

# About Your Abdominal Perineal Resection Surgery

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# About Your Surgery

This guide will help you prepare for your abdominal perineal resection (APR) surgery at Memorial Sloan Kettering (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).

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.

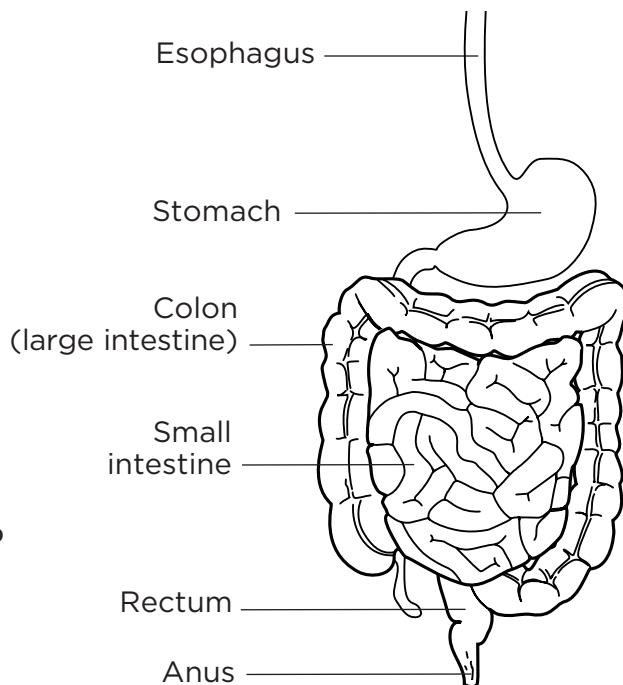


Figure 1: The digestive system

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 wound, ostomy, continence (WOC) nurse 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.

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.

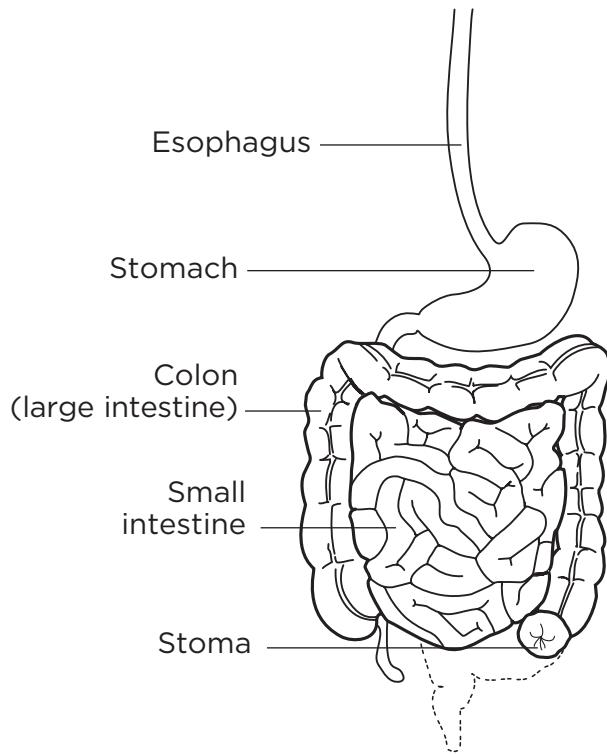


Figure 2: Colostomy

Notes \_\_\_\_\_

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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 Treatment 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 have an appointment for presurgical testing (PST). The date, time, and location of your PST appointment will be printed on the appointment reminder from your surgeon's office.

You can eat and take your usual medications the day of your PST appointment. During your appointment, you will meet with a nurse practitioner who works closely with anesthesiology staff (doctors and specialized nurses who will be giving you medication to put you to sleep during your surgery). He or she 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 11 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.

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### Meet With a Wound, Ostomy, Continence (WOC) Nurse

You will meet with a WOC nurse during your PST appointment. A WOC nurse 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 WOC nurse will also show you a colostomy pouch so that you can become familiar with it.

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

Your WOC nurse 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 WOC nurse 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 already, 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 "After Your Surgery" section of this guide. If you have any questions, ask your nurse.

## **Exercise**

Try to do aerobic exercise every day, such as walking at least 1 mile, swimming, or biking. 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 this section.

