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

About Your Surgery ................................................................. 3
Before Your Surgery ................................................................ 5
  Common Medications Containing Aspirin and Other Nonsteroidal
  Anti-inflammatory Drugs (NSAIDs) ........................................ 13
  Herbal Remedies and Cancer Treatment ............................... 21
  Information for Family and Friends for the Day of Surgery .... 18
After Your Surgery ................................................................. 25
Resources .............................................................................. 31
  MSK Support Services ........................................................... 32
  External Resources ............................................................... 34
This guide will help you prepare for your endoscopic third ventriculostomy (ETV) surgery at Memorial Sloan Kettering (MSK). It will also help you understand what to expect during your recovery.

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

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

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).

![Diagram of brain with and without hydrocephalus](image)

Figure 1: Brain with and without hydrocephalus
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](image)
The information in this section will help you prepare for your surgery. Read through this section when your surgery is scheduled and refer to it as your surgery date gets closer. It contains important information about what you need to do before your surgery. Write down any questions you have and be sure to ask your doctor or nurse.
Preparing for Your Surgery

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

About Drinking Alcohol

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

- Stopping alcohol suddenly can cause seizures, delirium, and death. If we know you’re at risk for these complications, we can prescribe medications to help prevent them.

- If you drink alcohol regularly, you may be at risk for other complications during and after your surgery. These include bleeding, infections, heart problems, greater dependence on nursing care, and longer hospital stay.

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

- Be honest with your healthcare provider about how much alcohol you drink.

- Try to stop drinking alcohol once your surgery is planned. If you develop a headache, nausea, increased anxiety, or can’t sleep after you stop drinking, tell your doctor right away. These are early signs of alcohol withdrawal and can be treated.

- Tell your healthcare provider if you can’t stop drinking.

- Ask us any questions you have about drinking and surgery. As always, all of your medical information will be kept confidential.

About Smoking

People who smoke can have breathing problems when they have surgery. Stopping even for a few days before surgery can help. If you smoke, your nurse will refer you to our Tobacco Treatment Program. You can also reach the program at 212-610-0507.

Help us keep you safe during your surgery by telling us if any of the following statements apply to you, even if you aren’t sure.

- I take a blood thinner. Some examples are aspirin, heparin, warfarin (Coumadin®), clopidogrel (Plavix®), enoxaparin (Lovenox®), dabigatran (Pradaxa®), apixaban (Eliquis®), and rivaroxaban (Xarelto®). There are others, so be sure your doctor knows all the medications you’re taking.

- I take prescription medications, including patches and creams.

- I take any over-the-counter medications, herbs, vitamins, minerals, or natural or home remedies.

- I have a pacemaker, automatic implantable cardioverter-defibrillator (AICD), or other heart device.

- I have sleep apnea.

- I have had a problem with anesthesia (medication to make you sleep during surgery) in the past.

- I am allergic to certain medication(s) or materials, including latex.

- I am not willing to receive a blood transfusion.

- I drink alcohol.

- I smoke.

- I use recreational drugs.
About Sleep Apnea

Sleep apnea is a common breathing disorder that causes a person to stop breathing for short periods while sleeping. The most common type is obstructive sleep apnea (OSA). With OSA, the airway becomes completely blocked during sleep. It can cause serious problems during and after surgery.

Please tell us if you have sleep apnea or if you think you might have it. If you use a breathing machine (such as a CPAP) for sleep apnea, bring it with you the day of your surgery.

Within 30 Days of Your Surgery

Presurgical Testing

Before your surgery, you will have an appointment for presurgical testing (PST). 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.

Use this area to write your PST appointment information:

Date: ______________    Time: ______________

Location:

☐ Pediatric Ambulatory Care Center (PACC)
  1275 York Avenue (between East 67th and East 68th Streets)
  Take the B elevator to the 9th floor

☐ Presurgical Testing (PST)
  160 East 53rd Street (at Third Avenue)
  Take the elevator to 7th 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 necessary 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 if you bring the following with you to your PST appointment:

☐ A list of all the medications you’re taking, including patches and creams

☐ Results of any tests done outside of MSK, such as a cardiac stress test, echocardiogram (echo), or carotid doppler study

☐ The name(s) and telephone number(s) of your doctor(s)
Parking at the PACC

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

1275 York Avenue  
(between East 67th and East 68th Streets)  
New York, NY 10065  
Take the B elevator to the 9th floor

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

To reach the garage, turn onto East 66th Street from York Avenue. The garage is located about a quarter of a block in from York Avenue, on the right-hand (north) side of the street. There is a pedestrian tunnel that you can walk through that connects the garage to the hospital.

