

#### PATIENT & CAREGIVER EDUCATION

### About Your Endoscopic Third Ventriculostomy (ETV) Surgery for Pediatric Patients

This guide will help you get ready for your endoscopic third ventriculostomy (ETV) surgery at MSK. It will also help you know what to expect as you recover.

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

For the rest of this resource, our use of the words "you" and "your" refers to you or your child.

our care team	
Doctor:	_
lurse:	
Phone number:	_
ax number:	

#### Your caregiver

Your caregiver will learn about your surgery with you. They'll also help you care for yourself while you're healing after surgery. Write their name below.

#### Caregiver: \_



Visit www.msk.org/pe/ etv\_surgery\_peds to view this guide online.

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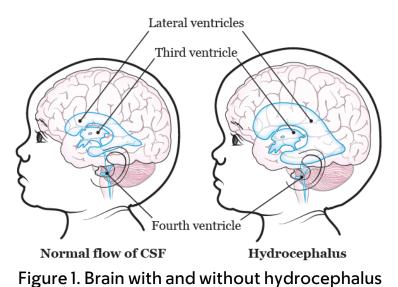
Herbal Remedies and Cancer Treatment

# About your (ETV) surgery for pediatric patients

# About your surgery

ETV is a surgery to drain extra cerebrospinal fluid (CSF) from your brain. CSF is the fluid that surrounds your brain and spinal cord. It's made in the ventricles (hollow spaces) inside your brain.

CSF protects your brain and spinal cord by acting like a cushion. However, when you have too much of it, it puts pressure on your brain and skull. This extra fluid also makes your ventricles grow bigger (see Figure 1). This is called hydrocephalus (hy-dro-ceph-a-lus).



The most common symptoms of hydrocephalus include:

- Headache
- Nausea and vomiting
- Fatigue, drowsiness, or both

- Irritability
- Personality changes
- Problems with thinking and memory (confusion)
- Trouble with balance and walking
- Poor coordination
- Loss of control over urination
- Visual disturbances, including blurred vision, double vision, or having your eyes turn downward with the whites showing above
- Seizures
- Increased head size and bulging soft spot in infants
- High pitched cry in infants
- Poor feeding in infants

Your ETV surgery will be done in the operating room. Before your surgery, you will get anesthesia (medication to make you sleep during your surgery). Once you're asleep, a nurse will shave the hair in the area where your incisions (surgical cuts) will be. Your entire head won't be shaved.

During your surgery, your neurosurgeon will make a tiny hole in the third ventricle of your brain (see Figure 2). This will let the excess CSF drain into another area of your brain to be absorbed.

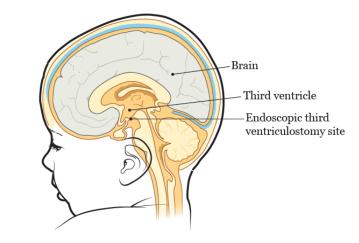


Figure 2. ETV

# Before your surgery

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.

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# Getting ready for your (ETV) surgery for pediatric patients

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



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

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### Getting ready for your surgery

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

- I take an anticoagulant (blood thinner), such as:
  - o Aspirin
  - o Heparin
  - Warfarin (Jantoven®, Coumadin®)
  - Clopidogrel (Plavix®)
  - Enoxaparin (Lovenox®)
  - Dabigatran (Pradaxa®)
  - Apixaban (Eliquis®)
  - Rivaroxaban (Xarelto®)
- I take an SGLT2 inhibitor, such as:
  - Canagliflozin (Invokana®)
  - Dapagliflozin (Farxiga®)
  - Empagliflozin (Jardiance®)
  - Ertugliflozin (Steglatro®)
- I take prescription medicine(s), including patches and creams. A
  prescription medicine is one you can only get with a prescription from
  your healthcare provider.
- I take over-the-counter medicine(s), including patches and creams.
   An over-the-counter medicine is one you can buy without a prescription.
- I take dietary supplements, such as herbs, vitamins, minerals, or natural or home remedies.

