MSK Kids

PATIENT & CAREGIVER EDUCATION

About Your Endoscopic Third Ventriculostomy (ETV) Surgery at MSK Kids

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.

In this resource, the words "you" and "your" mean you or your child.

Your care team

Doctor: _____

Nurse: _____

Phone number: _____

Fax number: _____



Visit www.msk.org/pe/etv_surgery_peds to view this guide online.

Memorial Sloan Kettering Cancer Center

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About your surgery

An endoscopic third ventriculostomy (ven-TRI-cu-LUS-to-my), or 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. It also brings nutrients throughout your brain and carries waste away. You're making new CSF all the time.

CSF flows from your ventricles, around your brain and spinal cord, and into your bloodstream. If extra CSF builds up in your ventricles, 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-droh-SEH-fuh-lus).

Hydrocephalus can happen if the flow of CSF is blocked. It also happens if not enough CSF is absorbed into your bloodstream.

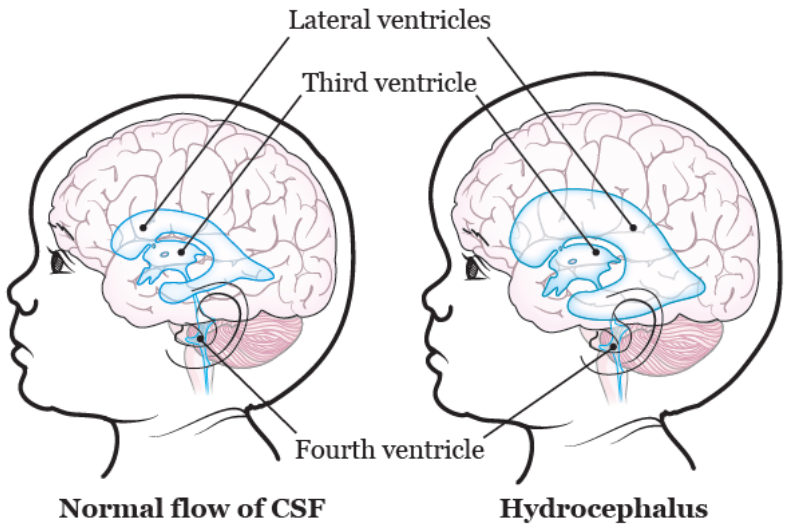


Figure 1: Brain with and without hydrocephalus

Your ETV surgery will be done in the operating room while you're asleep. The nurse may need to shave a small amount of hair in the area where your incision (surgical cut) will be. They will not shave your entire head.

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

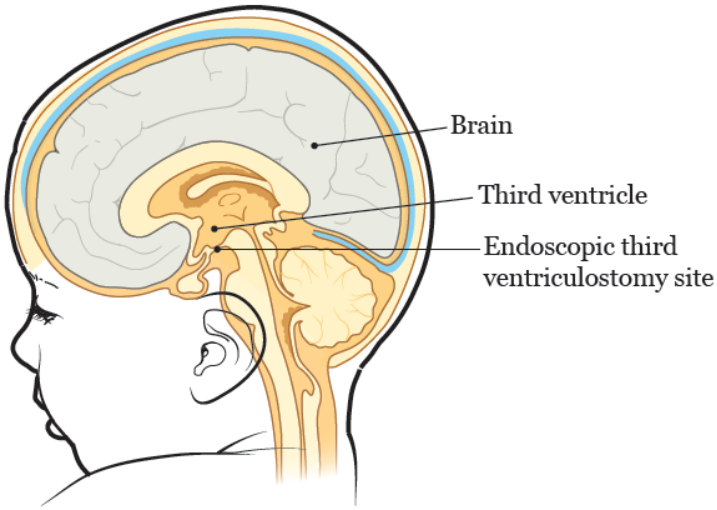


Figure 2. ETV

Symptoms of hydrocephalus

Symptoms are different depending on your age and the stage of disease. The most common symptoms of hydrocephalus include:

- Increased head size and bulging soft spot in baby's head.
- A headache that does not get better after resting or taking medicine.
- Vomiting (throwing up) with little or no nausea (feeling like you're going to throw up).
- Fatigue (feeling unusually tired or weak).
- Irritability (becoming easily frustrated or annoyed).

