

# MSK Kids

PATIENT & CAREGIVER EDUCATION

## About Your Convection-Enhanced Delivery (CED) of Radioimmunotherapy (RIT) for Pediatric Patients With Diffuse Intrinsic Pontine Glioma (DIPG)

This guide will help you get ready for your convection-enhanced delivery (CED) of radioimmunotherapy (RIT) at Memorial Sloan Kettering (MSK). It will also help you understand what to expect during and after your surgery and treatment.

Read through this guide at least once before your surgery and use it as a reference in the days leading up to your surgery. Bring this guide with you every time you come to MSK, including the day of your surgery. You and your healthcare team will refer to it throughout your care.

In this resource, the words “you” and “your” refer to you or your child.



To view this guide online, visit [www.mskcc.org/pe/ced\\_rit\\_dipg](http://www.mskcc.org/pe/ced_rit_dipg)



Memorial Sloan Kettering  
Cancer Center

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1275 York Avenue, New York, New York 10065  
A-076-5

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# About Your Surgery

## About DIPG

DIPG is a type of tumor in your brain stem. Your brain stem is located at the base of your brain, near where your spinal cord connects to your brain (see Figure 1). Your brain stem controls things such as:

- Your heartbeat
- Your breathing
- Your eye movements
- Your face muscles
- Your swallowing

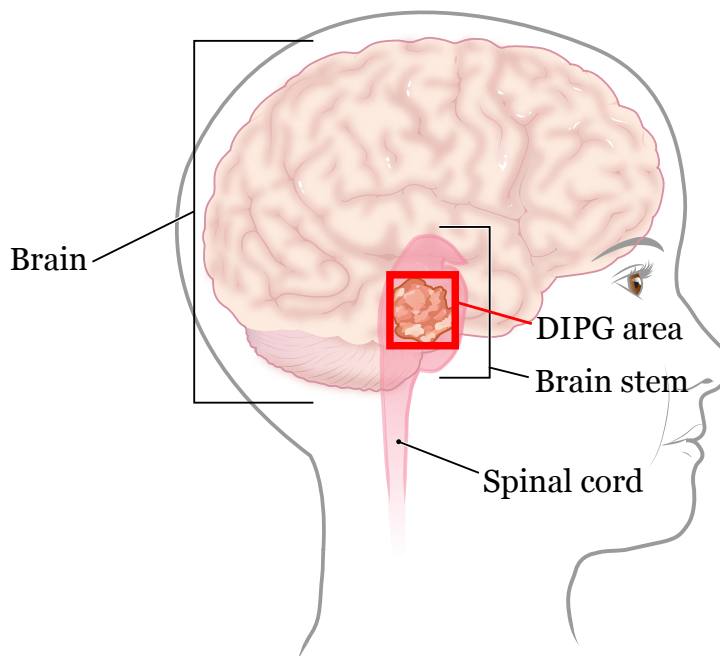


Figure 1. Your brain stem and DIPG

DIPG is treated with radiation therapy, but the tumors usually come back within months after treatment. There's no known chemotherapy that effectively treats DIPG.

MSK is doing a clinical trial (research study) for people diagnosed with DIPG. The purpose of the trial is to test a new way to treat DIPG with an infusion of radioimmunotherapy directly into your brainstem. This is called convection-enhanced delivery (CED) of radioimmunotherapy (RIT). If you have questions about the clinical trial, talk with your neurosurgeon, neurooncologist, or nurse practitioner (NP).

## About Radioimmunotherapy (RIT)

RIT is a type of treatment that combines radiation therapy and immunotherapy. With RIT, radiolabeled monoclonal antibodies deliver radiation directly to the cancer cells.

- An **antibody** is a protein that's made by your immune system and released into your blood. Antibodies fight against harmful substances, such as bacteria, fungi, parasites, and viruses.
- A **radiolabeled monoclonal antibody** is an antibody that's made in a lab and specially designed to attach to cancer cells. The antibody has liquid radiation attached to it. This radiation kills the cancer cells directly without damaging normal tissue (see Figure 2).

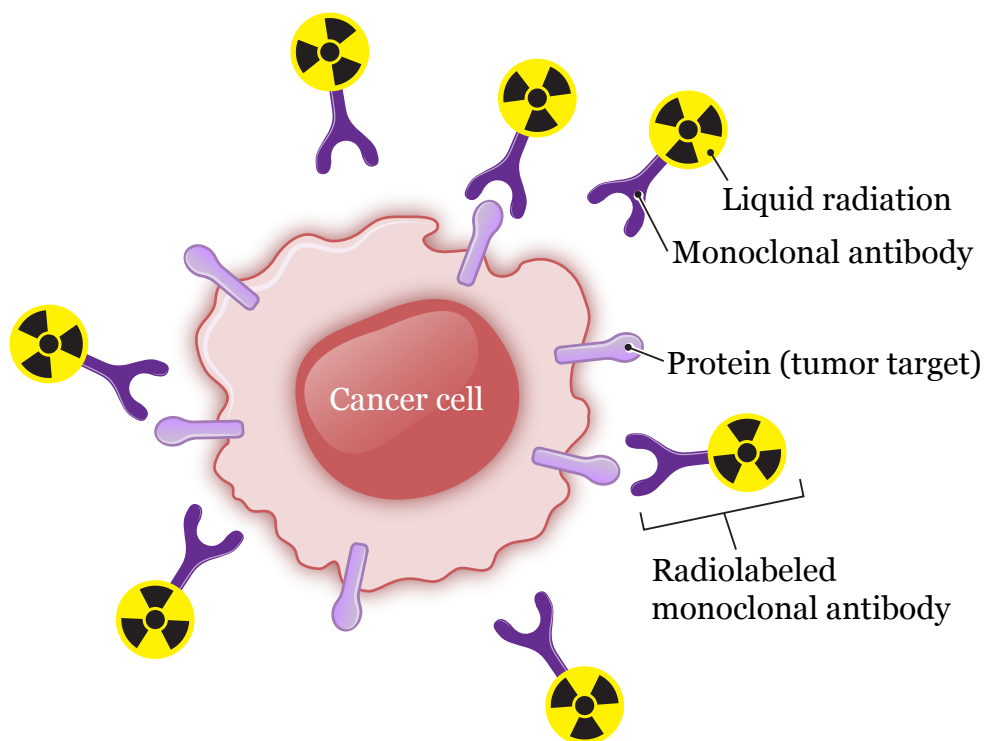


Figure 2. Radiolabeled monoclonal antibody attaching to cancer cell

## About Convection Enhanced Delivery (CED)

CED is a new way to use RIT to treat DIPG. With CED, a catheter (thin, flexible tube) is placed into your brain stem. A radiolabeled monoclonal antibody is slowly infused (dripped) through the catheter into your brain stem. The antibodies deliver radiation directly to the cancer cells. CED is a type of targeted therapy.