These are examples of medicines. There are others.

Be sure your healthcare provider knows all the medicines you're taking.

- I have a pacemaker, automatic implantable cardioverter-defibrillator (AICD), or other heart device.
- I have sleep apnea.
- I have had a problem with anesthesia (A-nes-THEE-zhuh) in the past. Anesthesia is medicine to make you sleep during a surgery or procedure.
- I'm allergic to certain medicines or materials, including latex.
- I'm not willing to receive a blood transfusion.
- I drink alcohol.
- I smoke or use an electronic smoking device, such as a vape pen or ecigarette.
- I use recreational drugs, such as marijuana.

#### About drinking alcohol

It's important to talk with your healthcare providers about how much alcohol you drink. This will help us plan your care.

If you drink alcohol regularly, you may be at risk for problems during and after your surgery. These include bleeding, infections, heart problems, and a longer hospital stay.

If you drink alcohol regularly and stop suddenly, it can cause seizures, delirium, and death. If we know you're at risk for these problems, we can prescribe medicine to help prevent them.

Here are things you can do before your surgery to keep from having problems.

• Be honest with your healthcare providers about how much alcohol you drink.

- Try to stop drinking alcohol once your surgery is planned. Tell your healthcare provider right away if you:
  - Get a headache.
  - Feel nauseous (like you're going to throw up).
  - Feel more anxious (nervous or worried) than usual.
  - Cannot sleep.

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

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

#### About smoking

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

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

#### About sleep apnea

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

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

# Within 30 days of your Endoscopic Third Ventriculostomy (ETV) surgery for pediatric patients

#### Presurgical testing (PST)

Before your surgery, you will have an appointment for presurgical testing (PST). Depending on your age, your testing can take place in a variety of places. The date, time, and location of your PST appointment will be printed on the appointment reminder from your surgeon's office.

Your appointment will be at one of the following places:

 Pediatric Ambulatory Care Center (PACC)
 1275 York Avenue
 (between East 67<sup>th</sup> and East 68<sup>th</sup>
 Streets)
 B elevator to 9<sup>th</sup> floor
 Presurgical Testing (PST)
 160 East 53<sup>rd</sup> Street (at Third Avenue)
 Elevator to 7<sup>th</sup> floor

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

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

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

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

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

#### Parking at the PACC

The PACC is located at Memorial Hospital (MSK's main hospital). The address is:

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

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 is 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.

#### Parking at PST

PST is located in the Rockefeller Outpatient Pavilion, also known as MSK 53<sup>rd</sup> Street. The address is:

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

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

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

There are additional parking garages located at East 53<sup>rd</sup> Street between Second and Third Avenues and East 54<sup>th</sup> Street between Second and Third Avenues.

#### Talk with your social worker about housing, if needed

The Ronald McDonald House provides temporary housing for out-of-town pediatric patients and their families. MSK also has arrangements with several

local hotels and housing facilities that may give you a special reduced rate. Your social worker can discuss your options and make reservations.

#### Tell us if you're sick

If you develop any illness before your surgery, call the doctor who scheduled your surgery. This includes a fever, cold, sore throat, or the flu.

# 10 Days Before Your Surgery

#### Stop Taking Vitamin E

# Stop taking vitamin E, multivitamins, herbal remedies, and other dietary supplements

Vitamin E, multivitamins, herbal remedies, and other dietary supplements can cause bleeding. Stop taking them 10 days before your surgery. If your healthcare provider gives you other instructions, follow those instead.

To learn more, read *Herbal Remedies and Cancer Treatment*. You can find it in the "Educational resources" section of this guide.

# 7 Days Before Your Surgery

# Stop taking nonsteroidal anti-inflammatory drugs (NSAIDs)

NSAIDs, such as ibuprofen (Advil® and Motrin®) and naproxen (Aleve®), can cause bleeding. Stop taking them 7 days before your surgery. If your healthcare provider gives you other instructions, follow those instead. To learn more, read How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil. You can find it in the "Educational resources" section of this guide.