## 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 this section.

## 2 Days Before Your Surgery

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

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	<ul style="list-style-type: none"> <li>• Clear broth, bouillon</li> <li>• Clear consommé</li> <li>• Packaged vegetable, chicken, or beef broth mixes</li> </ul>	Any products with any particles of dried food or seasoning
Sweets and Desserts	<ul style="list-style-type: none"> <li>• Gelatin, such as Jell-O®</li> <li>• Flavored ices</li> <li>• Hard candies such as Lifesavers®</li> </ul>	All others
Beverages	<ul style="list-style-type: none"> <li>• Clear fruit juices, such as white cranberry, white grape, apple</li> <li>• Soda, such as 7-Up®, Sprite®, ginger ale, seltzer</li> <li>• Gatorade®</li> <li>• Decaffeinated black coffee</li> <li>• Decaffeinated tea</li> </ul>	<ul style="list-style-type: none"> <li>• Juices with pulp</li> <li>• Nectars</li> <li>• Milk or cream</li> <li>• Alcoholic beverages</li> </ul>

**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 the Friday before. 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 67<sup>th</sup> and East 68<sup>th</sup> Streets. Take the B elevator to the 6<sup>th</sup> 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. Do not use any other soap. 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.**

## 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. Take any medication as instructed with a small 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 jewelry, 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.
- If you wear contact lenses, wear your glasses instead.
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- \_\_\_\_\_
- \_\_\_\_\_



## 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.
- 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.
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- \_\_\_\_\_
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## Parking When You Arrive

Parking at MSK is available in the garage on East 66<sup>th</sup> Street between York and First Avenues. To reach the garage, enter East 66<sup>th</sup> 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 you can walk through that connects the garage to the hospital. If you have questions about prices, call 212-639-2338.

There are also other garages located on East 69<sup>th</sup> Street between First and Second Avenues, East 67<sup>th</sup> Street between York and First Avenues, and East 65<sup>th</sup> Street between First and Second Avenues.

## 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.

## 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 with you about your comfort and safety during your surgery.
- Talk with 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* located in this section.

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.



P = Parking

M = Memorial Sloan Kettering

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.

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

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

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

## 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®	Datril®	Norco®	Tylenol with Codeine No. 3
<b>Aceta® with Codeine</b>	<b>Di-Gesic®</b>	Panadol®	
<b>Acetaminophen with Codeine</b>	Esgic®	<b>Percocet®</b>	Vanquish
Aspirin-Free Anacin	Excedrin P.M.	Repan	Vicodin®
Arthritis Pain Formula	<b>Fioracet®</b>	<b>Roxicet®</b>	Wygesic®
Aspirin-Free	<b>Loracet®</b>	Talacen®	Zydome®
<b>Darvocet-N 100®</b>	<b>Lortab</b>	Tempra®	
	Naldegesic®	Tylenol	

**! 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 1 day. It's possible to take too much acetaminophen without knowing because it's in many different medications, so always read and follow the label on the product you are taking. Do not take more than 1 medication at a time that contains acetaminophen without talking with a member of your healthcare team.

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 am to 5:00 pm at \_\_\_\_\_. After 5:00 pm, during the weekend, and on holidays, please call \_\_\_\_\_. If there's no number listed, or you're not sure, call (212) 639-2000.

# 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

## Common Herbs and 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 the About Herbs, Botanicals & Other Products website at [mskcc.org/aboutherbs](http://mskcc.org/aboutherbs).

You can also download the Memorial Sloan Kettering About Herbs app from the Apple App Store at [itunes.apple.com/us/app/about-herbs/id554267162?mt=8](http://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.

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 am to 5:00 pm at \_\_\_\_\_ . After 5:00 pm, during the weekend, and on holidays, please call\_\_\_\_\_. If there's no number listed, or you're not sure, call (212) 639-2000.

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# Information for Family and Friends for the Day of Surgery

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

## ■ Before the Surgery

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

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

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

Please remember the following:

- Do not bring food or drinks into the waiting area or the PSC. Patients are not allowed to eat before their surgery or procedure.
- Our patients are at high risk for infection. Please do not visit if you have any cold or flu symptoms (fever, sneezing, sniffles, or a cough). We may ask you to wear a mask if there are any concerns about your health.
- If the patient brought any valuables, such as a cell phone, iPod, iPad, etc., please keep them safe for him or her during surgery.
- Sometimes, surgeries are delayed. We make every effort to tell you when this happens.