- Personality changes (not acting like your normal self).
- Problems with thinking and memory, such as confusion.
- Trouble with balance or walking.
- Trouble waking up or staying awake.
- Trouble holding in your urine (pee).
- Seizures (uncontrollable shaking).
- High pitched cry in babies.
- Trouble eating.
- Problems seeing, such as:
    - Blurred vision
    - Double vision
    - Vision loss
    - Eyes that turn downward (also called sunsetting)

Notes

Getting ready for your surgery

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.

Notes _____

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 any prescription medicines. A prescription medicine is one you can only get with a prescription from a healthcare provider. Examples include:
    - Medicines you swallow.
    - Medicines you take as an injection (shot).
    - Medicines you inhale (breathe in).
    - Medicines you put on your skin as a patch or cream.
- I take any over-the-counter medicines, including patches and creams. An over-the-counter medicine is one you can buy without a prescription.
- I take any dietary supplements, such as herbs, vitamins, minerals, or natural or home remedies.
- I have a pacemaker, automatic implantable cardioverter-defibrillator (AICD), or other heart device.
- I have 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 use recreational drugs, such as marijuana.

Always be sure your healthcare providers know all the medicines and supplements you're taking.

You may need to follow special instructions before surgery based on the medicines and supplements you take. If you do not follow those instructions, your surgery may be delayed or canceled.

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 surgery to keep from having problems.

- Be honest with us about how much alcohol you drink.
- Try to stop drinking alcohol once your surgery is planned. Tell us 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 us if you cannot stop drinking.
- Ask us questions about drinking and surgery. We will keep all your medical information private, as always.

About smoking

If you smoke or use an electronic smoking device, you can have breathing problems when you have surgery. Vapes and e-cigarettes are examples of electronic smoking devices. Stopping for even a few days before surgery can help prevent breathing problems during and after surgery.

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

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.

Using MSK MyChart

MSK MyChart (mskmychart.mskcc.org) is MSK's patient portal. You can use it to send and read messages from your care team, view your test results, see your appointment dates and times, and more. You can also invite your caregiver to make their own account so they can see information about your care.

If you do not have an MSK MyChart account, you can sign up at mskmychart.mskcc.org. You can also ask a member of your care team to send you an invitation.

If you need help with your account, call the MSK MyChart Help Desk at 646-227-2593. They are available Monday through Friday between 9 a.m. and 5 p.m. (Eastern time).

Help your body get ready for surgery

You can recover faster and easier if you help your body get in its best shape for your surgery. This section has examples of things you can do to get your body ready for surgery. Your care team will help you decide which activities are best for you.

Practice breathing and coughing

Practice taking deep breaths and coughing before your surgery. You can do this by:

- Walking around or playing.
- Blowing bubbles or blowing a tissue in the air.
- Using your incentive spirometer, if your care team gave you one.

Move around and be active

Try to do physical activity every day. Examples include walking, swimming, or biking. MSK also offers free virtual classes for all ages that can help you be active. Ask your healthcare provider for more information.

Practice meditation and mindfulness

Mindful breathing, meditation, yoga, movement practice, massage, and acupressure techniques can support you as you get ready for surgery.

Our Integrative Medicine Service's videos can help you find the right activities to add into your daily routines before your surgery. Visit www.msk.org/integrative-medicine-multimedia to find the videos. You can also visit www.msk.org/meditation to see guided meditation videos created by our expert mind-body specialists.

Follow a healthy diet

A clinical dietitian nutritionist can talk with you about how to get ready for surgery. You can learn how to make sure your nutrition is the best it can be.

If you're getting other cancer treatments before your surgery, they can cause taste changes, appetite loss, and trouble digesting food. This can make it hard to eat enough food, which can lead to weight loss. Your clinical dietitian nutritionist can work with you on a plan that helps with eating challenges.

It's also helpful to follow these general eating and drinking guidelines.

- Have small, frequent meals. For example, have a half-sized meal every 2 to 3 hours. Aim for 6 to 8 small meals a day instead of 3 large meals.
- Make and follow a meal schedule. Do not wait to eat until you're hungry. Put the schedule in a place for everyone to see.
- Keep your favorite foods in your home where you can get to them easily.
- Buy single-serving food items that you can eat easily, such as drinkable yogurt smoothies or cheese sticks.
- Cook in batches so you have leftovers.
    - Keep 1 extra serving in your refrigerator for the next day, but not longer.
    - Freeze the other extra servings. When you're ready to use a serving, thaw it in the refrigerator or microwave, not on the kitchen counter. Then reheat it until it's steaming hot.
- Include many different food groups and food types in your diet, unless your doctor or clinical dietitian nutritionist tells you not to.
- Sometimes drinking is easier than eating. Try getting more calories from liquids than solid foods. For example, have milkshakes or nutritional supplements such as PediaSure® or Carnation Breakfast Essentials®.
- Keep your dining experience enjoyable, with no stress. Try having family mealtimes or group snack times with family.