# Stop taking vitamin E, multivitamins, herbal remedies, and other dietary supplements

Vitamin E, multivitamins, herbal remedies, and other dietary supplements can cause bleeding. Stop taking them 7 days before your surgery. If your healthcare provider gives you other instructions, follow those instead.

To learn more, read *Herbal Remedies and Cancer Treatment*. You can find it in the "Educational resources" section of this guide.

# 2 Days Before Your Surgery

# Stop taking nonsteroidal anti-inflammatory drugs (NSAIDs)

NSAIDs, such as ibuprofen (Advil® and Motrin®) and naproxen (Aleve®), can cause bleeding. Stop taking them 2 days before your surgery. If your healthcare provider gives you other instructions, follow those instead.

To learn more, read How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil. You can find it in the "Educational resources" section of this guide.

- Pediatric Ambulatory Care Center (PACC)
   1275 York Avenue
   (between East 67th and East 68th Streets)
   B elevator to 9th floor
- Presurgical Center (PSC) on the 6th floor
   1275 York Avenue
   (between East 67th and East 68th Streets)
   B elevator to 6th floor

# 1 Day Before Your Surgery

#### Note the time of your surgery

A clerk from the Admitting Office will call you after 2:00 p.m. the day before your surgery. If you're scheduled for surgery on a Monday, you will be called on the Friday before.

The clerk will tell you what time you should arrive at the hospital for your surgery. They will also tell you where to go on the day of your surgery. This will be one of the following locations:

If you don't receive a call by 4:00 p.m., please call <u>212-639-7056</u>.

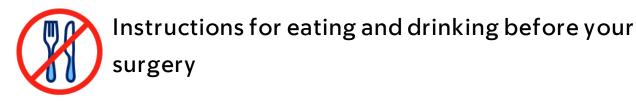
# The Night Before Your Surgery

#### Shower

Unless you're given other instructions, you can shower and wash your hair. Do not use any hair products such as hair spray or gel.

#### Sleep

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



Do not eat or drink anything after a certain time on the night before your surgery. This exact time is based on your age and any other medical problems that you may have. Your NP will talk with you about what you can and cannot eat before surgery.

If you do not follow the instructions you are given, your surgery may be cancelled.

# The Morning of Your Surgery

#### Take your medications

If your doctor or NP 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.

Starting 2 hours before your surgery, do not take any medications.



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 sip of water.

#### Things to remember

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

- Remove nail polish and nail wraps.
- 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.
- Leave valuable items (such as credit cards, jewelry, or your checkbook) at home.
- Before you're taken into the operating room, you will need to remove your hearing aids, dentures, prosthetic device(s), wig, and religious articles.
- Wear something comfortable and loose-fitting.
- If you wear contact lenses, wear your glasses instead. Wearing contact lenses during surgery can damage your eyes.

#### What to bring

- Your breathing machine for sleep apnea (such as your CPAP), if you have one.
- Your portable music player, if you choose. However, someone will need to hold it for you when you go into surgery.
- Your cell phone and charger.
- 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 resource. Your healthcare team will use this resource to teach you how to care for yourself after your surgery.

#### Where to park

For information about parking at Memorial Hospital, read the "Parking at the PACC" section.

#### 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. People with the same or similar names may be having surgery on the same day.

#### Get dressed for surgery

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

#### Meet with your nurse

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

#### Meet with your anesthesiologist

Your anesthesiologist 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 you will receive.
- Answer questions you have about your anesthesia.

#### Prepare for your surgery

You will either walk into the operating room or be taken in on a stretcher. A member of the operating room team will help you onto the operating bed. Compression boots will be placed on your lower legs. These gently inflate and deflate to help blood flow in your legs. Once you're comfortable, your anesthesiologist will give you anesthesia through your IV line, MediPort<sup>®</sup>, or central line, and you will fall asleep.

Once you're asleep, your surgery will begin. You won't feel any pain during your surgery.

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# Recovering after your (ETV) surgery for pediatric patients

This section will help you know what to expect after your surgery. You'll learn how to safely recover from your surgery both in the hospital and at home.