## Catheter Placement Surgery

Your catheter will be placed during surgery in an operating room, procedure room, or diagnostic suite with a magnetic resonance imaging (MRI) scanner. You'll get general anesthesia (medication to make you sleep) before your surgery. Once you're asleep, a surgical nurse will shave the hair along your incision (surgical cut) line. Your whole head won't be shaved.

During your surgery, your neurosurgeon will drill a burr hole (small hole) in the top of your skull. They'll guide the catheter through the hole to your brain stem (see Figure 3). They'll use MRI scans before and during your surgery to help them see your brain as they're doing this. They'll also use a special real-time MRI imaging system to help them guide the catheter.

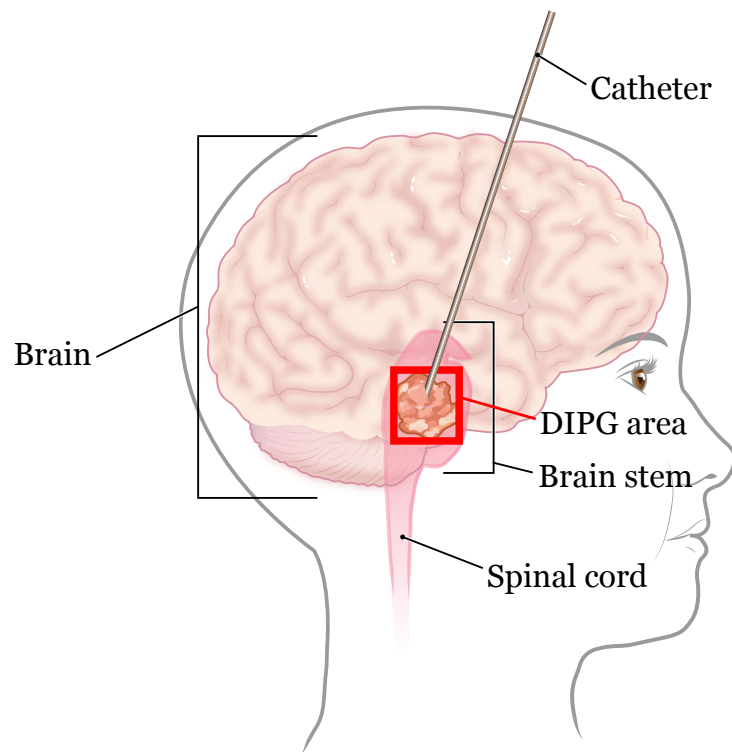


Figure 3. Catheter in your brain stem

Once the catheter is in the right place, your neurosurgeon will secure it to your head. They'll usually also put a soft bandage or head wrap over the catheter. The catheter will still be in place when you wake up after surgery.

## RIT Infusion

Once you're awake after your surgery, you'll be moved to a monitored care unit for your RIT infusion. The radioactive antibody will be slowly infused into your brain stem through the catheter placed during your surgery. You'll be monitored closely during and after the infusion.

Once your infusion is finished, your neurosurgeon will take out the catheter and close the incision with a few stitches. This will be done in your hospital room while you're in bed.

## Your Treatment Team

You'll have many different healthcare providers working together before, during, and after your surgery and treatment. Your treatment team will include your:

- Neurosurgeon
- Oncologist (cancer doctor)
- Neurologist
- Nurse practitioner (NP)
- Nuclear medicine doctor
- Radiation safety officer
- Pediatric nurse
- Child life specialist
- Social worker

A financial counselor is also available to meet with you to talk with you about any insurance issues. Please bring all your insurance information to your appointment. If you have any questions, call Patient Financial Services at 212-639-3810.



## Within **2** Weeks of Your Surgery

Before your surgery, you'll meet with your doctor and NP. They'll talk with you about the details of your CED surgery and antibody infusion. This includes side effects you might have and what to expect before, during, and after your treatment. They'll ask you to sign a consent form. They may also recommend that you see other healthcare providers, such as a child life specialist or social worker.

You'll need to have the following exams and tests to make sure it's safe for you to have CED surgery:

- Physical exam
- Neurological exam
- Blood tests to check your blood counts, blood type, blood clotting, and kidney, liver, and thyroid function
- Brain MRI scan
- Pregnancy test (if you're able to have children)
- Electrocardiogram (EKG), if needed
- Chest x-ray, if needed

It's very helpful if you bring the following with you to your appointment:

- A list of all the medications you're taking, including prescription and over-the-counter medications, patches, and creams.
- Results of any tests done outside of MSK, such as a cardiac stress test, echocardiogram (echo), EKG, or chest x-ray.
- Programmable VP (ventriculoperitoneal) shunt information (shunt type and setting), if you have one.
- The name(s) and telephone number(s) of your doctor(s).



Use this area to write your appointment information.

Neurosurgeon: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Oncologist: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Neurologist: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_



## Where to Go

Your appointments will be at the Pediatric Ambulatory Care Center (PACC). The PACC is located at Memorial Hospital (MSK's main hospital). The address is:

Memorial Hospital  
1275 York Avenue (between East 67<sup>th</sup> and East 68<sup>th</sup> Streets)  
New York, NY 10065  
Take the B elevator to the 9<sup>th</sup> floor

## Where to Park

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

To reach the garage, turn onto 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's a pedestrian tunnel that you can walk through that connects the garage to the hospital.