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

Parking at PST

PST is located in the Rockefeller Outpatient Pavilion, also known as MSK 53rd Street.

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

There are several options for parking during your PST appointment. The Bristol Garage offers 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 56th Street (between First and Second Avenues)  
New York, NY 10022

There are additional parking garages located at East 53rd Street between Second and Third Avenues and East 54th 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

If you take vitamin E, stop taking it 10 days before your surgery, because it can cause bleeding. For more information, read Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), located in this section.

7 Days Before Your Surgery

Stop Taking Certain Medications

If you take aspirin, ask your surgeon if you should continue. Aspirin and medications that contain aspirin can cause bleeding. For more information, read Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), located in this section.

Stop Taking Herbal Remedies and Other Supplements

Stop taking herbal remedies and other supplements 7 days before your surgery. If you take a multivitamin, ask your doctor or nurse if you should continue. For more information, read Herbal Remedies and Cancer Treatment, located in this section.

2 Days Before Your Surgery

Stop taking nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Advil®, Motrin®) and naproxen (Aleve®), 2 days before your surgery. These medications can cause bleeding. For more information, read Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs), located in this section.
Day Before Your Surgery

A clerk from the Admitting Office will call you after 2:00 PM the day before your surgery. If you're scheduled for surgery on 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 the day of your surgery.

If you don’t receive a call by 4:00 PM, please call 212-639-7056.

Use this area to write in your surgery information:

Date: ______________    Time: ______________

Location:

☐ Pediatric Ambulatory Care Center (PACC)
  B elevator to 9th floor

☐ Presurgical Center (PSC)
  B elevator to 6th floor

Both locations are at 1275 York Avenue between East 67th and East 68th Streets.

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.

Instructions for Eating and Drinking Before Your 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 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.**

Write down your instructions here:

_________________________________________________________________________________________________
_________________________________________________________________________________________________
The Morning of Your Surgery

Take Your Medications as Instructed

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, or perfume.
- 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 valuables, 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.

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 it.
- This guide. Your healthcare team will use this guide to teach you how to care for yourself after your surgery.
Parking When You Arrive

For information about parking at Memorial Hospital, read the “Parking at the PACC” section above.

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 name may be having surgery on the same day.

Get Dressed for Surgery

When it’s time to change for surgery, you’ll get a hospital gown, robe, and non-skid socks to wear.

Meet With Your Nurse

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

Prepare for Surgery

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

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

Once you’re comfortable, your anesthesiologist will give you anesthesia through your IV line, MediPort®, or central line.

Once you’re asleep, your surgery will begin. You won’t feel any pain during your surgery.
Common Medications Containing Aspirin and Other Nonsteroidal Anti-inflammatory Drugs (NSAIDs)

This information will help you identify medications that contain aspirin and other nonsteroidal anti-inflammatory drugs (NSAIDs). It’s important to stop these medications before many cancer treatments.

Aspirin, other NSAIDs (such as ibuprofen), and vitamin E can increase your risk of bleeding during cancer treatment. These medications affect your platelets, which are blood cells that clot to prevent bleeding.

Read the section “Examples of Medications” to see if your medications contain aspirin, other NSAIDs, or vitamin E.

If you take aspirin, medications that contain aspirin, other NSAIDs, or vitamin E, tell your doctor or nurse. They will tell you if you need to stop taking these medications before your treatment. You will also find instructions in the information about the treatment you’re having.

Before Your Surgery

If you’re having surgery, follow the instructions below.

- Stop taking medications that contain vitamin E 10 days before your surgery, or as directed by your doctor.