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

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## What to expect

When you wake up after your surgery, you will be in the Post Anesthesia Recovery Unit (PACU).

You may have a mask over your face that will give you air and help you wake up after surgery. You will be attached to machines that will monitor your body temperature, heart rate, blood pressure, and oxygen level. You may also have dressings (bandages) over your incisions.

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

Once you're awake and your pain is under control, you will be taken to your hospital room. Depending on your age and condition, you may be taken to the Pediatric Intensive Care Unit (PICU), the Adult Intensive Care Unit (ICU), or the Neurology Advanced Care Unit (NACU) for close observation and monitoring.

Read our resource <u>Call! Don't Fall! for Pediatric Patients</u> for information about how to avoid falling and stay safe while you're in the hospital.

After 24 hours, you will be taken to the pediatric or neurology floor for continued care. If you have a bandage over your incision, your doctor will take it off around this time. After the bandage is removed, your incision(s) will be left uncovered.

While you're in the hospital, you will frequently be asked to move your arms, fingers, toes and legs. Your nurse will check your pupils with a flashlight and ask questions such as "What is your name?"

# Commonly asked questions

#### Will I have any pain?

You may have a mild headache or feel discomfort from your incision for the first few days after your surgery. Your nurse will give you pain medication. Please tell your nurse if the medication isn't helping your pain.

You may have a sore throat after your surgery. This is caused by the breathing tube that was used during your surgery. You will be given cool liquids to drink and lozenges to suck on to help with the discomfort.

#### How long will I be in the hospital?

Most people stay in the hospital 1 night, but this will depend on your recovery.

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

#### When will I be able to eat and drink?

You will be given ice chips to eat after your surgery. You will start with a liquid diet and then progress to solid food.

#### When will my sutures or staples be removed?

The sutures or staples in your incision will be removed 7 to 10 days after your surgery. They may need to stay in longer if you have had this surgery before. Your doctor or NP will remove them during your follow-up visit at the clinic.

#### How do I care for my incision?

- Check your incision daily for any signs of redness, swelling, or drainage.
- Keep your incision clean and dry for 5 days after your surgery. Don't shower for 5 days after your surgery.

#### When can I shower?

- Your doctor or nurse will tell you when it's safe to shower after your surgery.
- Keep your incision dry for 5 days following your surgery. If your doctor or nurse says it's okay to shower before then, wear a shower cap to keep your incision dry.
- When you wash your hair, use a gentle shampoo, such as baby shampoo.
- Don't let your incision soak in water. Avoid baths, hot tubs, and swimming pools for at least 2 weeks after your surgery.
- Don't use a hair dryer, creams, ointments, or hair products on your incision until it's completely healed. This takes about 6 weeks.

#### When can I go back to work?

Your doctor will tell you when you can go back to work. This depends on your age, type of work, medical condition, and other factors.

#### When can I go back to school?

You can go back to school as soon as you feel ready. Tell your school nurse that you have an ETV.

#### When can I go back to my normal activities?

You can participate in all noncontact sports (such as swimming and running), exercise, and go to the gym 2 weeks after your surgery. You can't participate in any contact (collision) sports (such as football, boxing and wresting) until your neurosurgeon says it's okay. Remember to wear a helmet to decrease the risk of head injury, if needed. Ask your neurosurgeon for specific guidelines on wearing a helmet.

#### When can I swim?

Don't swim for at least 2 weeks after your surgery. If your incision needs more time to heal, you may need to wait longer. Your doctor or NP will tell you when it's okay to swim at your first follow-up appointment after your surgery.

#### When can I travel?

Don't travel on an airplane until your doctor says it's okay.

#### What follow-up care will I receive?

You will have regular visits with your neurologist, neurosurgeon, or both. They will monitor the function of your ETV over time.

#### Do I need to take any precautions when I have an MRI?

No. The magnet in the MRI scanner will not affect your ETV.