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.



P = Parking

M = Memorial Sloan Kettering

## MRI Scans

Before your surgery, you'll need an MRI scan of your brain to make sure there's no new or growing cancer. Your doctor will also use this scan to help map your brain and plan where the catheter will go.



**If you have a programmable VP shunt, write down the shunt type and setting below.** If you don't know, ask the doctor who placed your VP shunt to tell you the exact type and setting.

Shunt type: \_\_\_\_\_

Date shunt was placed: \_\_\_\_\_

Hospital where shunt was placed: \_\_\_\_\_

Shunt setting: \_\_\_\_\_

Name of neurosurgeon who placed the shunt: \_\_\_\_\_

## Instructions Before MRI Scans With Anesthesia

If you're getting anesthesia (medication to make you sleepy) during your MRI scans, you need to stop eating and drinking for a certain amount of time before your scans. Your NP will talk with you about when you need to stop eating and drinking before your MRIs. **If you don't follow the instructions they give you, your MRIs may be canceled.**



Use this area to write your instructions for eating and drinking before your MRI scans.

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## Note the Time and Location of Your MRIs

A staff member will call you the day before your MRIs. If your MRIs are scheduled for a Monday, they'll call you on the Friday before. If you don't get a call by 4:00 PM, please call 212-639-7056.

The staff member will tell you what time to arrive at the hospital for your MRIs. They'll also remind you where to go.



Use this area to write your scan information.

Date: \_\_\_\_\_

Time: \_\_\_\_\_

## Arrange for Housing, If Needed

The Ronald McDonald House provides temporary housing for out-of-town pediatric cancer patients and their families. MSK also has arrangements with several local hotels and housing facilities that may give you a special lower rate. Your social worker can talk with you about your options and help you make reservations.

## Tell Us if You're Sick

If you get sick before your surgery, call the doctor who scheduled your surgery. This includes a fever, cold, sore throat, or the flu. Contact your primary care provider and schedule a sick visit.

## 7 Days Before Your Surgery

### Follow Your Healthcare Provider's Instructions for Taking Aspirin

If you take aspirin or a medication that contains aspirin, you may need to change your dose or stop taking it 7 days before your surgery. Aspirin can cause bleeding.

Follow your healthcare provider's instructions. **Don't stop taking aspirin unless they tell you to.** For more information, read *Common Medications Containing Aspirin, Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), or Vitamin E*, located in the "Educational Resources" section of this guide.

## Stop Taking Vitamin E, Multivitamins, Herbal Remedies, and Other Dietary Supplements

Stop taking vitamin E, multivitamins, herbal remedies, and other dietary supplements 7 days before your surgery. These things can cause bleeding. For more information, read *Herbal Remedies and Cancer Treatment*, located in the “Educational Resources” section of this guide.

## 5 Days Before Your Surgery

### Start Taking Potassium Iodide (SSKI®) and Liothyronine (Cytomel®)

Start taking potassium iodide and liothyronine 5 days before your surgery. These medications will help protect your thyroid during your treatment. Keep taking these medications every day until 2 weeks after your surgery. Follow the guidelines below.

Start Date	End Date	Medication	Dose	How Often
		Potassium iodide (SSKI)		
		Liothyronine (Cytomel)		

Your doctor or NP will give you a medication diary. Use it to record the potassium iodide and liothyronine you take. Write your initials in each box when you take your medication. Be sure to write any missed doses in your diary. Bring your diary to all your appointments.



**Take the potassium iodide (SSKI) and liothyronine (Cytomel) until the end date your doctor gave you. Read your medication diary for more information.**

## 2 Days Before Your Surgery

### Stop Taking Nonsteroidal Anti-inflammatory Drugs (NSAIDs)

Stop taking NSAIDs, such as ibuprofen (Advil®, Motrin®) and naproxen (Aleve®), 2 days before your surgery. These medications can cause bleeding. For more information, read *Common Medications Containing Aspirin, Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), or Vitamin E*, located in the “Educational Resources” section of this guide.

# 1 Day Before Your Surgery

## Note the Time and Location of Your Surgery

A staff member will call you, usually after 2:00 PM the day before your surgery. If your surgery is scheduled for a Monday, they'll call you on the Friday before. If you don't get a call by 4:00 PM, please call 212-639-7056.

The staff member will tell you what time to arrive at the hospital for your surgery. **Your arrival time will be about 2 hours before your surgery start time.** Please arrive on time.



Use this area to write your surgery information.

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

Scheduled arrival time: \_\_\_\_\_

The staff member will also remind you where to go. This will be one of the following locations:

- Presurgical Center (PSC) on the 6<sup>th</sup> floor  
1275 York Avenue (between East 67<sup>th</sup> and East 68<sup>th</sup> Streets)  
New York, NY 10065  
B elevator to 6<sup>th</sup> floor
- Center for Image-Guided Interventions (CIGI) on the 2<sup>nd</sup> floor  
1275 York Avenue (between East 67<sup>th</sup> and East 68<sup>th</sup> Streets)  
New York, NY 10065  
B elevator to 2<sup>nd</sup> floor
- Pediatric Ambulatory Care Center (PACC) on the 9<sup>th</sup> floor  
1275 York Avenue (between East 67<sup>th</sup> and East 68<sup>th</sup> Streets)  
New York, NY 10065  
B elevator to 9<sup>th</sup> floor

## The Night Before Your Surgery

### Shower

Unless you're given other instructions, you should shower and wash your hair. Use your normal soap, shampoo, and conditioner.

After your shower, dry yourself off with a clean towel. Don't use any hair products (such as hair spray or hair gel).