## ■ During the Surgery

After the patient is taken to the OR, please wait in the main lobby on the 1<sup>st</sup> floor. While you are waiting, here are some things you can do:

- Food and drinks are available on the 1<sup>st</sup> floor in the cafeteria and in the gift shop. You can also bring your own food and eat it in the cafeteria.
- The coat-check room is located at the bottom of the escalator on the ground level. It 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 can also use the computers in

the rooms off the main lobby.

- Please be courteous and mindful of others while using your cell phone. Use the designated area to accept and make calls on your cell phone. It may be useful to bring your phone charger to the hospital.
- The Mary French Rockefeller All Faith Chapel is an interfaith chapel located in room M106 near the main lobby on the 1<sup>st</sup> floor. It is open at all times for meditation and prayer.
- The Patient Recreation Pavilion is open daily from 9:00 AM to 8:00 PM for patients and their visitors. Children are allowed in the pavilion as long as they are supervised by an adult. Arts and crafts, a library, an outdoor terrace, and scheduled entertainment events are available in this area. To get to the pavilion, take the M elevators to the 15<sup>th</sup> floor.

### **Surgery updates**

A nurse liaison will keep you updated on the progress of surgery. He or she will:

- 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).

To contact the nurse liaison:

- 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 can also ask the information desk staff to contact the nurse liaison for you.

## **■ After the Surgery**

### **Meeting with the surgeon**

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

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

### **Visiting the patient in the PACU**

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

When the patient is able to have visitors, a staff member will take you to the PACU. Please remember that only a limited number of visitors can go into the PACU. This is to keep the area quiet and avoid overcrowding. The patients in the PACU need time for rest and nursing care after surgery.

### **While visiting in the PACU**

- Silence your cell phone.

- Apply an alcohol-based hand sanitizer (such as Purell®) before entering. There are hand sanitizer stations located throughout the hospital.
- Speak quietly.
- Respect other patients' privacy by staying at the bedside of your friend or family member.
- Do not bring food or flowers into the PACU.
- If any PACU patient needs special nursing attention, we may ask you to leave or to delay your visit.

After your visit, the nurse will escort you back from the PACU. He or she 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. If the patient is going home the same day, a responsible adult must take him or her home.

We will give you a card with the PACU phone number. Please appoint one person to call for updates.

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 am to 5:00 pm at \_\_\_\_\_. After 5:00 pm, during the weekend, and on holidays, please call \_\_\_\_\_. If there's no number listed, or you're not sure, call (212) 639-2000.

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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)*, in this section.

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*, in this section.

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.

# 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)*, in this section. 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 WOC nurse will teach you how to care for your colostomy. For more information, please read *A Guide for Patients With an Ileostomy or Colostomy*, in this section.

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.



### 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 \_\_\_\_\_

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# Patient-Controlled Analgesia (PCA)

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

Patient-controlled analgesia (PCA) helps you control your pain by administering your pain medication. PCA uses a computerized pump to deliver pain medication 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 Medication is Given with PCA

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

- As needed - You get your pain medication only when you press the button. It will not allow you to get more medication than prescribed. The pump is set to allow only a certain number of doses per hour.
- Continuous - You get your pain medication at a constant rate all the time. This can be combined with the as needed mode. That allows you to take extra doses safely if you are having pain.

## ■ Possible Side Effects

Pain medication delivered by the PCA pump can have 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 your 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.

- People 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 medication is not controlling your pain.
- You are having side effects.
- Your pain changes, such as if:
  - It gets worse
  - You feel it in a new place
  - Feels different than before

Your doctor may be able to change the medication to one that may work better for you or give you fewer side effects.

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 am to 5:00 pm at \_\_\_\_\_. After 5:00 pm, during the weekend, and on holidays, please call \_\_\_\_\_. If there's no number listed, or you're not sure, call (212) 639-2000.

# How to Use Your Incentive Spirometer

This information will help you learn 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 after your surgery, along with deep breathing and coughing exercises, will help keep your lungs active throughout the recovery process and prevent complications such as pneumonia.