- Stop taking medications that contain aspirin 7 days before your surgery, or as directed by your doctor. If you take aspirin because you’ve had a problem with your heart or you’ve had a stroke, be sure to talk with your doctor.
before you stop taking it.

- Stop taking NSAIDs 48 hours before your surgery, or as directed by your doctor.

**Before Your Radiology Procedure**

If you’re having a radiology procedure (including Interventional Radiology, Interventional Mammography, and General Radiology), follow the instructions below.

- Stop taking medications that contain vitamin E 10 days before your procedure, or as directed by your doctor.

- If your doctor tells you to stop taking aspirin, stop taking it 5 days before your procedure, or as directed by your doctor. If you take aspirin because you’ve had a problem with your heart or you’ve had a stroke, be sure to talk with your doctor before you stop taking it.
  - If you take low dose aspirin (81 mg), you may not need to stop it before your procedure. Your doctor will tell you if you should stop taking low dose aspirin.

- Stop taking NSAIDs 24 hours before your procedure, or as directed by your doctor.

**Before and During Your Chemotherapy**

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

**Examples of Medications**

Medications are often called by their brand name, which can make it hard to know their ingredients. To help you identify medications that contain aspirin, other NSAIDs, and vitamin E, please review the lists below.

These lists include the most common products, but there are others. Check with your healthcare provider if you aren’t sure. **Always be sure your doctor**
knows all of the medications you’re taking, both prescription and over-the-counter (not prescription).

<table>
<thead>
<tr>
<th>Common Medications that Contain Aspirin</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggrenox®</td>
</tr>
<tr>
<td>Alka Seltzer®</td>
</tr>
<tr>
<td>Anacin®</td>
</tr>
<tr>
<td>Arthritis Pain Formula</td>
</tr>
<tr>
<td>Arthritis Foundation Pain Reliever®</td>
</tr>
<tr>
<td>ASA Enseals®</td>
</tr>
<tr>
<td>ASA Suppositories®</td>
</tr>
<tr>
<td>Ascriptin® and Ascriptin A/D®</td>
</tr>
<tr>
<td>Aspergum®</td>
</tr>
<tr>
<td>Asprin®</td>
</tr>
<tr>
<td>Axotal®</td>
</tr>
<tr>
<td>Azdone®</td>
</tr>
<tr>
<td>Bayer® (most formulations)</td>
</tr>
</tbody>
</table>
Common Medications that are NSAIDs that Don’t Contain Aspirin

<table>
<thead>
<tr>
<th>Advil®</th>
<th>Clinoril®</th>
<th>Indocin®</th>
<th>Motrin®</th>
<th>Ponstel®</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advil Migraine®</td>
<td>Daypro®</td>
<td>Ketoprofen</td>
<td>Nabumetone</td>
<td>Relafen®</td>
</tr>
<tr>
<td>Aleve®</td>
<td>Diclofenac</td>
<td>Keterolac</td>
<td>Nalfon®</td>
<td>Saleto 200®</td>
</tr>
<tr>
<td>Anaprox DS®</td>
<td>Etodolac®</td>
<td>Lodine®</td>
<td>Naproxen</td>
<td>Sulindac</td>
</tr>
<tr>
<td>Ansaid®</td>
<td>Feldene®</td>
<td>Meclofenamate</td>
<td>Naprosyn®</td>
<td>Toradol®</td>
</tr>
<tr>
<td>Arthrotec®</td>
<td>Fenoprofen</td>
<td>Mefenamic Acid</td>
<td>Nuprin®</td>
<td>Voltaren®</td>
</tr>
<tr>
<td>Bayer® Select Pain Relief Formula Caplets</td>
<td>Flurbiprofen</td>
<td>Meloxicam</td>
<td>Orudis®</td>
<td></td>
</tr>
<tr>
<td>Celebrex®</td>
<td>Genpril®</td>
<td>Menadol®</td>
<td>Oxaprazin</td>
<td></td>
</tr>
<tr>
<td>Celecoxib</td>
<td>Ibuprofen</td>
<td>Midol®</td>
<td>PediaCare Fever®</td>
<td></td>
</tr>
<tr>
<td>Children’s Motrin®</td>
<td>Indomethacin</td>
<td>Mobic®</td>
<td>Piroxicam</td>
<td></td>
</tr>
</tbody>
</table>