- Think of your nutrition as being just as important as your medicines.

Remember to choose foods that are high in calories and protein. Talk with your clinical dietitian nutritionist about foods that work best based on what you like or your meal patterns.

Fill out a Health Care Proxy form, if needed

If you're age 18 or older and haven't already filled out a Health Care Proxy form, we recommend you do now. If you already filled one out or have any other advance directives, bring them to your next appointment.

A health care proxy is a legal document. It says who will speak for you if you cannot communicate for yourself. This person is called your health care agent.

- To learn more about health care proxies and other advance directives, read *Advance Care Planning for People With Cancer and Their Loved Ones*. You can find it at www.msk.org/pe/advance_care_planning or ask for a printed copy.
- To learn more about being a health care agent, read *How to Be a Health Care Agent*. You can find it at www.msk.org/pe/health_care_agent or ask for a printed copy.

Talk with a member of your care team if you have questions about filling out a Health Care Proxy form.

Within 30 days of your surgery

Presurgical testing (PST)

You'll have a PST appointment before your surgery. You'll get a reminder from your surgeon's office with the appointment date, time, and location.

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

It's helpful to bring these things to your appointment:

- A list of all the medicines you're taking, including prescription and over-the-counter medicines, patches, and creams.
- Results of any medical tests done outside of MSK in the past year, if you have them. Examples include results from a cardiac stress test, echocardiogram, or carotid doppler study.
- The names and telephone numbers of your healthcare providers.

You'll meet with an advance practice provider (APP) during your PST appointment. They work closely with MSK's anesthesiology (A-nes-THEE-zee-AH-loh-jee) staff. These are doctors with special training in using anesthesia during a surgery or procedure.

Your APP will review your medical and surgical history with you. You may have tests to plan your care, such as:

- An electrocardiogram (EKG) to check your heart rhythm.
- A chest X-ray.
- Blood tests.

Your APP may recommend you see other healthcare providers. They'll also talk with you about which medicine(s) to take the morning of your surgery.

Visit www.msk.org/parking for parking information and directions to all MSK locations.

Meet with other healthcare professionals, if needed

MSK has many different healthcare professionals who can help you before, during, and after your cancer treatment.

- **Social workers** can help you cope with the emotional, social, and physical effects of a cancer diagnosis. Our social workers provide

counseling and practical assistance. They help families cope with their child's disease, improve communication with family and friends, share information on community resources, and help adjust to medical treatment.

- **Child life specialists** are trained professionals who are experts in human growth and development. If you're worried or stressed about your procedure, they can help you plan ways to be more comfortable and relaxed. MSK's child life specialists have a variety of backgrounds and interests, including education, psychology, fine arts, and art therapy. Together, our skills and certifications offer a full range of child life services that educate and empower patients and their families during an illness.
- **Counselors** and **therapists** can meet with you and your family members and provide counseling for emotional problems related to coping with cancer. MSK's counseling center also has support groups that meet regularly.

Your healthcare provider may offer you a referral to these services. You can also ask for a referral if you're interested.

Talk with your social worker about 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. You can also call 212-639-8315 to talk with the Pediatric Patient Services Coordinator.

Tell us if you're sick

If you get sick before your surgery, call the healthcare provider who scheduled your surgery. This includes a fever, cold, sore throat, or the flu.

7 days before your surgery

Follow your healthcare provider's instructions for taking aspirin

Aspirin can cause bleeding. 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 they tell you to.**

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 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.

Have imaging scans, if needed

You will need to have imaging scans to help your healthcare providers plan your surgery. If you have them done somewhere other than MSK, your healthcare provider may ask you to bring the disc with copies of the imaging scans to one of your appointments.

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.

1 day before your surgery

Note the time of your surgery

A staff member will call you after 2 p.m. the day before your surgery. If your surgery is scheduled for a Monday, they'll call you the Friday before. If you do not get a call by 4 p.m., call 212-639-7056.

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

Visit www.msk.org/parking for parking information and directions to all MSK locations.

The night before your surgery

Shower

You can shower and wash your hair unless you're given other instructions, you. **Do not apply any hair products such as hair spray or hair gel.**

Instructions for eating and drinking before surgery



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 you have.