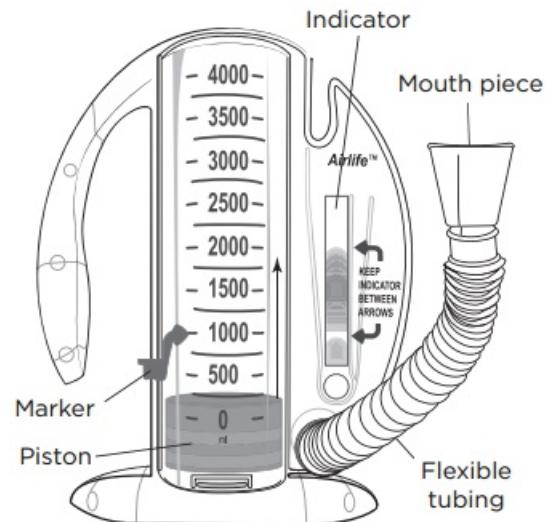
A video demonstrating how to use your incentive spirometer can be found on the Memorial Sloan Kettering (MSK) website at:

▶ [www.mskcc.org/videos/how-use-your-incentive-spirometer](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.

To use your incentive spirometer:

1. Sit upright in a chair or in bed. Hold the incentive spirometer upright at eye level.
2. Exhale (breathe out) 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 slow, deep breath, you will see the piston rise inside the large column. While the piston rises, the indicator on the right should move upwards. It should stay in between the 2 arrows (see figure). 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 2 to 5 seconds or longer, if possible.
6. Exhale slowly, allowing the piston to fall all the way back to the bottom. Rest for a few seconds.
7. Take 10 breaths with your incentive spirometer every hour while you are awake, or as instructed by your clinician. Try to get the piston to the same level with each breath.
8. 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.
- If you had surgery on your chest or abdomen, hug or hold a pillow to help splint your incision. 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.

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 am to 5:00 pm at \_\_\_\_\_. After 5:00 pm, during the weekend, and on holidays, please call \_\_\_\_\_. If there's no number listed, or you're not sure, call (212) 639-2000.

# A Guide for Patients With an Ileostomy or Colostomy

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

An ostomy is an opening created during surgery, in which a piece of your intestine is brought to the outside of your abdomen (belly). It is created so that stool and gas can exit your body. The part of your intestine that is on the outside of your body is called a stoma. Your stoma will look red and moist, similar to the inside of your mouth. Your stoma will be swollen right after surgery, but the size will decrease in 6 to 8 weeks. You will not feel any pain or pressure within your stoma. You will also not feel any sensations of heat or cold.

Some ostomies are permanent, while others are temporary. Your surgeon will tell you if your ostomy is permanent or temporary.

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

## ■ **Types of Ostomies**

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

The consistency of stool differs depending on the part of the intestine that is used to create the ostomy. The stool may be liquid, soft, or solid.

The most common types of ostomies are listed below.

### **Ileostomy**

- Created out of the part of the small intestine called the ileum.
- Stool is liquid or semiliquid.
- Stoma is usually located on the right lower side of the abdomen.

### **Ascending colostomy**

- Created out of the ascending colon.
- Stool is liquid or semiliquid.
- Stoma is usually located on the right side of the abdomen.

### **Descending colostomy**

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

### **Sigmoid colostomy**

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

### **Loop ostomy**

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

In some surgeries, a second opening is created on the abdomen called a mucous fistula. It secretes left over stool or a mucus-like fluid and leads to the rectum. If you have a mucous fistula, your WOC nurse will teach you how to care for it while you are in the hospital. Usually, a small pouch or dressing is placed over the mucus fistula. It will need to be cleaned with water and emptied. Once there is no drainage, the mucus fistula can be covered with a pad and tape.

## **■ Learning to Care for Your Stoma and Ostomy**

Your WOC nurse and nursing staff will teach you how to care for your stoma and ostomy while you are in the hospital. When you are discharged from the hospital, you will be given the basic supplies you need to care for your ostomy. Then, you will order the supplies from a medical supplier. There is a list of medical suppliers at the end of this resource.

You will also be set up with a visiting nurse, who will come to your home after you are discharged from the hospital. He or she can help you care for your stoma and adjust to being home. If you have any questions or problems once you are home, call your WOC nurse or social worker.