### Sleep

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

## Instructions for Eating and Drinking

Don't eat or drink anything after a certain time on the night before your surgery. Your NP will tell you when this is. This exact time is based on your age and any other medical problems you may have. Your NP will talk with you about what you can and can't eat before surgery. **If you don't follow the instructions you're given, your surgery may be cancelled.**



Use this area to write your instructions for eating and drinking the night before your surgery.

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## The Morning of Your Surgery



**Don't 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.

## Take Your Medications as Instructed

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

Starting 2 hours before your surgery, don't take any medications.

## Things to Remember

- Wear something comfortable and loose-fitting.
- If you wear contact lenses, wear your glasses instead. Wearing contact lenses during surgery can damage your eyes.
- Don't wear any metal objects. Remove all jewelry, including body piercings. The equipment used during your surgery can cause burns if it touches metal.
- Don't put on any lotion, cream, deodorant, makeup, powder, perfume, or cologne.
- Leave valuable items (such as credit cards, jewelry, and your checkbook) at home.

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_



## What to Bring

- Your Health Care Proxy form and other advance directives, if you completed them.
- Your cell phone and charger.
- Only the money you may want for small purchases (such as a newspaper).
- A case for your personal items (such as eyeglasses, hearing aid(s), dentures, prosthetic device(s), wig, and religious articles), if you have one.
- This guide. Your healthcare team will use this guide to teach you how to care for yourself after your surgery.
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## Once You're in the Hospital

When you get to the hospital, take the B elevator to the 2<sup>nd</sup> floor (If you're going to the CIGI), the 6<sup>th</sup> floor (if you're going to the PSC), or the 9<sup>th</sup> floor (if you're going to the PACC).

Doctors, nurses, and other staff members will ask you to say and spell your name and date of birth many times. This is for your safety. People with the same or a similar name may be having surgery on the same day.

### Get Dressed for Surgery

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

### Meet With Your Nurse

You'll meet with a nurse before surgery. Tell them the dose of any medications you took after midnight (including prescription and over-the-counter medications, patches, and creams) and the time you took them.

Your nurse may place an intravenous (IV) line into one of your veins or access your central line (implanted port). If your nurse doesn't do this, your anesthesiologist will do it later once you're in the operating room.

### Meet With an Anesthesiologist

You'll also meet with an anesthesiologist before surgery. They will:

- Review your medical history with you.
- Ask you if you've had any problems with anesthesia in the past, including nausea or pain.
- Talk with you about your comfort and safety during your surgery.

- Talk with you about the kind of anesthesia you'll have.
- Answer your questions about your anesthesia.

## **Get Ready for Your Surgery**

One or 2 visitors can keep you company as you wait for your surgery to start. When it's time for your surgery, you'll need to remove your hearing aids, dentures, prosthetic device(s), wig, and religious articles, if you have them. Your visitor(s) will be taken to the waiting area. They should read *Information for Family and Friends for the Day of Surgery*, located in the "Educational Resources" section.

You'll either walk into the operating room or be taken in on a stretcher. A member of the operating room team will help you onto the operating bed.

Once you're comfortable, your anesthesiologist will give you anesthesia through your IV line or implanted port and you'll fall asleep. You'll also get fluids through your IV line or implanted port during and after your surgery.

## **During Your Surgery**

After you're taken to the operating room, your visitors should wait in the main lobby on the 1<sup>st</sup> floor of Memorial Hospital. The main lobby is located at the top of the escalator at MSK's York Avenue entrance. Your visitors should check in at the information desk.

A nurse liaison will bring your visitors updates on the progress of your surgery. They'll tell your visitors how you're doing, what time your surgery started, and give an estimate of when your surgery will be over. They may also bring your visitors messages from your surgeon.

When your surgery is done, your visitors will be asked to go back to the 6<sup>th</sup> floor concierge desk. The staff member at the desk will tell you where to go to meet with the surgeon.







# Waking Up After Surgery

When you wake up after your surgery, you'll be in the Post Anesthesia Recovery Unit (PACU) or one of the following monitored care units:

- The Pediatric Intensive Care Unit (PICU)
- The adult Intensive Care Unit (ICU)
- The Neurology Advanced Care Unit (NACU)

As soon as you're settled, a nurse will bring your visitors in to be with you.

A nurse will be monitoring your body temperature, pulse, blood pressure, and oxygen levels. You may be getting oxygen through a thin tube that rests below your nose or a mask that covers your nose and mouth.

It's normal to feel very tired after surgery. Your nurse will make sure you're comfortable and answer your questions.

## **Tubes and Bandages**

The infusion catheter will be in place and secured on your head. You'll have a soft bandage or head wrap over your incision.

## **Managing Your Pain**

It's normal to have some pain near your incision after surgery. Your doctor and nurse will ask you about your pain often. They'll give you medication to control your pain as needed. If your pain isn't relieved, please tell your doctor or nurse.

You might be nauseous (feel like you're going to throw up) or have a headache after your surgery. Your doctor and nurse will check how you're feeling often. They'll give you medication to help with these symptoms as needed.

You might have a sore throat after your surgery. This is from the breathing tube that was used during your surgery. If you have a sore throat, tell your doctor or nurse. They can give you lozenges or a cool drink to help soothe your throat.

## **Eating and Drinking**

Most people can start drinking liquids a few hours after their surgery. After you're able to drink, you'll slowly go back to your usual diet.


## **Moving to a Monitored Care Unit**

If you're not already in a monitored care unit, you'll be moved to one once you're awake and comfortable.

# Radiation Safety Precautions

A radiation safety officer will talk with you about the precautions you'll need to follow during and after your antibody infusion. They'll also give you written guidelines to follow. **Tell us if anyone who's caring for you is pregnant or if you're staying at the Ronald McDonald House.**

Depending on your antibody dose, you might be radioactive after your antibody infusion. Some of the radiation will leave your body through urine (pee) and bodily secretions. You'll need to be careful so people near you aren't exposed to too much radiation. Your radiation safety officer will tell you what precautions you need to take.



Use this area to write down your radiation safety precautions.

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The radiation safety officer will give you a wallet card that describes your treatment. They'll tell you how long you need to keep it with you. **During that time, keep it with you at all times.** If you need emergency medical care or are stopped by security, show this card.