Your healthcare provider will talk with you about what you can and cannot eat before surgery.

If you do not follow the instructions your care team gives you, your surgery may be cancelled.

Write your instructions here.

_____

_____

_____

_____

The morning of your surgery

Take your medicines as instructed

A member of your care team will tell you which medicines to take the morning of your surgery. Take only those medicines with a sip of water. Depending on what medicines you take, this may be all, some, or none of your usual morning medicines.

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



Do not eat or drink anything the morning of your surgery. This includes water, hard candy, and gum. **If you do not follow the instructions your care team gives you, your surgery may be cancelled.**

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.
- Do not wear any metal objects. Remove all jewelry, including body piercings. The tools used during your surgery can cause burns if they touch metal.
- Do not wear any lotion, cream, deodorant, makeup, powder, perfume, or cologne.
- Do not wear any hair products, such as hair spray or hair gel.
- Leave valuable items at home.

What to bring

- Pajamas with a loose-fitting or button-down shirt that will go over your head easily.
- 1 comfort item, such as a blanket or teddy bear.
- 1 or 2 portable electronic devices, such as a smartphone or tablet, and their chargers.
- All the medicines you're taking, including prescription and over-the-counter medicines, supplements, patches, and creams.
- Your Health Care Proxy form and other advance directives, if you filled them out.
- A case for your personal items, if you have any. Eyeglasses, hearing aids, dentures, prosthetic devices, wigs, and religious articles are examples of personal items.
- This guide. You'll use it to learn how to care for yourself after surgery.

Once you're in the hospital

When you get to the hospital, take the B elevator to the 6th floor (the PSC) or the 9th floor (the PACC). Check in at the desk in the waiting room.

Many staff members will ask you to say and spell your name and birth date. This is for your safety. People with the same or a similar name may be having surgery on the same day.

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



For caregivers, family, and friends

Read *Information for Family and Friends for the Day of Surgery* to help you know what to expect on the day of your loved one's surgery. You can ask for a printed copy or find it at www.msk.org/pe/info-family-friends

Meet with a nurse

You'll meet with a nurse before surgery. Tell them the dose of any medicines you took after midnight (12 a.m.) and the time you took them. Make sure to include prescription and over-the-counter medicines, patches, and creams.

If you have an implanted port or central venous catheter (CVC), your nurse will access it. If you don't, your nurse may place an intravenous (IV) line in one of your veins, usually in your arm or hand. If your nurse does not place the IV, your anesthesiologist (A-nes-THEE-zee-AH-loh-jist) will do it 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 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 get.
- Answer your questions about your anesthesia.

Get ready for surgery

When it's time for your surgery, you'll need to take off your eyeglasses, hearing aids, dentures, prosthetic devices, wig, and religious articles.

You'll either walk into the operating room or a staff member will bring you there on a stretcher. Babies and young children may be carried into the operating room. A member of the operating room team will help you onto the operating bed.

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

During your surgery

After you're fully asleep, your care team will place a breathing tube through your mouth into your airway. It will help you breathe. They'll also place a urinary (Foley) catheter in your bladder. It will drain your urine (pee) during your surgery.

Your care team will shave a small amount of hair on your head in the area where you'll be having surgery.

Your surgeon will close your incisions with staples or stitches once they finish your surgery. They'll cover your incision with a bandage or head wrap.

Your care team will usually take out your breathing tube while you're still in the operating room.

After your surgery

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.

Notes _____

What to expect

You will be in one of the following units when you wake up after surgery.

- The Pediatric Intensive Care Unit (PICU)
- The Intensive Care Unit (ICU)
- The Post-Anesthesia Care Unit (PACU)
- The Neurology Advanced Care Unit (NACU)

Before your surgery, your care team will talk with you about what to expect when you wake up.

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

A nurse will be keeping track of your temperature, pulse, blood pressure, and oxygen levels. You may get oxygen through a tube resting below your nose or a mask over your nose and mouth. You will also have dressings (bandages) over your incisions.

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.**

Pain medicine

Right after your surgery, you will get IV pain medicine through your implanted port, CVC, or IV line. Tell one of your healthcare providers if the medicine isn't helping your pain.

Tubes and drains

You may have the following tubes and drains. Your healthcare provider will talk with you about what to expect.

- **A urinary (Foley) catheter:** This is a tube that drains urine from your bladder. Your care team will keep track of how much urine you're making while you're in the hospital.
- **An IV:** You will get fluids and medicines through your IV after surgery.