### **Pouching systems**

After your surgery, you will wear an odor-proof pouch over your ostomy. Pouching systems include a 1-piece or 2-piece system. Both kinds include a wafer (skin barrier) and a collection pouch. Together, these are referred to as an “appliance”. The pouch (1- or 2-piece) attaches to your abdomen by the wafer and is fitted over and around your stoma to collect your stool and gas. The wafer protects the skin around your stoma from getting irritated by stool leakage.

Your WOC nurse will help you find the best pouching system for your stoma. Please note that as the size of your stoma changes, you may need to change your pouching system.

Some people find it helpful to buy incontinence bed pads or cloth underpads to place over bed sheets. This protects the bed in case the pouch leaks accidentally during the night.

## **Emptying your pouch**

Empty your pouch when it is one-third to one-half full. The pouch should not become overly full. Your WOC nurse will teach you how to empty your pouch.

If you squeeze every bit of air out your pouch, the sides are likely to stick together and make it more difficult to collect stool. There are lubricants to help with this. This is more of an issue if your stool output is thicker. If you have thinner output, you can put something in the pouch to thicken it.

## **Changing your appliance**

Your WOC nurse will teach you how to change your appliance. Generally, you should change your appliance every 3 to 5 days. If you have leakage, change it immediately. This is to protect the skin around your stoma from getting irritated from stool leakage. If you are having any leakage or irritation that has lasted for a few days, call your WOC nurse.

## **■ Lifestyle Issues**

### **Body image and depression**

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

- Look at your stoma to help you get comfortable with it.
- Remind yourself about the positive aspects of your ostomy, such as its role in possibly prolonging your life.
- Talk with 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, feelings, and quality of life. At Memorial Sloan Kettering (MSK), counseling is available from social workers and at the Counseling Center. You can reach the Social Work Department at 212-639-7020 and the Counseling Center at 646-888-0200.

### **Nutrition**

Your doctor will give you dietary guidelines to follow after your surgery. A dietitian will see you while you are in the hospital to review these guidelines with you.

Below are some recommended guidelines if you have an ileostomy:

- Stay well-hydrated.
  - Drink 8 to 10 (8-ounce) glasses of liquids a day.
  - Limit your intake of caffeine and alcohol, as they can dehydrate you.
  - Limit foods high in fiber and simple sugars (e.g., glucose, sucrose, fructose), as they can dehydrate you.

- Keep in mind that the foods that disagreed with you before your surgery will have the same effect after your surgery. If you feel bloating and pain after eating a certain food, remove this food from your diet. Try eating it again in a few weeks. If you are still having pain and bloating after eating this food, avoid it.
- Some people with ostomies choose to limit gas by regulating their diet. The following can increase gas:
  - Foods such as cabbage and broccoli
  - Carbonated beverages
  - Drinking through a straw
  - Chewing gum
- If you have tried limiting gas and still have a problem, talk with your WOC nurse. He or she may suggest using pouches with charcoal filters. The filter can help prevent the buildup of gas and avoid inflation of the pouch. Some people also find it useful to use pouches with filters for airplane travel.
  - Do not prick your pouch to release built-up gas because this will destroy the pouch's odor proof system.
  - Do not rinse your pouch with water, as this will deactivate the filter.
- If you are constipated:
  - Increase your liquid intake.
  - Eat foods that are high in fiber, such as fruits, vegetables, and bran.
  - Walk, if the weather allows.

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

- Call your doctor if you:
  - Vomit
  - Have a colostomy and have not passed any stool for 3 days
  - Have an ileostomy and have not passed any stool for 3 to 6 hours
- Develop abdominal pain or symptoms of dehydration (this is more common for those with an ileostomy), including:
  - Increased thirst
  - Dry mouth
  - Loss of appetite
  - Weakness
  - Decreased urine output or dark amber urine
  - Muscle, abdominal, or leg cramps
  - Feeling faint
  - Increased stool output or changes in consistency
  - Increased frequency of emptying pouch

## **Medication**

If you have an ileostomy, your body may not be able to completely absorb some medications. This can happen because of the decrease in the length of your bowel and because some medications are absorbed slowly. This happens most often with:

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

Ask your doctor if you are taking any of these medications. If you see a tablet in your pouch that is not absorbed, call your doctor.