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

About Acetaminophen

Acetaminophen (Tylenol®) is generally safe to take during your cancer treatment. It doesn’t affect platelets, so it won’t increase your chance of bleeding. However, talk with your doctor before taking acetaminophen if you’re getting chemotherapy.
Medications that Contain Acetaminophen

<table>
<thead>
<tr>
<th>Acetophen®</th>
<th>Di-Gesic®</th>
<th>Norco®</th>
<th>Tylenol®</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aceta® with Codeine</td>
<td>Esgic®</td>
<td>Panadol®</td>
<td>Tylenol® with Codeine No. 3</td>
</tr>
<tr>
<td>Acetaminophen with Codeine</td>
<td>Excedrin P.M.®</td>
<td>Percocet®</td>
<td>Vanquish®</td>
</tr>
<tr>
<td>Aspirin-Free Anacin®</td>
<td>Fiorcet®</td>
<td>Repan</td>
<td>Vicodin®</td>
</tr>
<tr>
<td>Arthritis Pain Formula® Aspirin-Free</td>
<td>Lorcet®</td>
<td>Roxicet®</td>
<td>Wygesic®</td>
</tr>
<tr>
<td>Darvocet-N 100®</td>
<td>Lortab®</td>
<td>Talacen®</td>
<td>Zydone®</td>
</tr>
<tr>
<td>Datril®</td>
<td>Naldegesic®</td>
<td>Tempra®</td>
<td></td>
</tr>
</tbody>
</table>

Read the labels on all your medications

Acetaminophen is safe when used as directed, but there’s a limit to how much you can take in 1 day. It’s possible to take too much acetaminophen without knowing because it’s in many different medications.

Make sure to always read and follow the label on the product you’re taking. Acetaminophen is a very common ingredient found in over-the-counter and prescription medications. It’s often an ingredient in pain relievers, fever reducers, sleep aids, and cough, cold, and allergy medications.

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

<table>
<thead>
<tr>
<th>Common Abbreviations for Acetaminophen</th>
</tr>
</thead>
<tbody>
<tr>
<td>APAP</td>
</tr>
<tr>
<td>Acetamin</td>
</tr>
</tbody>
</table>

Don’t take more than 1 medication that contains acetaminophen at a time without talking with a member of your healthcare team.
Herbal Remedies and Cancer Treatment

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

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

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

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

Common Herbal Supplements and Their Effects

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

Echinacea

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

**Garlic**

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

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

• Can increase your risk of bleeding.

**Ginseng**

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

**Turmeric**

• Can make chemotherapy less effective.

**St. John’s Wort**

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

**Valerian**

• Can increase the effects of anesthesia or sedation.

**Herbal formulas**

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

This information does not cover all herbal remedies or possible side effects. Speak with your healthcare provider if you have any questions or concerns.
For more information about herbs and botanicals, visit the Memorial Sloan Kettering (MSK) Integrative Medicine Service website at www.aboutherbs.com.
Information for Family and Friends for the Day of Surgery

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

Before the Surgery

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

Once the patient is checked in, they will go to the Presurgical Center (PSC) to be examined before surgery. Sometimes, they may need to wait before they are admitted to the PSC.

In the PSC, the nurse will do an exam. One person can come along to the PSC, but other visitors should wait in the waiting area. If the patient wants, other visitors may join them when the nurse has finished the exam.

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

Please remember the following:

- **Do not bring food or drinks to the waiting area.** Patients are not allowed to eat or drink before their surgery or procedure.

- Our patients are at high risk for infection. Please do not visit if you have any cold or flu symptoms (fever, sneezing, sniffles, or a cough). We may ask you...
to wear a mask if there are any concerns about your health.