If you have any questions about radiation safety, call 212-639-7391 Monday through Friday from 9:00 AM to 5:00 PM.

## During Your Antibody Infusion

You'll get your antibody infusion in the monitored care unit. You'll be awake during your infusion. If you're very anxious, your nurse will give you medication to help. They might also give you dexamethasone (a medication called a steroid that lowers swelling in your brain) before, during, or after your infusion.

Your catheter will be attached to a special infusion pump. The pump will slowly infuse the antibody into your brain stem through your catheter. How long your infusion takes depends on how much of the antibody you're getting. Your care team will tell you what to expect.

During your infusion, you'll need to stay in your bed. You can eat and sleep as usual. You can have visitors, but they'll need to follow your healthcare team and radiation safety officer's instructions.

Your nurse or doctor will do neurological exams often during your infusion. During these exams, they will:

- Ask you to move your arms, fingers, toes, and legs.
- Check your pupils with a flashlight.
- Ask you simple questions. For example, they might ask, "What's your name?"

If your doctors notice any changes while they're doing the neurological exams, they might decide to pause or stop your antibody infusion.

## After Your Antibody Infusion

Once your infusion is finished, your neurosurgeon will take out the catheter. They'll close the wound with a few stitches. This will be done in your hospital room while you're in bed. You'll get an injection (shot) of a local anesthetic (medication to numb the area) before they start.

### Imaging Scans

Within 24 hours after your antibody infusion, you'll have imaging scans. Your doctor will use the scans to look at your brain after the catheter is removed and check exactly where in the tumor the antibody went. You'll have:

- MRI and PET/CT (positron emission tomography and computed tomography) scans
- A PET/MRI scan

Your nurse will tell you which scans you'll have and what time you'll have them.

### Instructions Before Imaging Scans With Anesthesia

If you're getting anesthesia during your scans, you need to stop eating and drinking for a certain amount of time before your scans. Your NP will talk with you about when you need to stop eating and drinking before your scans. **If you don't follow the instructions you're given, your MRIs may be canceled.**

### Moving to the Pediatric Inpatient Unit

You'll stay in the monitored care unit for about 24 hours after your infusion. After that, you'll be moved to the pediatric inpatient unit for the rest of your hospital stay.

You'll stay in the hospital for at least 2 nights after your surgery. Exactly how long you stay in the hospital depends on your recovery.

## In the Pediatric Inpatient Unit

### Caring for Your Incision

You can shower right after your surgery. For the first 5 days after your surgery, wear a shower cap to keep your incision from getting wet.

## Medications

You can take your usual medications right away after your surgery. Your doctor may also give you 1 or more of the following medications after your surgery:

- Steroids to decrease the swelling in your brain.
- An antacid to protect your stomach while you're taking steroids.
- Pain medication to help manage headaches or other pain.

Keep taking potassium iodide (SSKI) and liothyronine (Cytomel) once a day until 2 weeks after your surgery. Remember to write each dose you take in your medication diary. Be sure to write any missed doses in your diary. Bring your diary to all your appointments.

## Blood Draws

You'll have blood drawn as needed while you're in the hospital. Your blood will be tested to make sure you're recovering well after your surgery and treatment.

You'll also have blood drawn to measure the amount of radioactivity in your blood. This blood draw is for research, not treatment.

## Visitors

Your parents, other family members, and friends can visit you while you're in the hospital, as long as they're healthy. No one with any signs of being sick (such as a fever, cough, congestion, sore throat, or rash) can visit.

Visiting hours might be different depending on where in the hospital you're staying. Ask your nurse about visiting hours and other guidelines for visitors. Visitors on the Pediatric Unit are limited to parents and 2 other visitors daily.

Parents can call the inpatient unit at any time. Ask your nurse for the phone number. Because of privacy concerns, staff can only give information to parents or spouses. Please tell friends and other relatives not to call the inpatient unit for information.

**If your radiation safety officer gives you different instructions for having visitors, follow those instructions.**





# After Discharge

## Medications

Keep taking potassium iodide (SSKI) and liothyronine (Cytomel) once a day until 2 weeks after your surgery. Your doctor will tell you what date you should stop taking the medication. Remember to write each dose you take in your medication diary. Be sure to write any missed doses in your diary. Bring your diary to all your appointments.

Don't take aspirin, products containing aspirin, or NSAIDs (such as ibuprofen). These things can cause bleeding. Your surgeon will tell you when it's okay to take these medications. For more information, read *Common Medications Containing Aspirin, Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), or Vitamin E*, located in the "Educational Resources" section of this guide.

## Caring for Your Incision

- You can leave your incision uncovered. When you're outside, protect it from the sun by wearing a hat or scarf.
- Keep your incision dry for the first 5 days after your surgery.
- Don't put any creams, ointments, or hair products on your incision while it's healing. This may take about 6 weeks.
- Don't use a hair dryer until your incision is completely healed. This may take about 6 weeks.

You may have some mild swelling around your incision. Your incision may burn, itch, or feel numb as it heals. These things are normal.

Your surgeon or NP will remove your sutures about 7 to 10 days after your surgery, depending on how your incision is healing.

## Showering

You can shower right away after your surgery, but don't get your incision wet for the first 5 days after surgery. Wear a shower cap when you shower.

Starting 5 days after your surgery, wash your hair every day. You can let the shower water run over your incision. This helps loosen the crusting on your incision and will make it easier for your surgeon or NP to remove your sutures. When you wash your hair:

- Use a gentle shampoo (such as baby shampoo) to clean the area around your incision. Gently massage the area to wash off any dried blood or drainage.
- Gently clean your incision with soap and water. Don't use a washcloth or scrub your incision.
- After your shower, pat your incision dry with a clean towel.

Don't let your incision soak in water until it's completely healed. Avoid baths, hot tubs, and swimming pools for at least 2 weeks after your surgery. If your incision needs more time to heal, you may need to wait longer. Your neurosurgeon or NP will tell you when it's okay to take baths and swim at your first follow-up appointment after your surgery.