Do not crush pills unless your doctor or pharmacist says it is okay. Taking crushed pills can cause irritation or interfere with digestion.

## **Exercise**

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

Do not do sit-ups, pushups, or any strenuous exercise for 2 to 3 months after your surgery. This will help prevent a hernia or weakening of a muscle near your stoma. It will also help prevent a stomal hernia (bulging out of your stoma).

## **Odor control**

Appliances are designed to be odor proof. Unless you are leaking stool underneath the wafer, there should be no odor while the appliance is attached. However, if odor is a problem for you, there are deodorants that you can put into the pouch to help. Some examples are drops, charcoal tablets, or lubricating gel. You may need to experiment to find one that works best for you. There are also deodorants you can take orally (by mouth) to decrease fecal odor. Check with your doctor or nurse before using any of these.

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

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

## **Sexual activity**

Talk with your doctor about when it is safe to resume sexual activity. Generally, after your incision is healed, you can resume sexual activity. This usually takes about 2 months. As long as excessive pressure is not placed on your stoma, there should be no harm done to it. Do not use your stoma as a sexual orifice.

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

Check to see if your appliance fits well and if there is any odor. Some people prefer to cover their appliance with a cloth band, shirt, or lingerie during sexual activity. You can buy ready-made covers from many ostomy supply companies. Some companies also make a pouch with a cotton cover attached to it.

You may also be able to plan your sexual activity for times when you are less likely to be actively draining, such as after irrigation, if you are able to do so (for more information about irrigation, see the section titled “Frequently Asked Questions About Ostomy Care”).

Talk with your doctor or nurse if surgery or radiation therapy caused changes that make it hard to have sex. Examples are erectile dysfunction (inability to develop or maintain an erection) in men or vaginal dryness or tightness in women. If these problems do not get better, you can talk with a sexual health specialist. MSK has a Sexual Health Program to help people address the impact of their disease and treatment on sexuality.

The United Ostomy Associations of America, Inc. ([www.uoaa.org](http://www.uoaa.org) or 1-800-826-0826) has information on sex for both men and women with ostomies.

Other good sources of information are the following resources published by the American Cancer Society. You can get these resources by calling 1-800-ACS-2345 or by going to the links below.

#### *Sexuality for the Man With*

*Cancer* : [www.cancer.org/acs/groups/cid/documents/webcontent/002910-pdf.pdf](http://www.cancer.org/acs/groups/cid/documents/webcontent/002910-pdf.pdf) 

#### *Sexuality for the Woman With*

*Cancer* : [www.cancer.org/acs/groups/cid/documents/webcontent/002912-pdf.pdf](http://www.cancer.org/acs/groups/cid/documents/webcontent/002912-pdf.pdf) 

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

You can shower with your appliance on or off. You can also use waterproof tape around the edges of the wafer. Depending on your skin and the type of pouch, you can place a piece of plastic over the whole appliance. This will prevent it from getting wet.

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

#### **Work**

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 appliance will be visible. You will probably be able to wear all of the same clothes you wore before your surgery.

## Travel

**Bring extra appliances with you wherever you go, even if it is only a short 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 may be reduced by thinking ahead. First, think about where the bathroom is located and what you may need. Second, get the supplies you plan to take with you. Place 2 of every item in a travel bag. This way, if you have an emergency or are away from home longer than you expected, you will be prepared. Remember to bring:

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

When you are traveling by air:

- Pack your ostomy supplies in at least 2 places, such as in your carry-on and checked luggage.
- Take extra supplies in case you are stranded where supplies may not be available.
- You may want to bring a letter from your doctor stating your need for ostomy supplies, as well as a private area be used in case of an extended search by TSA agents.
- If you are traveling to a foreign country, it is a good idea to have critical ostomy information written in that language. One of the 70 member associations of the International Ostomy Association ([www.ostomyinternational.org](http://www.ostomyinternational.org)) may be able to help with this translation, as well as with locating supplies while visiting their country.
- You may want to carry photocopies of the catalog pages displaying and explaining your equipment for TSA agents.