Physical therapy and occupational therapy

If you need help moving, crawling, walking, playing, or doing self-care tasks after your surgery, a physical therapist (PT), occupational therapist (OT), or both may visit you.

- Your PT can help you move and function better after surgery. They'll help you get back the strength, balance, and coordination you need to do things like crawling, walking, climbing stairs, playing, or doing sports.
- Your OT can help you improve the skills you need to do important everyday activities. They'll help you if you have trouble with self-care tasks (such as getting dressed and brushing your teeth), play activities, or skills you need for school or work.

Your PT and OT will talk with you about how often you will have physical therapy, occupational therapy, or both. To learn more, read *Staying Active Before and After Surgery for Pediatric Patients*. You can find it at www.msk.org/pe/staying_active_peds or ask for a printed copy.

Moving to your hospital room

You may stay in the PACU for a few hours or overnight. How long you stay depends on the type of surgery you had. A staff member will bring you to your hospital room after your stay in the PACU.

Once you're fully awake, you will be moved to your hospital room. Your room will be in one of these places:

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

The place that your room is depends on your age and condition.

In your hospital room

The length of time you're in the hospital after your surgery depends on your recovery. Most people stay in the hospital for 1 night.

In your hospital room, you'll meet one of the nurses who will care for you during your stay. A nurse will help you out of bed and into your chair soon after you get there.

Your care team will teach you how to care for yourself while you're healing from your surgery.

You will be asked to move your arms, fingers, toes, and legs often. Your nurse will check your pupils with a flashlight and ask questions such as "What is your name?"

Depending on your treatment plan, you may start to work with a physical therapist. Over the next couple of days, you will increase your activity until you're ready to go home.

Managing your pain

You may have some pain after your surgery. At first, you'll get your pain medicine through your IV line. Once you're able to eat, you'll get oral pain medicine (medicine you swallow).

Your healthcare providers will ask you about your pain often and give you medicine as needed. If your pain is not relieved, tell one of your healthcare providers. It's important to control your pain so you can use your incentive spirometer and move around. Controlling your pain can help you recover faster.

You'll get a prescription for pain medicine before you leave the hospital. Talk with your healthcare provider about possible side effects. Ask them when to start switching to over-the-counter pain medicine.

You may have a headache after surgery. You will get medicine to help with these symptoms.

You may have a sore throat after surgery. This is because of the breathing tube you had during surgery. Your nurse will give you cool liquids to drink and lozenges to suck on to help with the discomfort.

Moving around and walking

Moving around and walking will help lower your risk for blood clots and pneumonia (lung infection). It will also help you start passing gas and having bowel movements (pooping) again. Your nurse, physical therapist, or occupational therapist will help you move around, if needed.

To learn more about how walking can help you recover, read *Frequently Asked Questions About Walking After Your Surgery*. You can find it at www.msk.org/pe/walking_after_surgery or ask for a printed copy.

To learn what you can do to stay safe and keep from falling while you're in the hospital, read *Call! Don't Fall! for Pediatric Patients*. You can find it at www.msk.org/pe/call_dont_fall_peds or ask for a printed copy.

Eating and drinking

Your nurse will give you ice chips after your surgery. You will most likely be able to drink liquids a few hours after your surgery. After that, you will slowly go back to your normal diet.

If you have questions about your diet, ask to see a clinical dietitian nutritionist.

Leaving the hospital

Before you leave, look at your incision with one of your healthcare providers. Knowing what it looks like will help you notice any changes later.

Your healthcare provider will write your discharge order and prescriptions. You'll also get written discharge instructions. One of your healthcare providers will review them with you before you leave.

At home

Read *What You Can Do to Avoid Falling* to learn what you can do to keep from falling at home and during your appointments at MSK. You can find it at www.msk.org/pe/avoid_falling or ask for a printed copy.

Managing your pain

People have pain or discomfort for different lengths of time. You may still have some pain when you go home and will probably be taking pain medicine.

Follow these guidelines to help manage your pain at home.