#### What other precautions do I need to take?

You should always wear a MedicAlert<sup>®</sup> bracelet or necklace stating that you have hydrocephalus with an ETV. If you're ever seriously ill or hurt and need medical help, it will inform emergency services workers about your ETV.

You can buy a MedicAlert bracelet or necklace at most drug stores. For more information, visit the MedicAlert website at <u>www.medicalert.com</u>.

You should also carry a wallet card at all times that states you have hydrocephalus with an ETV. Your nurse will give you a wallet card to fill out.

#### When should I call my doctor or NP?

Call your doctor or NP if you're having any of the following signs and symptoms that your ETV isn't working properly or you have an infection:

- A temperature of 100.4° F (38.0° C) or higher
- Vomiting with little or no nausea
- A constant, unrelieved headache
- Vision problems (blurry, double vision, or loss of vision)
- Irritability

- Fatigue
- Personality changes
- Loss of coordination or balance
- A bulging soft spot on an infant's head
- Difficulty waking up or staying awake
- Decrease in school performance

These warning signs can appear quickly. If any of these signs or symptoms develop, call your doctor or NP immediately.

If you cannot wake your child, call 911 or go to the nearest emergency room immediately.

Notes

# **Contact information**

If you have any questions or concerns, please talk with your doctor or nurse. You can reach them Monday through Friday from 9:00 a.m. to 5:00 p.m. at <u>212-639-7056</u>.

After 5:00 p.m., during the weekend, and on holidays, please call <u>212-639-</u> <u>2000</u> and ask for the pediatric neurosurgery fellow on call.

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# Support services

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



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

Notes \_\_\_\_\_\_

## MSK support services

Admitting Office

212-639-7606

Call if you have questions about your hospital admission, such as asking for a private room.

Anesthesia

212-639-6840

Call if you have questions about anesthesia.

**Blood Donor Room** 

212-639-7643

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

**Bobst International Center** 

888-675-7722

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

Counseling Center www.msk.org/counseling 646-888-0200

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

Food Pantry Program 646-888-8055

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

#### Integrative Medicine Service

www.msk.org/integrativemedicine

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

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

MSK Library library.mskcc.org 212-639-7439

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

**Nutrition Services** 

www.msk.org/nutrition

212-639-7312

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

Patient and Community Education

www.msk.org/pe

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

Patient Billing 646-227-3378

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

Patient Representative Office

212-639-7202

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

Perioperative Nurse Liaison

212-639-5935

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

Private Duty Nurses and Companions

917-862-6373

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

**Rehabilitation Services** 

www.msk.org/rehabilitation

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

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

PT can teach you exercises to help build strength and flexibility. Call Rehabilitation Therapy at 646-888-1900 to learn more.

Resources for Life After Cancer (RLAC) Program

#### 646-888-8106

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

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

#### Sexual Health Programs

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

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

#### Social Work

www.msk.org/socialwork

#### 212-639-7020

Social workers help patients, families, and friends deal with common issues for people who have cancer. They provide individual counseling and support groups throughout your treatment. They can help you communicate with children and other family members. Our social workers can also help refer you to community agencies and programs. If you're having trouble paying your bills, they also have information about financial resources. Call the number above to learn more.

### Spiritual Care

212-639-5982

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

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

Tobacco Treatment Program www.msk.org/tobacco

212-610-0507

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

#### **Virtual Programs**

www.msk.org/vp

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

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

## External support services

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

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

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# **Educational resources**

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



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

Notes	

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

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



#### PATIENT & CAREGIVER EDUCATION

# How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil

This information will help you check if your medicines or dietary supplements have aspirin, other NSAIDs, vitamin E, or fish oil as an active ingredient. NSAID stands for nonsteroidal anti-inflammatory drug.

It's important to stop taking these medicines and supplements before many cancer treatments. They affect your platelets (blood cells that clot to prevent bleeding) and can raise your risk of bleeding.

Other dietary supplements, such as vitamins and herbal remedies, can also affect your cancer treatment. Read *Herbal Remedies and Cancer Treatment* (www.mskcc.org/pe/herbal\_remedies) to learn more.