## ■ Frequently Asked Questions About Ostomy Care

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

Irrigation is a type of enema that eliminates the need for wearing a pouching system over the stoma. This means you would not have any stool between the irrigations. Irrigation is done every day or every other day. People who have a sigmoid colostomy may be able to irrigate. Most people who have had an abdominal perineal resection have a sigmoid colostomy. **People with an ileostomy should never irrigate because it can cause dehydration.**

You also cannot irrigate:

- If you have a stomal hernia (bulge around the stoma).
- While you are receiving chemotherapy.
- While you are receiving radiation therapy.

Ask your doctor or WOC nurse for more information about irrigation.

### **What color should my stoma be?**

Your stoma should be a deep pink or red color at all times. While it is contracting and expanding to move stool out of your body, you may notice a slight change in its color. This should only be for a few seconds to

a minute. If your stoma looks grey, brown, or black, call your doctor immediately.

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

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

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

If you have a change in the curve around your stoma, tell your doctor or WOC nurse. You may have a stomal hernia. Often, this happens because the abdominal wall muscle is weak and this causes a bulge to form in the area of the stoma. Your doctor or WOC nurse will examine you to see if you have a stomal hernia.

Often, people with a stomal hernia do not have any symptoms. Surgery is not needed unless you have a complication, including a blockage or twisting of the herniated bowel. If you have any of the following symptoms, call your doctor or nurse:

- Nausea
- Vomiting
- Pain
- Abdominal bloating and lack of gas and stool in your pouch

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

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

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

- Irritation
- Bleeding
- An overgrowth of tissue

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

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

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

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

Always take an extra set of supplies when going to the doctor for tests because you may have to remove your appliance.

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

### **Do I need to wear gloves when I change my appliance?**

This is a personal choice. There is no risk of infection from changing your appliance. However, some people prefer to wear gloves because some stool could come into contact with your fingers.

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

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 and apply a zinc ointment such as Desitin® around your anus to prevent irritation.

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

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

## **■ Support Groups**

You may find it helpful to join a support group for people with ostomies. MSK has a virtual program for people with ostomies. This is a live, online support group in which people can share their experiences and provide practical and emotional support for one another. Discussions are co-facilitated by a social worker and nurse. The group is open to all MSK and non-MSK patients. The group is held every other month on the 3<sup>rd</sup> Thursday of the month from 4:00 PM to 5:00 PM. To learn more about the program, or to register for the program, please contact: [virtualprograms@mskcc.org](mailto:virtualprograms@mskcc.org)

On the United Ostomy Associations of America (UOAA) website, you can search for UOAA-affiliated online and in-person support groups for people with ostomies. To find a group, go to:

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

## **■ Ordering Supplies**

Speak with your WOC nurse about ordering supplies. He or she is familiar with the latest products on the market. You can also call companies and ask for samples of their products.

### **Mail order medical supply companies**

Listed below are some mail order medical supply companies. Some accept Medicare and other types of insurance. Call the company directly to see if they take your insurance. If they do not, call your insurance company to get 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 the supplies. The company will work with your doctor's office and your insurance company. These companies offer a wide variety of products. Call and ask for their catalog or view it online.

#### **Byram Healthcare**

877-902-9726

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

**CCS Medical**

1-800-260-8193

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

**Edgepark Medical Supplies**

888-394-5375

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

**Landauer Metropolitan**

800-631-3031

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

(Accepts Medicaid in New York State)

**Liberty Medical**

1-800-723-9558

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

**Sterling Medical Services**

1-888-907-8775

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

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

**Ostomy product manufacturers**

Listed below are companies that manufacture ostomy products. These companies make products, such as wafers and pouches, and ostomy accessories, such as pastes, powder, rings, etc. Many of these companies also have WOC nurse on staff to answer questions. Feel free to call and ask for samples of products.