## Activities and Exercise

You can go back to doing most of your usual activities right after your surgery. Your doctors and nurses will give you instructions on what exercises and movements you can do while your incision is healing.

Don't lift objects heavier than 10 pounds (4.5 kilograms) until your doctor says it's safe. This is usually 4 weeks after your surgery. Examples of objects heavier than 10 pounds include a large purse or bag, backpack, or briefcase. It may be helpful to use a wheeled backpack for heavy textbooks.

Don't participate in gym class for 6 weeks after your surgery. It will take at least 6 weeks for your skull to heal. Check with your doctor or nurse before starting any exercise or gym activity, such as running, jogging, or lifting weights. You can exercise by walking.

## Going Back to School or Work

You can go back to school or work as soon as you feel ready. If your job involves lots of movement or heavy lifting, you may need to stay out a little longer than if you sit at a desk. Talk with your doctor about when it would be safe to go back.

## Driving

Don't drive:

- For 2 weeks after your surgery.
- If you're having problems with your vision or memory.
- While you're taking prescription pain medication. These medications can make you drowsy and make it unsafe for you to drive.

If you're taking antiseizure medications, don't drive until your neurologist gives you permission.

## Follow-Up Appointments

**During the first 4 weeks (about 30 days) after your surgery, your follow-up appointments and scans must be done at MSK.** Bring your medication diary with you to all your appointments.

You'll have appointments at least once a week for the first 4 weeks after your surgery. During these appointments, you'll have detailed physical and neurological exams. You may also have imaging scans and blood tests during some appointments. About 4 weeks after your surgery, you'll have an MRI scan of your brain.

Use the chart below to write your weekly appointment information. Write down your appointment date, time, and which healthcare provider you're seeing. Use checkmarks to show which tests will be done.

Week #	When do I come?		Who will I see?	What tests will be done?				
	Date	Time	Doctor or NP	Exam	Blood Tests	PET Scan	MRI Scan	Other



If you're having an imaging scan, use this area to write your scan information.

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_

If you're having anesthesia during your scan, write your eating and drinking instructions below.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## More than 4 Weeks After Surgery

Starting about 4 weeks after your surgery, it's best to see your MSK doctor about every month. If you live far away from New York City, it's okay to see your local oncologist. If you're seen locally, we will ask your local oncologist to send us updates about your health.



### When to Contact Your Healthcare Provider

Call your healthcare provider right away if you have:

- A fever of 100.4 °F (38.0 °C) or higher
- Drainage from your incision
- Shortness of breath
- Severe swelling or redness around your incision
- Increased pain
- Seizures
- Increased sleepiness
- Severe worsening speech, strength, vision, or sensation
- Change in your mental status
- Lack of bowel or bladder control
- Pain in your calf
- Severe headaches, nausea, and vomiting
- Any other concerns

## Contact Information

If you have any questions or concerns, talk with your doctor or NP. You can reach them Monday through Friday from 9:00 AM to 5:00 PM. Call the office directly at 212-639-7056.

After 5:00 PM, during the weekend, and on holidays, call 212-639-2000 and ask for the pediatric neurosurgery fellow on call.

To speak with a social worker, call the Social Work department at 212-639-7020.





# MSK Support Services

## **Admitting Office**

212-639-7606

Call if you have questions about your hospital admission, including requesting a private room.

## **Anesthesia**

212-639-6840

Call if you have questions about anesthesia.

## **Blood Donor Room**

212-639-7643

Call if you're interested in donating blood or platelets.

## **Bobst International Center**

888-675-7722

MSK welcomes patients from around the world. If you're an international patient, call for help arranging your care.

## **Chaplaincy Service**

212-639-5982

Our chaplains are available to listen, help support family members, pray, contact community clergy or faith groups, or simply be a comforting companion and a spiritual presence. Anyone can request spiritual support, regardless of formal religious affiliation. The interfaith chapel is located near Memorial Hospital's main lobby and is open 24 hours a day. If you have an emergency, call 212-639-2000 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. To make an appointment, ask your healthcare provider for a referral or call the number above.

## **Food Pantry Program**

646-888-8055

The food pantry program gives food to people in need during their cancer treatment. For more information, talk with your healthcare provider or call the number above.

## **Integrative Medicine Service**

646-888-0800

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

## **MSK Library**

[library.mskcc.org](http://library.mskcc.org)

212-639-7439

You can visit our library website or speak with the library reference staff to find more information about your specific cancer type. You can also visit LibGuides on MSK's library website at [libguides.mskcc.org](http://libguides.mskcc.org).

## **Patient and Caregiver Education**

[www.mskcc.org/pe](http://www.mskcc.org/pe)

Visit the Patient and Caregiver Education website to search our virtual library. There, you can find written educational resources, videos, and online programs.

## **Patient and Caregiver Peer Support Program**

212-639-5007

You may find it comforting to speak with someone who has been through a treatment like yours. You can talk with a former MSK patient or caregiver through our Patient and Caregiver Peer Support Program. These conversations are confidential. They may take place in person or over the phone.

## **Patient Billing**

646-227-3378

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

## **Patient Representative Office**

212-639-7202

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

## **Perioperative Nurse Liaison**

212-639-5935

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

## **Private Duty Nursing Office**

212-639-6892

You may request private nurses or companions. Call for more information.

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

646-888-8106

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

## **Sexual Health Programs**

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

- Our Female Sexual Medicine and Women's Health Program helps women who are dealing with cancer-related sexual health challenges, including premature menopause and fertility issues. For more information, or to make an appointment, call 646-888-5076.
- Our Male Sexual and Reproductive Medicine Program helps men who are dealing with cancer-related sexual health challenges, including erectile dysfunction. For more information, or to make an appointment, call 646-888-6024.