- Take your medicines as directed and as needed.
- Call your healthcare provider if the medicine prescribed for you does not help your pain.
- Do not drive or drink alcohol while you're taking prescription pain medicine. Some prescription pain medicines can make you drowsy (very sleepy). Alcohol can make the drowsiness worse.
- You'll have less pain and need less pain medicine as your incision heals. An over-the-counter pain reliever will help with aches and discomfort. Acetaminophen (Tylenol®) and ibuprofen (Advil or Motrin) are examples of over-the-counter pain relievers. **Call your healthcare provider before taking ibuprofen (Advil or Motrin).**
    - Follow your healthcare provider's instructions for stopping your prescription pain medicine.
    - Do not take too much of any medicine. Follow the instructions on the label or from your healthcare provider.
    - Read the labels on all the medicines you're taking. This is very important if you're taking acetaminophen. Acetaminophen is an ingredient in many over-the-counter and prescription medicines. Taking too much can harm your liver. Do not take more than one medicine that has acetaminophen without talking with a member of your care team.
- Pain medicine should help you get back to your usual activities. Take enough to do your activities and exercises comfortably. You may have a little more pain as you start to be more active.
- Keep track of when you take your pain medicine. It works best 30 to 45 minutes after you take it. Taking it when you first have pain is better than waiting for the pain to get worse.

Some prescription pain medicines, such as opioids, may cause constipation. Constipation is when you poop less often than usual, have a harder time pooping, or both.

Caring for your incision

Your healthcare provider will take your sutures or staples in your incision out during your first appointment after surgery. This is about 7 to 10 days after surgery. They may need to stay in longer if you have had this surgery before.

It's common for the skin below your incision to feel numb. This happens because some of your nerves were cut during your surgery. The numbness will go away over time.

Check your incision for any signs of redness, swelling, or drainage. Keep them clean and dry for 5 days after your surgery.

Call your healthcare provider's office if:

- The skin around your incision is very red or getting more red.
- The skin around your incision is warmer than usual.
- The area around your incision is starting to swell or getting more swollen.
- You see drainage that looks like pus (thick and milky).
- Your incision smells bad.

Take off your bandage or head wrap, if you have one

If you have a bandage or head wrap over your incision, your surgeon will take it off 1 to 2 days after your surgery. After that, you can leave the incision uncovered. Once your incision is healed, it does not need to be covered.

Protect your incision from the sun

Protect your incision from the sun by wearing a hat or scarf. You should also wear sunscreen, but make sure your incision is fully healed before you put sunscreen on it.

Do not put anything on your incision

As your incision heals, it may burn, itch, or feel numb. Do not put on any creams, sunscreens, ointments, hair products, or use a hairdryer on your incision until it is completely healed. This may take about 6 weeks.

Showering

You may shower or bathe 24 hours (1 day) after surgery. **But do not get your incision(s) wet for the first 5 days after surgery.** Wear a shower cap to keep your incision from getting wet. It's best to shower with someone in the bathroom to help you.

Starting 5 days after your surgery, take a shower and wash your hair every day to clean your incision. This helps loosen up any crusting on your incision. It will also help your healthcare provider remove your staples or sutures. If you have staples or stitches in your incision, it's OK to get them wet.

When you wash your hair, use a gentle shampoo, such as baby shampoo. You can gently massage the area near your incision to wash off any dried blood or drainage. You can let the shower water run over your incision.

After you shower, pat the area dry with a clean towel.

Do not let your incision soak in water. If you're taking a bath, do not put your head under water.

Eating and drinking

You can eat all the foods you did before your surgery, unless your healthcare provider gives you other instructions. Eating a balanced diet with lots of calories and protein will help you heal after surgery. Try to eat a good protein source (such as meat, cheese, tofu, fish, or eggs) at each meal. You should also try to eat fruits, vegetables, and whole grains.

It's also important to drink plenty of liquids. Try to drink 8 to 10 (8-ounce) cups of liquids every day. Choose liquids without alcohol. Limit liquids with caffeine.

If you have questions about your diet, ask to see a clinical dietitian nutritionist.

Physical activity and exercise

Your incision may look like it's healed on the outside when you leave the hospital. It will not be healed on the inside. For the first 6 weeks after your surgery:

- Do not lift anything heavier than 10 pounds (4.5 kilograms).
- Do not do any high-energy activities, such as jogging and tennis.

Do not play any contact sports, such as football, boxing, or wrestling, until your neurosurgeon says it's OK. Wear a helmet to protect your head. Talk with your neurosurgeon for more information.

Exercise, such as walking and stair climbing, will help you gain strength and feel better. Try to walk each day. Have someone next to you to make sure you are safe. Start by walking a little more than you did the day before. Slowly increase the amount you walk.

It's common to have less energy than usual after surgery. Recovery time is different for everyone. Do more activity each day as much as you can.

Always balance activity periods with rest periods. Rest is an important part of your recovery.