**Coloplast Corporation**

1-800-533-0464

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

**Convatec Professional Services**

1-800-422-8811

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

**Cymed**

1-800-582-0707

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

**Hollister, Inc.**

1-888-740-8999

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

## **Marlen Manufacturing & Development Company**

216-292-7060

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

## **Nu-Hope Laboratories, Inc.**

1-800-899-5017

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

## **■ MSK Support Services**

### **[Resources for Life After Cancer \(RLAC\) Program](#)**

646-888-8106

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

### **Social Work Department**

646-888-5271 or 646-888-5203

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

### **Sexual Health Program**

For women: 646-888-5076

For men: 646-422-4359

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

## **■ Resources**

### **Books**

*100 Questions & Answers about Colorectal Cancer*

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

Boston, MA: Jones and Bartlett Publishers; 2003

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

Authors: Barbara Dorr Mullen and Kerry Anne McGinn

Boulder, CO: Bull Publishing; 2008

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

Author: David Landay

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

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

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

Alameda, CA: Hunter House; 2002

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

Authors: Jimmie Holland and Sheldon Lewis

New York, NY: Harper Collins Publishers; 2000

## **Organizations**

### **Cancercare**

1-800-813-HOPE (4673)

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

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

### **Caregiver Action Network**

<http://caregiveraction.org>

Provides support to caregivers of those who are ill, elderly, or disabled. Works to provide caregivers with support, empowerment, education, and advocacy.

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

877-422-2030 (toll-free helpline)

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

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

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

1-800-932-2423

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

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

### **C3Life.com**

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

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

### **Gilda's Club New York City**

195 West Houston St.

New York, NY 10014

212-647-9700

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

Provides meeting places for people living with cancer and their family and friends. Gives people a place where they can meet others to build support systems. Offers free support and networking groups, lectures, workshops, and social events.

**International Ostomy Association (IOA)**

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

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

**National Ovarian Cancer Coalition (NOCC)**

888-682-7426

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

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

**NCI's Cancer Information Service**

1-800-4 CANCER

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

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

**Ovarian Cancer National Alliance (OCNA)**

866-399-6262 (toll free)

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

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

**Shaz's Ostomy Pages**

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

Provides easy-to-understand information about ileostomy, colostomy, and urostomy surgeries.

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

1-800-826-0826

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

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

**Women's Cancer Network**

312-578-1439

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

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

**Wound, Ostomy, Continence Nurses Society**

888-224-WOCN (9626)

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

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

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 am to 5:00 pm at \_\_\_\_\_. After 5:00 pm, during the weekend, and on holidays, please call \_\_\_\_\_. If there's no number listed, or you're not sure, call (212) 639-2000.

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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 212-639-7874.

## **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**

646-888-0800

Integrative Medicine Service offers patients many services to complement traditional medical care, including music therapy, mind/body therapies, dance and movement therapy, yoga, and touch therapy.

## **Look Good Feel Better Program**

800-227-2345

Learn techniques to help you feel better about your appearance by taking a workshop or visiting the program online at [www.lookgoodfeelbetter.org](http://www.lookgoodfeelbetter.org).

## **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**

646-888-8106

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

**Social Work**

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 Treatment 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](http://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](http://www.aircharitynetwork.org)

877-621-7177

Provides travel to treatment centers.

## **American Cancer Society (ACS)**

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

A comprehensive resource for education, tools, and events for employees with cancer.

## **CancerCare**

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

800-813-4673

275 Seventh Avenue (between West 25<sup>th</sup> & West 26<sup>th</sup> 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](http://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](http://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](http://www.corpangelnetwork.org)

866-328-1313

Free travel to treatment across the country using empty seats on corporate jets.

**fertileHOPE**

[www.fertilehope.org](http://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](http://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](http://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](http://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](http://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 online support groups and a database of LGBT friendly clinical trials.

**National Cancer Institute**

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

**National Cancer Legal Services Network**

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

Free cancer legal advocacy program.

**National LGBT Cancer Network**

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

Provides education, training, and advocacy for LGBT cancer survivors and those at risk.

**Needy Meds**

[www.needy meds.com](http://www.needy meds.com)

Lists Patient Assistance Programs for brand and generic name medications.

**NYRx**

[www.nyrxplan.com](http://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](http://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](http://www.panfoundation.org)

866-316-7263

Provides assistance with copayments for patients with insurance.

**Patient Advocate Foundation**

[www.patientadvocate.org](http://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](http://www.rxhope.com)

877-267-0517

Provides assistance to help people obtain medications that they have trouble affording.

**The Ostomy Association**

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

**Wound Ostomy Continence Organization**

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

Go to this website to find a WOC nurse in your area. The website also has information on resources, suppliers of ostomy products, and support groups.