Make sure your healthcare provider always knows all the prescription and over-the-counter medicines and supplements you're taking. This includes patches and creams.

A prescription medicine is one you can only get with a prescription from your healthcare provider. An over-the-counter medicine is one you can buy without a prescription.

# What is an active ingredient?

An active ingredient is the part of a medicine or supplement that makes it work. Some medicines and supplements have just one active ingredient. Others have more. For example:

- Ibuprofen is the active ingredient in Advil® and Motrin®. Ibuprofen is an NSAID.
- Naproxen is the active ingredient in Aleve®. Naproxen is an NSAID.
- Acetaminophen is the active ingredient in Tylenol<sup>®</sup>.
- Aspirin, acetaminophen, and caffeine are the active ingredients in Excedrin<sup>®</sup>.

Generic medicines sometimes use their active ingredient as their name. But people often call medicines and supplements by a brand name, even if they're generic. This can make it hard to know their active ingredients.

## How to find a medicine or supplement's active ingredients

You can always find the active ingredients by reading the label.

### **Over-the-counter medicines**

Over-the-counter medicines list their active ingredients in the "Drug Facts" label (see Figure 1). Active ingredients are always the first thing on the Drug Facts label.

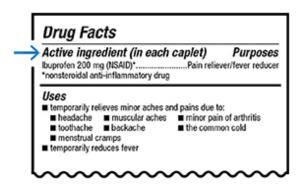


Figure 1. Active ingredients on an over-the-counter medicine label

### **Prescription medicines**

Prescription medicines list their active ingredients on the label. Their active ingredients and their generic name are the same thing.

Labels often look different depending on which pharmacy you use. Here's an example of where to find a medicine's active ingredients (generic name) on a label from MSK's pharmacy (see Figure 2).

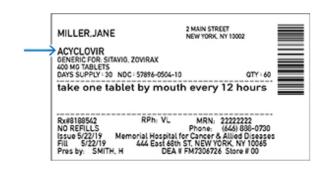


Figure 2. Active ingredients on a prescription medicine label

### **Dietary supplements**

Dietary supplements list their active ingredients in the "Supplement Facts" label (see Figure 3). The active ingredients always have an amount per serving and % daily value included.

	Amount Per Serving	% Daily Value
/itamin A (as retinyl acetate and 50% as beta-carotene)	5000 IU	100%
/itamin C (as ascorbic acid)	60 mg	100%
/tamin D (as cholecalciferol)	400 IU	100%
/itamin E (as di-alpha tocopheryl acetate)	30 IU	100%
Thiamin (as thiamin monoitrate)	1.5 mg	100%
Riboflavin	1.7 mg	100%
viacin (as niacinamide)	20 mg	100%
/tamin B <sub>e</sub> (as pyridoxine hydrocholride)	2.0 mg	100%
Folate (as folic acid)	400 mcg	100%
/itamin B (2 (as cyanocobalamin)	6 mcg	100%
Biotin	30 mog	10%
Pantothenic Acid (as calcium pantothenate)	10 mg	100%

Figure 3. Active ingredients on a supplement label

### Active ingredients to look for

If your medicine or supplement has any of these active ingredients, you may need to stop taking it before, during, or after your cancer treatment or surgery. Follow your care team's instructions.

Active ingredients to look for			
<ul> <li>Acetylsalicylic acid</li> <li>Alpha-linolenic acid (ALA)</li> <li>Aspirin</li> <li>Acetaminophen*</li> <li>Celecoxib</li> <li>Diclofenac</li> <li>Diflunisal</li> <li>Docosahexaenoic acid (DHA)</li> <li>Eicosapentaenoic acid (EPA)</li> </ul>	<ul> <li>Etodolac</li> <li>Fish oil</li> <li>Fenoprofen Flurbiprofen</li> <li>Ibuprofen</li> <li>Indomethacin</li> <li>Ketoprofen</li> <li>Ketorolac</li> <li>Meclofenamate</li> <li>Mefenamic acid</li> <li>Meloxicam</li> </ul>	<ul> <li>Nabumetone</li> <li>Naproxen</li> <li>Omega-3 fatty acids</li> <li>Omega-6 fatty acids</li> <li>Oxaprozin</li> <li>Piroxicam</li> <li>Sulindac</li> <li>Tolmetin</li> <li>Vitamin E</li> </ul>	