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

**During the Surgery**

After the patient is taken to the OR, please wait in the main lobby on the 1st floor, where you will be updated by the nurse liaison. While you’re waiting, here are some things you can do:

- Food and drinks are available in the cafeteria and gift shop. You can also bring your own food and eat it in the cafeteria.
- The coat-check room is located at the bottom of the escalator on the ground level. It’s open Monday through Friday from 11:00 am to 4:00 pm.
- Wireless Internet access is available in most areas of the hospital. The wifi network name is MSK_guest. You can also use the computers in the room off the main lobby.
- Please be courteous and mindful of others while using your cell phone. Use the designated area to accept and make calls on your cell phone. It may be useful to bring your phone charger to the hospital.
- The Mary French Rockefeller All Faith Chapel is an interfaith chapel located in room M106 near the main lobby on the 1st floor. It’s open at all times for meditation and prayer.
- The Patient Recreation Pavilion is open daily from 9:00 am to 8:00 pm for patients and their visitors. Children are allowed in the pavilion as long as they are supervised by an adult. The pavilion has arts and crafts, a library, an outdoor terrace, and scheduled entertainment events. To get to the pavilion, take the M elevators to the 15th floor.

**Surgery updates**

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

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

To contact the nurse liaison:

• From inside the hospital, use a hospital courtesy phone. Dial 2000 and ask for beeper 9000. Please be patient, as this can take up to 2 minutes.
• Ask the information desk staff to contact the nurse liaison for you.

After the Surgery

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

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

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

When the patient is able to have visitors, a staff member will take you to the PACU for one brief visit. No one is allowed to stay overnight with the patient in the PACU, except for caregivers of pediatric patients.

Please follow these guidelines before your visit:

• Silence your cell phone.
• Apply an alcohol-based hand sanitizer (such as Purell®) before entering. There are hand sanitizer stations located throughout the hospital.
• Do not bring food or flowers into the PACU.

Please remember that only a limited number of visitors can go into the PACU. This is to keep the area quiet and allow the patients to rest and receive care.
While visiting in the PACU

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

The nurse will update you with the plan of care for the patient, such as whether the patient is staying overnight and when they will be moved to an inpatient room. If the patient is staying overnight, you may visit them again in the PACU. If the patient is going home the same day, a caregiver must take them home.

After your visit, a staff member will escort you back from the PACU.

We will give you a card with the PACU phone number. Please choose one person to call for updates.
The information in this section will tell you what to expect after your surgery, both during your hospital stay and after you leave the hospital. You will learn how to safely recover from your surgery. Write down any questions you have and be sure to ask your doctor or nurse.
What to Expect

When you wake up after your surgery, you will be in the Post Anesthesia Recovery Unit (PACU). As soon as you’re settled in the PACU, a nurse will bring your family members in to be with you.

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.

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.

Can family and friends visit me in the hospital?
Your parents, other family members, and friends are welcome to visit you during your hospital stay as long as they’re in good health. No one with any signs of sickness, such as fever, cough, congestion, sore throat, or rash, is allowed to visit.

Visiting hours may be different depending on where you will be staying. Ask your nurse about the visitation policy in the area you’re staying. Visitors on the Pediatric Unit are limited to parents and 2 other visitors per day.

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 wrestling) 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® 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: www.medicalert.com

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.**

**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 AM to 5:00 PM at 212-639-7056.

After 5:00 PM, during the weekend, and on holidays, please call 212-639-2000 and ask for the pediatric neurosurgery fellow on call.
This section contains a list of support services available at MSK, as well as the resources that were referred to throughout this guide. These resources will help you prepare for your surgery and recover safely. Write down any questions you have and be sure to ask your doctor or nurse.
**MSK Resources**

**Anesthesia**
212-639-6840
Call with any questions about anesthesia.

**Blood Donor Room**
212-639-7643
Call for more information if you're interested in donating blood or platelets.

**Bobst International Center**
888-675-7722
MSK welcomes patients from around the world. If you're an international patient, call for help arranging your care.

**Chaplaincy Service**
212-639-5982
At MSK, our chaplains are available to listen, help support family members, pray, contact community clergy or faith groups, or simply be a comforting companion and a spiritual presence. Anyone can request spiritual support, regardless of formal religious affiliation. The interfaith chapel is located near the main lobby of Memorial Hospital, and is open 24 hours a day. If you have an emergency, please call the hospital operator and ask for the chaplain on call.

