Your Epilepsy Surgery

A Guide For Kids and Teens





This book is meant to be a basic guide for Epilepsy surgery. If you have additional questions, please contact Lauren Suttle, Program Manager for the Children's Epilepsy Center. Office number is (214) 456-0614 and email is epilepsyprogram@childrens.com. Additionally, there is a Parents' Guide to Pediatric Epilepsy Surgery located on the Epilepsy page on childrens.com.

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Why Do You Need Epilepsy Surgery?

For some kids and teens that have epilepsy, medicine works well to stop their seizures. But sometimes the medicine does not work well enough. When that happens, you doctor may think you need to have surgery to stop your seizures. Your doctor has come to this decision after having you do several tests and after taking with you and your parents.

This booklet will help you know what to expect. But it may not answer every question you have. If there is something you do not understand, please ask your nurse or doctor to explain.

TESTS DONE BEFORE SURGERY

Before you have surgery, your doctor may need some more medical information. In that case, your doctor will ask you to get some medical tests done. Here are the tests your doctor might ask for:

- Video EEG is done in the Epilepsy Monitoring Unit (EMU) to monitor you for seizures. With the video EEG, electrodes, or small sensors, are placed on your head and covered with a wrap. You would need to stay in the hospital for a few nights
- You may meet with a psychologist who will find out about the way you think and act. This
 information can help your doctor.
- You may have pictures taken of your brain. If you would like to see those pictures, feel free to ask your doctor.





Common Questions About Epilepsy Surgery

Kids and teens often have questions before surgery. Your doctors and nurses will talk to you and answer your questions. Child life specialists are also available to talk with you about any questions you may have before or after your surgery. There are no silly questions!

This box gives answers to questions that other kids have asked before having surgery for their seizures:

Will the doctor shave my head?

The doctor will only cut the hair around the surgery spot. The rest of your hair will not be cut.

Will I be able to walk after surgery?

Yes! And it is very important for you to get up and walk after surgery.

Will surgery hurt?

You will be asleep during surgery so you will not feel anything. After surgery, if you are sore, you can ask your nurse for pain medicine.



Where Will You Be Having Surgery?

This is where you will be having surgery:



You will stay here after surgery while your body heals. The doctors will make a plan for how long you will need to stay. You can bring stuffed animals, blankets, games, movies from home to make your stay more comfortable.

On the day of surgery, you will check in at the registration desk. They will put an ID bracelet on your arm. Then you walk to the Surgery Center on the 2nd floor. After you check in at the Surgery Center desk, you will stay in the waiting room until they call your name. Then someone will take you to the pre-operative area, which is also called pre-op. This is where you will meet with your doctors before going to the operating room.





What Will Happen Before Surgery?

GETTING YOUR VITALS CHECKED

When you get to pre-op, they will see how tall you are and how much you weigh. They will also take your temperature and your blood pressure. These four things are called "getting your vitals checked." It will not hurt and there will not be any pokes this time.





THE PRE-OP ROOM

Next you will go to your pre-op room. It is a private room and your family can stay with you there. You will change into your hospital pajamas and relax in bed while you wait. The TV in the room has cable channels and movies.

A nurse will come in and talk with you and your family. Then the doctor who is doing the surgery will come in and talk to you. That doctor is called the *surgeon*. You can ask the doctor or nurse any questions. You will also meet with the doctor that will be giving you the medicine to go to sleep. That doctor is called the *anesthesiologist*.

Right before it is time to leave your pre-op room, you will be given medicine that helps you relax. We call this medicine "silly juice" because it makes kids a little goofy. This medicine does not hurt.







THE OPERATING ROOM

When it is time to go to the Operating Room, you will say goodbye to your family. The nurses will roll you in your bed down the hallway. Yes, your bed has wheels! You can take your favorite blanket or stuffed animal if you brought one. Your parents will wait for you in the waiting room.

You will be asleep during surgery. When you get to the operating room, the anesthesiologist will give you medicine that will make you sleep during the surgery. While you are asleep, the anesthesiologist will be watching your heart rate, breathing, and blood pressure to make sure your body stays asleep.





What Will Happen During And After Surgery?

FIRST SURGERY

Some kids will have their surgery done in two parts. If this is the plan for you, your doctor will talk with you and your family. Your doctor will prepare you for this part of the surgery.

MAIN SURGERY

Most kids need only one surgery. After surgery, you will take up in an Intensive Care Unit (or ICU) room after surgery. Your family will be able to meet you in your room. You will have an IV, which is a very tiny straw in your hand or your arm, when you wake up. This is how the nurse can give your body medicine or water. You will have nurses checking on you often to make sure you are not in pain. If you are hurting, please tell your nurse so you can get medicine.

You may not feel like eating much after surgery. That is ok! There will be popsicles, water, and clear soda available. When you feel like eating more, you can order food.



When it is time to leave the ICU, you will go back to the 10th floor. You will not be in the EMU this time. You will be on the side where other kids are recovering from surgery like you. There is a playroom on this floor and other activities around the hospital. You can ask your nurse to have a child life specialist come talk with you. They can bring fun things for you to do in your room.





What Will Happen After You Leave The Hospital?

Most kids go home from the hospital 3-4 days after surgery. Some kids need a longer time to heal and may go to a different hospital to work on getting stronger. If your doctors think that you might need more time after surgery to heal they will talk with you and your family before surgery.

Going back to school:

Most kids can go back to school about two weeks after surgery. Your doctor may ask you to stay home and rest longer if you need more time.

It's important for YOU to decide what you want to tell your classmates about your surgery. You have been through something very challenging. You should be proud of what you have done!

Clinic visits:

Your doctor will have you come visit them in the clinic to see how you are feeling now that you have had surgery.

Taking medicine:

You will continue to take medicine to control your seizures after the surgery. Most kids will take their medicine for at least 2 years to keep them protected from seizures. If your doctor feels it is safe to stop taking medicine after that time, he or she will talk with you and your family during your clinic visit.









Note Page