Driving

Ask your healthcare provider when you can drive. Most people can start driving again 2 weeks after surgery. Do not drive while you're taking pain medicine that may make you drowsy.

You can ride in a car as a passenger at any time after you leave the hospital.

Going back to work

Talk with your healthcare provider about your job. They'll tell you when it may be safe for you to start working again based on what you do. If you move around a lot or lift heavy objects, you may need to stay out a little longer. If you sit at a desk, you may be able to go back sooner.

Going back to school

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

Swimming

Do not swim in a pool or hot tub for at least 2 weeks after your surgery. If your incisions need more time to heal, you may need to wait longer. Your healthcare provider will tell you when it's OK to swim at your first follow-up appointment after your surgery.

Traveling

Do not travel on an airplane until your doctor says it's OK.

Safety guidelines to follow after ETV surgery

Wear MedicAlert® jewelry

You should always wear a MedicAlert bracelet or necklace that says you have hydrocephalus and had ETV surgery. This will help emergency service workers care for you if you're ever badly ill or hurt and need medical help.

You can buy a MedicAlert bracelet or necklace at most drug stores. You can also ask a member of your care team for an application. Visit the MedicAlert website at www.medicalert.org to learn more.

Magnetic resonance imaging (MRI) and other imaging scans

You can have any imaging scan done after your surgery. This includes a magnetic resonance imaging (MRI), computed tomography (CT), or X-ray scan. You do not need to take any special care.

Wear a helmet, if needed

Wear a helmet to lower your risk of head injury, if needed. Ask your neurosurgeon for specific guidelines on wearing a helmet.

Follow-up care

You will have regular visits with your neurologist, neurosurgeon, or both.

Managing your feelings

You may have new and upsetting feelings after a surgery for a serious illness. Many people say they felt weepy, sad, worried, nervous, irritable, or angry at one time or another. You may find that you cannot control some of these feelings. If this happens, it's a good idea to seek emotional support. Your healthcare provider can refer you to MSK's Counseling Center. You can also reach them by calling 646-888-0200.

The first step in coping is to talk about how you feel. Family and friends can help. We can also reassure, support, and guide you. It's always a good idea to let us know how you, your family, and your friends are feeling emotionally. Many resources are available to you and your family. We're here to help you and your family and friends handle the emotional aspects of your illness. We can help no matter if you're in the hospital or at home.

Contact information

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call.

If you're not sure how to reach your healthcare provider, call 212-639-2000.

When to call your healthcare provider



Call your healthcare provider if you have any of the following.

- A fever of 100.4 °F (38 °C) or higher.
- Increased head size and bulging soft spot in baby's head.
- A headache that does not get better after resting or taking medicine.
- Vomiting (throwing up), nausea (feeling like you're going to throw up), or both.
- Fatigue (feeling unusually tired or weak).
- Irritability (becoming easily frustrated or annoyed).
- Personality changes (not acting like your normal self).
- Problems with thinking and memory (such as confusion).
- Trouble with balance or walking.
- Trouble waking up or staying awake.
- Trouble holding in your urine (pee).
- Seizures (uncontrollable shaking).
- High pitched cry in babies.
- Trouble eating.
- Problems seeing, such as blurred vision or vision loss.
- Eyes that turn downward (also called sunsetting).

These warning signs can appear quickly. **If your child has any of these signs or symptoms, call their healthcare provider right away.**



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

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

www.msk.org/international

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.

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.

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.

Educational resources

This section has the educational resources mentioned in this guide. 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 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 for People With Cancer and Their Loved Ones* (www.msk.org/pe/advance_care_planning)
- *Call! Don't Fall! for Pediatric Patients* (www.msk.org/pe/call_dont_fall_peds)
- *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 Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil* (www.msk.org/pe/check-med-supplement)
- *How to Use Your Incentive Spirometer* (www.msk.org/pe/incentive_spirometer)
- *Staying Active Before and After Surgery for Pediatric Patients* (www.msk.org/pe/staying_active_peds)
- *What You Can Do to Avoid Falling* (www.msk.org/pe/avoid_falling)

Memorial Sloan Kettering Cancer Center

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®.
- Aspirin, acetaminophen, and caffeine are the active ingredients in Excedrin®.

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.