## **Social Work**

212-639-7020

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

### **Tobacco Treatment Program**

212-610-0507

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

### **Virtual Programs**

[www.mskcc.org/vp](http://www.mskcc.org/vp)

MSK's Virtual Programs offer online education and support for patients and caregivers, even when you can't come to MSK in person. Through live, interactive sessions, you can learn about your diagnosis, what to expect during treatment, and how to prepare for the various stages of your cancer care. Sessions are confidential, free, and led by expert clinical staff. If you're interested in joining a Virtual Program, visit our website at [www.mskcc.org/vp](http://www.mskcc.org/vp) for more information.

For more online information, visit the "Cancer Types" section of [www.mskcc.org](http://www.mskcc.org).

## External Support Services

### **Access-A-Ride**

[new.mta.info/accessibility/paratransit](http://new.mta.info/accessibility/paratransit)

877-337-2017

In New York City, the MTA offers a shared ride, door-to-door service for people with disabilities who aren't able to take the public bus or subway.

### **Air Charity Network**

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

877-621-7177

Provides travel to treatment centers.

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

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

800-ACS-2345 (800-227-2345)

Offers a variety of information and services, including Hope Lodge, a free place for patients and caregivers to stay during cancer treatment.

### **Cancer and Careers**

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

646-929-8032

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

### **CancerCare**

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

800-813-4673

275 Seventh Avenue (Between West 25<sup>th</sup> & 26<sup>th</sup> Streets)

New York, NY 10001

Provides counseling, support groups, educational workshops, publications, and financial assistance.

### **Cancer Support Community**

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

888-793-9355

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.

**Corporate Angel Network**

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

866-328-1313

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

**Gilda's Club**

[www.gildasclubnyc.org](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.

**Good Days**

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

877-968-7233

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

**Healthwell Foundation**

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

800-675-8416

Provides financial assistance to cover copayments, health care premiums, and deductibles for certain medications and therapies.

**Joe's House**

[www.joeshouse.org](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**

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

212-673-4920

Provides support and advocacy for the LGBT community, including online support groups and a database of LGBT-friendly clinical trials.

**LegalHealth**

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

212-613-5000

Provides free legal help to New Yorkers experiencing serious or chronic health problems and financial hardship.

**LIVESTRONG Fertility**

[www.livestrong.org/fertility](http://www.livestrong.org/fertility)

855-744-7777

Provides reproductive information and support to cancer patients and survivors whose medical treatments have risks associated with infertility.

**Look Good Feel Better Program**

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

800-395-LOOK (800-395-5665)

This program offers workshops to learn things you can do to help you feel better about your appearance. For more information or to sign up for a workshop, call the number above or visit the program's website.

**Medicine Assistance Tool**

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

A search engine with information about programs that can help people with financial need get access to medications.

**National Cancer Institute**

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

800-4-CANCER (800-422-6237)

**National LGBT Cancer Network**

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

212-675-2633

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

**Needy Meds**

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

800-503-6897

Lists Patient Assistance Programs for brand and generic name medications.

**Patient Access Network Foundation**

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

866-316-7263

Helps people with insurance pay their out-of-pocket medical costs.

**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

Helps people get medications they have trouble affording.



# Common Medications Containing Aspirin, Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), or Vitamin E

This information will help you identify medications that contain aspirin, other NSAIDs, or vitamin E. It's important to stop taking these medications before many cancer treatments. They affect your platelets (blood cells that clot to prevent bleeding) and can increase your risk of bleeding during treatment.

Other dietary supplements (such as other vitamins and herbal remedies) can also affect your cancer treatment. For more information, read the resource *Herbal Remedies and Cancer Treatment* ([www.mskcc.org/pe/herbal\\_remedies](http://www.mskcc.org/pe/herbal_remedies)).

## Instructions Before Your Surgery

If you take aspirin, other NSAIDs, or vitamin E, tell your healthcare provider. They'll tell you if you need to stop taking it. You'll also find instructions in the information about your treatment. Read the "Examples of Medications" section to see if your medications contain aspirin, other NSAIDs, or vitamin E.

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

- If you take aspirin or a medication that contains aspirin, you may need to change your dose or stop taking it 7 days before your surgery. Follow your healthcare provider's instructions. **Don't stop taking aspirin unless your healthcare provider tells you to.**

- If you take vitamin E or a supplement that contains vitamin E, stop taking it 7 days before your surgery or as directed by your healthcare provider.
- If you take an NSAID or a medication that contains an NSAID, stop taking it 48 hours (2 days) before your surgery or as directed by your healthcare provider.

## Examples of Medications

Medications are often called by their brand name. This can make it hard to know their ingredients. The lists below can help you identify medications that contain aspirin, other NSAIDs, or vitamin E.

These lists include the most common products, but there are others. **Make sure your healthcare provider always knows all the prescription and over-the-counter (not prescription) medications you're taking, including patches and creams.**

Common Medications Containing Aspirin			
Aggrenox®	Cama® Arthritis Pain Reliever	Heartline®	Robaxisal® Tablets
Alka Seltzer®	COPE®	Headrin®	Roxiprin®
Anacin®	Dasin®	Isollyl®	Saleto®
Arthritis Pain Formula	Easprin®	Lanorinal®	Salocol®
Arthritis Foundation Pain Reliever®	Ecotrin® (most formulations)	Lortab® ASA Tablets	Sodol®
ASA Enseals®	Empirin® Aspirin (most formulations)	Magnaprin®	Soma® Compound Tablets
ASA Suppositories®	Epromate®	Marnal®	Soma® Compound with Codeine Tablets
Ascriptin® and Ascriptin A/D®	Equagesic Tablets	Micrainin®	St. Joseph® Adult Chewable Aspirin
Aspergum®	Equazine®	Momentum®	Supac®
Asprimox®	Excedrin® Extra-Strength Analgesic	Norgesic Forte® (most formulations)	Synalgos®-DC Capsules

