patients and their families. Services are available during inpatient and outpatient visits.

Post-Treatment Resource Program (PTRP)
Memorial Sloan-Kettering Cancer Center
300 East 66th Street, 9th Floor
New York, NY 10065
(646) 888-4740

The PTRP facilitates support groups and provides educational lectures. Other support services are provided to people who have finished their cancer treatment.

Sexual Health Program
Memorial Sloan-Kettering Cancer Center
(646) 888-5076 for women
(646) 422-4359 for men

MSKCC has a *Sexual Health Program* to help patients address the sexual impact of their disease and treatment. You can meet with a specialist before, during, or after your treatment.

Cancer and Other Resources

CancerCare®, Inc.
275 7th Avenue, Floor 22
New York, NY 10001
(800) 813-HOPE
info@cancercare.org
www.cancercare.org

CancerCare is a national non-profit organization. They provide free help to people with all cancers. The services include:

- Counseling.
- Education.
- Information.
- Referral for and direct financial assistance.

Cancer Information Service
NCI Office of Cancer Communications
1-(800)-4 CANCER
http://cis.nci.nih.gov/

The Cancer Information Service (CIS) is a program of the National Cancer Institute. CIS gives information over the phone to cancer patients and their families. The specialists are trained to give up-to-date and clear information. The CIS offices serve specific areas. The offices have information about cancer-related services and resources in their area. They can be reached by calling 1-800-4-CANCER.

Colon Cancer Alliance (CCA)
1200 G Street, NW
Ste 800
Washington, DC 20005
(202) 434-8980
(877) 422-2030 (Toll-Free Helpline)
www.ccalliance.org

The CCA is dedicated to patient:

- Support.
- Advocacy.
- Education.

CAA gives information on colon cancer. They also have support programs, such as the online support group called CCAChat. Another program is the CCA Buddies Network. This is a peer support system. It links survivors and caregivers for one-on-one support. The "Resource Center" on the web site has helpful information. You can find books, helpful organizations, and much more.

Colorectal Cancer Network (CCNetwork)
P.O. Box 182
Kensington, MD 20895-0182
(301) 879-1500
www.colorectal-cancer.net

The aim of the CCNetwork is to reduce rates of colon cancer and support patients. The web site is for people with cancer, their family and friends. It has information that can help them make decisions about treatment and disease management.

Crohn's and Colitis Foundation of America
386 Park Avenue South, 17th Floor
New York, NY 10016
(800) 932-2423
info@ccfa.org
www.ccfa.org

The Crohn's and Colitis Foundation of America works to cure and prevent Crohn's disease and ulcerative colitis. They aim to improve the quality of life for people living with these diseases. This is done through research, education and support.

Gilda's Club
48 Wall Street, 11th floor
New York, NY 10005
(888) 445-3248
info@gildasclub.org
www.gildasclub.org

Gilda's Club provides meeting places for people living with cancer and their family and friends. It gives people a place where they can meet others to build support systems. Gilda's Club offers free:

- Support and networking groups.
- Lectures.
- Workshops.
- Social events in a homelike setting.

International Ostomy Association (IOA)
www.ostomyinternational.org/

The International Ostomy Association works to improve the quality of life for people who have ostomies or related surgeries.

National Family Caregivers Association (NFCA)
10400 Connecticut Avenue, Suite 500
Kensington, MD 20895-3944
(800) 896-3650
(301) 942-6430
info@thefamilycaregiver.org
www.nfcacares.org

The National Family Caregivers Association (NFCA) provides support to people who have to care for a loved one who is ill, old, or disabled. They work to provide caregivers with:

- Support
- Empowerment
- Education
- Advocacy

The NFCA gives support to caregivers who are taking care of people with all kinds of problems. They also address the different relationships that caregivers have with their loved ones. The goal is to address the common needs of all family caregivers.

National Ovarian Cancer Coalition (NOCC)
2501 Oak Lawn Avenue
Suite 435
Dallas, Texas 75219
((214) 273-4200
1-888-682-7426
nocc@ovarian.org
www.ovarian.org

The National Ovarian Caner Coalition (NOCC) works to make people more aware of ovarian cancer. They aim to educate people about this cancer. The group also works to make the survival rate and quality of life better for women who have this cancer.

Ovarian Cancer National Alliance (OCNA)
910 17th Street, N.W., Suite 1190
Washington, D.C. 20006
(202) 331-1332
866-399-6262 (Toll Free)
ocna@ovariancancer.org
www.ovariancancer.org

The goal of the Ovarian Cancer National Alliance is to put ovarian cancer on the agenda of policy makers and women's health care leaders.

Shaz's Ostomy Pages
www.ostomates.org

This web site provides information about

- Ileostomy surgery.
- Colostomy surgery.
- Urostomy surgery.

The information is provided by ostomates for ostomates (no "medical speak").

C3Life.com
www.c3life.com

A website dedicated to helping people with ostomies live their lives to the fullest. The online community includes a discussion forum, recipes, blogs, hints, and tips.

United Ostomy Associations of America, Inc. (UOAA)
P.O. Box 66
Fairview, TN 37062-0066
(800) 826-0826
www.uoaa.org

The United Ostomy Associations of America, Inc., is a volunteer-based health organization. They work to give support to people who have had or will have intestinal or urinary diversions. This includes providing:

- Education.
- Information.
- Support.
- Advocacy.

Wound, Ostomy, Continence Nurses Society
15000 Commerce Parkway
Suite C
Mt. Laurel, NJ 08054
(888) 224-WOCN (9626)
www.wocn.org

This is a professional nursing society. Members are experts in the care of patients with wounds, ostomies, and continence disorders.

Women's Cancer Network
230 W. Monroe, Suite 2528
Chicago, IL 60606
(312) 578-1439
info@thegcf.org
www.wcn.org

The Women's Cancer Network was developed by the Gynecological Cancer Foundation (GCF). They work to inform women around the world about gynecologic cancer. WCN provides a private risk assessment survey tool. Woman can use this tool to assess their risk for developing gynecologic or breast cancer. Visit their web site to:

- Understand more about the disease.
- Learn about treatment options.
- Find cancer treatment specialists.
- Learn ways to prevent the development of cancer.

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