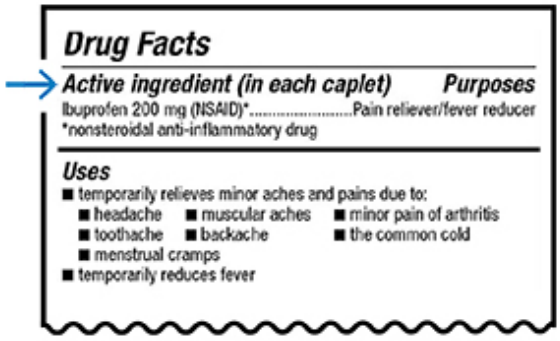


Figure 1. Active ingredients on an over-the-counter medicine label

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).

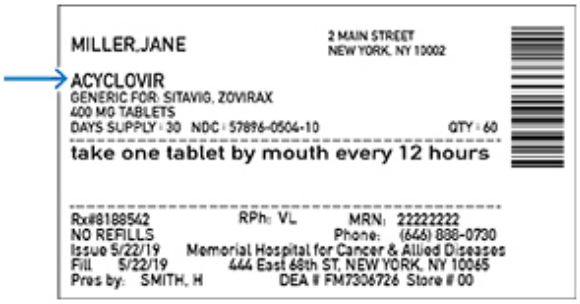
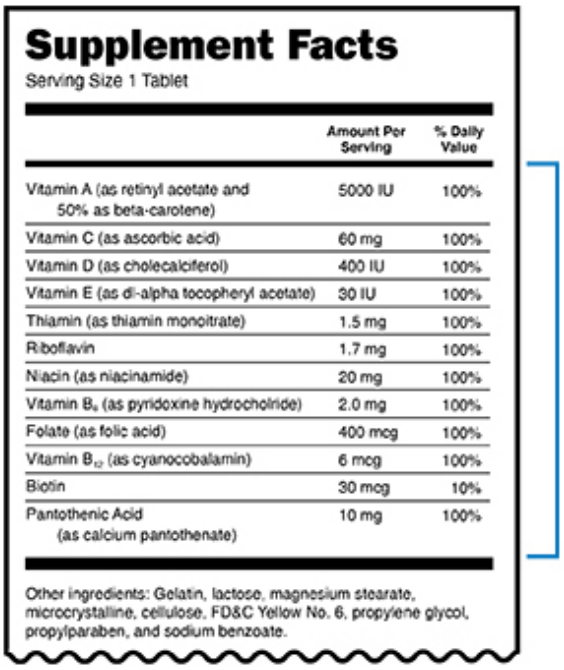


Figure 2. Active ingredients on a prescription medicine label

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.



Supplement Facts

Serving Size 1 Tablet

	Amount Per Serving	% Daily Value
Vitamin A (as retinyl acetate and 50% as beta-carotene)	5000 IU	100%
Vitamin C (as ascorbic acid)	60 mg	100%
Vitamin D (as cholecalciferol)	400 IU	100%
Vitamin E (as dl-alpha tocopheryl acetate)	30 IU	100%
Thiamin (as thiamin mononitrate)	1.5 mg	100%
Riboflavin	1.7 mg	100%
Niacin (as niacinamide)	20 mg	100%
Vitamin B_6 (as pyridoxine hydrochloride)	2.0 mg	100%
Folate (as folic acid)	400 mcg	100%
Vitamin B_{12} (as cyanocobalamin)	6 mcg	100%
Biotin	30 mcg	10%
Pantothenic Acid (as calcium pantothenate)	10 mg	100%

Other ingredients: Gelatin, lactose, magnesium stearate, microcrystalline, cellulose, FD&C Yellow No. 6, propylene glycol, propylparaben, and sodium benzoate.

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		
• Acetylsalicylic acid • Alpha-linolenic acid (ALA) • Aspirin • Acetaminophen* • Celecoxib • Diclofenac • Diflunisal • Docosahexaenoic acid (DHA) • Eicosapentaenoic acid (EPA)	• Etodolac • Fish oil • Fenoprofen Flurbiprofen • Ibuprofen • Indomethacin • Ketoprofen • Ketorolac • Meclofenamate • Mefenamic acid • Meloxicam	• Nabumetone • Naproxen • Omega-3 fatty acids • Omega-6 fatty acids • Oxaprozin • Piroxicam • Sulindac • Tolmetin • Vitamin E

* 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 • Acetamin	• AC • Acetam	• Acetaminop • 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.

How To Check if a Medicine or Supplement Has Aspirin, Other NSAIDs, Vitamin E, or Fish Oil - Last updated on November 29, 2023
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Memorial Sloan Kettering Cancer Center

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.

Herbal Remedies and Cancer Treatment - Last updated on May 5, 2022
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