	Tablets and Caplets		
Axotal®	Excedrin® Migraine	Norwich® Aspirin	Tenol-Plus®
Azdone®	Fiorgen®	PAC® Analgesic Tablets	Trigesic®
Bayer® (most formulations)	Fiorinal® (most formulations)	Orphengesic®	Talwin® Compound
BC® Powder and Cold formulations	Fiortal®	Painaid®	Vanquish® Analgesic Caplets
Bufferin® (most formulations)	Gelpirin®	Panasal®	Wesprin® Buffered
Buffets II®	Genprin®	Percodan® Tablets	Zee-Seltzer®
Buffex®	Gensan®	Persistin®	ZORprin®

### Common NSAID Medications That Don't Contain Aspirin

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

<b>Products Containing Vitamin E</b>			
Amino-Opt-E	Aquavit	E-400 IU	E complex-600
Aquasol E	D'alpha E	E-1000 IU Softgels	Vita-Plus E

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

## About Acetaminophen

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

<b>Medications Containing Acetaminophen</b>			
Acephen®	Esgic®	Percocet®	Vanquish®
Aceta® with Codeine	Excedrin P.M.®	Primlev®	Vicodin®
Acetaminophen with Codeine	Fiorcet®	Repan®	Wygesic®
Aspirin-Free Anacin®	Lorcet®	Roxicet®	Xartemis XR®
Arthritis Pain Formula® Aspirin-Free	Lortab®	Talacen®	Xodol®
Datril®	Naldegescic®	Tempra®	Zydone®
Di-Gesic®	Norco®	Tylenol®	
Endocet®	Panadol®	Tylenol® with Codeine No. 3	

## Read the labels on all your medications

Acetaminophen is safe when used as directed. But, there's a limit to how much you can take in a day. It's possible to take too much without knowing because it's in many different prescription and over-the-counter medications. It's often an ingredient in pain relievers, fever reducers, sleep aids, and cough, cold, and allergy

medications.

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

<b>Common Abbreviations for Acetaminophen</b>		
APAP	AC	Acetaminop
Acetamin	Acetam	Acetaminoph

Always read and follow the label on the product you're taking. Don't take more than 1 medication that contains acetaminophen at a time without talking with a member of your healthcare team.



# Herbal Remedies and Cancer Treatment

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

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

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

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

## Common Herbal Supplements and Their Effects

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

### Echinacea

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

## **Garlic**

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

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

- Can increase your risk of bleeding.

## **Ginseng**

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

## **Turmeric**

- Can make chemotherapy less effective.

## **St. John's Wort**

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

## **Valerian**

- Can increase the effects of sedation or anesthesia.

## **Herbal formulas**

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

This information doesn't cover all herbal remedies or possible side effects. Talk with your healthcare provider if you have any questions or concerns.

For more information about herbs and botanicals, visit the Memorial Sloan Kettering (MSK) Integrative Medicine Service website at [www.abouterbs.com](http://www.abouterbs.com).

# Information for Family and Friends for the Day of Surgery

This information explains what to expect on the day of your friend or family member's surgery at Memorial Hospital, Memorial Sloan Kettering (MSK)'s main hospital.

## Before the Surgery

After they get to the hospital, we'll ask the patient to provide contact information for the person who will meet 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, we'll also ask them to provide contact information for the person who will be taking them home.

Once the patient checks in, they'll go to the Presurgical Center (PSC) to be examined before their surgery. Sometimes they may need to wait before they're admitted to the PSC.

In the PSC, a nurse will do a full exam of the patient. When the operating room (OR) is ready, a member of the surgical team will come take the patient into the OR. They'll get the patient ready for surgery. This can take 15 to 90 minutes. Then, the surgery will start.

To keep patients and staff safe and healthy during the COVID-19 pandemic, we may change our visitor policy more often than usual. Visit [www.mskcc.org/visit](http://www.mskcc.org/visit) for the most up-to-date information. Please remember the following:

- Don't bring food or drinks into the hospital. Patients can't eat or drink before their surgery or procedure.

- If the patient brought any valuables, such as a cellphone, iPod, or iPad, keep them safe for them during surgery.
- Sometimes surgeries can be delayed. We make every effort to tell you when this happens.

## **During the Surgery**

### **Surgery updates**

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

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

To contact the nurse liaison:

- From inside the hospital, you can use a hospital courtesy phone. These are located on the walls all around the hospital. Dial 2000 and ask for beeper 9000. Please be patient because this can take up to 2 minutes.
- From outside of the hospital, call 212-639-2000. Ask for beeper 9000.
- Ask the information desk staff to contact the nurse liaison for you.

## **After Surgery**

### **Meeting with the surgeon**

When the patient's surgery is over, we'll call you and ask you to go back to the information desk. They'll tell you where to go to meet with the surgeon.

After meeting with the surgeon, go back to the information desk and let them know you've finished your meeting.

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

After surgery, the patient will be taken to the PACU. When patients first get to the

PACU, they're usually sleepy and want to rest. We ask that you wait 90 minutes before calling the PACU to check on the patient. This gives them time to wake up and get comfortable.

If your family member is an inpatient (staying in the hospital), you'll be allowed a one-time 30-minute visit. This can be coordinated when you speak with the nurse to find the best time for you and the patient.

- Please wear a mask.
- Make sure your cellphone is on silent before entering.
- Use an alcohol-based hand sanitizer (such as Purell®) or wash your hands before entering. There are hand sanitizer stations located throughout the hospital.
- Don't bring food or flowers into the PACU.
  - We can store flowers in the flower room (located on the entrance floor of Memorial Hospital) until patients are allowed to have them. Flowers are usually allowed when the patient moves to their inpatient room.

While visiting the patient in the PACU:

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

The nurse will update you with the plan of care for the patient, such as whether the patient is staying overnight and when they'll be moved to an inpatient room.

- If the patient moves to an inpatient room, a staff member will let you know the room number and the phone number to the nursing station on that floor. They'll also let you know the visiting hours for that floor.
- If the patient is going home the same day, a responsible care partner must take

them home.

We'll give you a card with the PACU phone number. Please choose 1 person who we should call for updates.

Visit [www.mskcc.org/visit](http://www.mskcc.org/visit) for more information about MSK's visitor policy.