**Counseling Center**
646-888-0200
Many people find that counseling helps them. We provide counseling for individuals, couples, families, and groups, as well as medications to help if you feel anxious or depressed.

**Integrative Medicine Service**
646-888-0800
Integrative Medicine Service offers patients many services to complement traditional medical care, including music therapy, mind/body therapies, dance and movement therapy, yoga, and touch therapy.

**Patient-to-Patient Support Program**
212-639-5007
You may find it comforting to speak with a cancer survivor or caregiver who has been through a similar treatment. Through our Patient-to-Patient Support Program, we are able to offer you a chance to speak with former patients and caregivers.

**Patient Billing**
646-227-3378
Call Patient Billing with any questions regarding preauthorization with your insurance company. This is also called preapproval.

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

**Perioperative Nurse Liaison**
212-639-5935
Call if you have any questions about MSK releasing any information while you're having surgery.
Private Duty Nursing Office
212-639-6892
You may request private nurses or companions. Call for more information.

Resources for Life After Cancer (RLAC) Program
646-888-8106
At MSK, care doesn’t end after active treatment. The RLAC Program is for patients and their families who have finished treatment. This program has many services, including seminars, workshops, support groups, counseling on life after treatment, and help with insurance and employment issues.

Social Work
212-639-7020
Social workers help patients, family, and friends deal with issues that are common for cancer patients. They provide individual counseling and support groups throughout the course of treatment, and can help you communicate with children and other family members. Our social workers can also refer you to community agencies and programs, as well as financial resources if you’re eligible.

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

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

Access-A-Ride
www.mta.info/nyct/paratran/guide.htm
877-337-2017
In New York City, the MTA offers a shared ride, door-to-door service for people with disabilities who are unable to take the public bus or subway.

Air Charity Network
www.aircharitynetwork.org
877-621-7177
Provides travel to treatment centers.

American Cancer Society (ACS)
www.cancer.org
800-ACS-2345 (800-227-2345)
Offers a variety of information and services, including Hope Lodge, a free place for patients and caregivers to stay during cancer treatment.

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

Cancer Support Community
www.cancersupportcommunity.org
Provides support and education to people affected by cancer.

Caregiver Action Network
www.caregiveraction.org
800-896-3650
Provides education and support for those who care for loved ones with a chronic illness or disability.

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

Gilda’s Club
www.gildasclubnyc.org
212-647-9700
A place where men, women, and children living with cancer find social and emotional support through networking, workshops, lectures, and social activities.

Healthwell Foundation
www.healthwellfoundation.org
800-675-8416
Provides financial assistance to cover copayments, health care premiums, and deductibles for certain medications and therapies.
Joe's House  
www.joeshouse.org 
877-563-7468 
Provides a list of places to stay near treatment centers for people with cancer and their families.

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

LIVESTRONG Fertility  
www.livestrong.org/we-can-help/fertility-services  
855-744-7777 
Provides reproductive information and support to cancer patients and survivors whose medical treatments have risks associated with infertility.

National Cancer Institute  
www.cancer.gov 
800-4-CANCER (800-422-6237)

National Cancer Legal Services Network  
www.nclsn.org 
Free cancer legal advocacy program.

National LGBT Cancer Network  
www.cancer-network.org 
Provides education, training, and advocacy for LGBT cancer survivors and those at risk.

Needy Meds  
www.needymeds.com 
Lists Patient Assistance Programs for brand and generic name medications.

NYRx  
www.nyrxplan.com 
Provides prescription benefits to eligible employees and retirees of public sector employers in New York State.

Partnership for Prescription Assistance  
www.pparx.org 
888-477-2669 
Helps qualifying patients without prescription drug coverage get free or low-cost medications.

Patient Access Network Foundation  
www.panfoundation.org 
866-316-7263 
Provides assistance with copayments for patients with insurance.
Patient Advocate Foundation
www.patientadvocate.org
800-532-5274
Provides access to care, financial assistance, insurance assistance, job retention assistance, and access to the national underinsured resource directory.

RxHope
www.rxhope.com
877-267-0517
Provides assistance to help people obtain medications that they have trouble affording.