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

Common abbreviations for acetaminophen			
• APAP	• AC	Acetaminop	
• Acetamin	Acetam	Acetaminoph	

### About acetaminophen (Tylenol)

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

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

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

# Instructions before your cancer treatment

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

### **Before your surgery**

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

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

### Before your radiology procedure

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

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

### Before and during your chemotherapy

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

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

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

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#### PATIENT & CAREGIVER EDUCATION

# Herbal Remedies and Cancer Treatment

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

# **About Herbal Remedies**

Herbal remedies are any herbs, botanical (plant-based) supplements, or dietary supplements you take for their health benefits. These may come as tablets, capsules, powders, teas, liquid extracts, and fresh or dried plants.

Some herbal remedies can help prevent or manage side effects of cancer or your treatment. The herbal remedies that can help you depend on what symptoms you have and what treatment you're getting.

Even though herbal remedies can feel safe, they may not all be safe. Herbal remedies do not go through the same testing as prescription medications to make sure they work and are safe.

Some herbal remedies may be harmful. This is because they can:

- Affect how your other medications work.
- Raise or lower your blood pressure.
- Thin your blood and increase your risk of bleeding.
- Keep radiation therapy from working as well as it should.
- Change how your body reacts to sedation (medication to make you calmer) or general anesthesia (medication to make you sleepy).

Talk with your healthcare provider about any herbal remedies or other

supplements you are taking. They can provide an open and safe space to talk about these products.

For more information about herbs and supplements, visit www.aboutherbs.com or call MSK's Integrative Medicine Service at 646-608-8550.

### Stop taking herbal remedies before your treatment

# Stop taking herbal remedies and other dietary supplements 7 days (1 week) before you:

- Have surgery.
- Start chemotherapy.
- Start radiation therapy.
- Have certain procedures. Your healthcare provider will let you know if you need to stop taking herbal remedies before your procedure.

Herbal remedies and other dietary supplements can cause bleeding and affect your treatment. Follow your healthcare provider's instructions for when to restart taking herbal remedies.

You can still use some herbs in your food and drinks, such as using spices in cooking and drinking tea. Herbal remedies are stronger than the herbs you cook with.

### **Common Herbal Remedies and Their Effects**

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

### Echinacea (EH-kih-NAY-shuh)

- Can cause rare but serious allergic reactions, such as a rash or trouble breathing.
- Can keep medications that weaken your immune system from working as well as they should.

### Garlic

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

### Gingko (also known as Gingko biloba)

• Can increase your risk of bleeding.

### Ginseng (JIN-seng)

- Can keep sedation or general anesthesia from working as well as they should.
- Can increase your blood pressure.
- Can increase your risk of bleeding.
- Can lower your blood glucose (sugar) level.

### Turmeric (TER-mayr-ik)

• Can keep chemotherapy from working as well as it should.

### St. John's Wort

- Can keep some medications from working as well as they should.
- Can make your skin more sensitive to radiation or laser treatment.

### Valerian (vuh-LEER-ee-un)

• Can make sedation or general anesthesia affect you more than they should.

### Herbal formulas

- Herbal formulas contain many different herbs and dosages.
- Stop taking these products 7 days (1 week) before treatment. Do not start taking herbal formulas again until your healthcare provider tells you it is safe.

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

### **Contact Information**

- To schedule a consultation with a healthcare provider in Integrative Medicine, call 646-608-8550.
- To make an appointment for Integrative Medicine Service's therapies, classes, and workshops, call 646-449-1010.

For more information, visit www.mskcc.org/IntegrativeMedicine or read Integrative Medicine Therapies and Your Cancer Treatment (www.mskcc.org/pe/integrative\_therapies).

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

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