

A Guide for Parents

EPILEPSY SURGERY

FREQUENTLY ASKED QUESTIONS WITH NEUROSURGEON **BENJAMIN KENNEDY, MD**



If your child has been struggling with epilepsy or a condition that causes seizures, you probably have a lot of questions about the condition and treatment options. At the Neuroscience Center at Children's Hospital of Philadelphia (CHOP), we want to make sure every family has the information, support and resources they need to make the best decisions about their child's care.



The Neuroscience Center at CHOP offers the most advanced techniques and highly innovative procedures to treat epilepsy. We are one of the highest-volume epilepsy surgery centers in the country.

Here, attending neurosurgeon <u>Benjamin Kennedy, MD</u>, Director of Epilepsy and Functional Neurosurgery at CHOP, weighs in on common questions families have. We hope this information helps you make the best care choices.

What is epilepsy?

Epilepsy is a condition that affects the brain and makes a child more likely to have seizures. When a child has two or more unprovoked seizures on different days, they are diagnosed with epilepsy. It is one of the most common brain disorders.

Epilepsy affects each child differently, and seizures can look different from one child to another. For some children, a seizure might be so mild they do not even know it is happening and there are no obvious signs. For others, seizures can cause convulsions (shaking), uncontrolled movements, or loss of consciousness.



Adrian, age 7, CHOP epilepsy patient

What is drug-resistant epilepsy?

Anti-seizure medications are usually the first treatment option to help control seizures. Drug-resistant epilepsy means that a child continues to have seizures even after trying two different medications that were "well tolerated" for their specific epilepsy type, meaning the child could take the medication without experiencing significant side effects at therapeutic doses. If two medications do not work, it is usually a sign that more medicine will not be the solution to the child's epilepsy. Once a child is diagnosed with drug-resistant epilepsy, we often recommend considering surgery.

About one-third of children with epilepsy develop drug-resistant epilepsy.

The more severe a child's epilepsy, the more likely it is that medications won't control the seizures.

What are the potential long-term effects of leaving drug-resistant epilepsy untreated or continuing ineffective treatment?

If drug-resistant epilepsy is not treated or managed well, it can have a serious impact on a child's development. In addition to delays in development, seizures can affect learning and thinking, cause sleep problems, and lead to emotional issues like depression and anxiety. Seizures also increase the risk of accidents, such as falls, injuries and even drowning, and in severe cases, they can be life-threatening. On top of all that, seizures can disrupt daily life and lead to postictal fatigue, which is the extreme tiredness children often feel after a seizure.



Dr. Kennedy performing a procedure.

What is epilepsy surgery?

Epilepsy surgery is when a brain surgeon (neurosurgeon) performs a procedure to do one of the following things:

- remove or interrupt the part of the brain causing seizures
- stop the seizures from spreading
- change how the brain circuits work

The main goal of the surgery is to reduce or stop the seizures.

It may seem counterintuitive, but sometimes removing or disconnecting part of the brain can actually improve brain function, especially when it comes to epilepsy.

This is because continuing to have seizures can damage brain function over time. For children with drug-resistant epilepsy, surgery can be a key tool in reducing those harms. An electroencephalogram (EEG) is a study that helps us determine the best treatment option.

What are the different types of epilepsy surgery techniques?

At CHOP's Neuroscience Center, the surgical procedures we offer for epilepsy fall under the following four categories:

1. RESECTION OR ABLATION

These are surgeries where the goal is to remove or disconnect the part of the brain that causes seizures (called the seizure onset zone) so a child will not have seizures anymore.

Resection generally involves cutting and removing tissue.

Types of resection surgeries include:

- **Temporal lobectomy:** A procedure where part of the temporal lobe is removed if seizures are found to be starting in that area of the brain.
- Selective amygdalohippocampectomy: A procedure where part of the amygdala and hippocampus are removed if seizures are found to be starting in that area of the brain.

Ablation is a surgical technique that creates heat with a small laser or ultrasound to destroy targeted brain tissue responsible for causing seizures, without removing it entirely. This is typically done when the seizure onset zone is deep within the brain or in locations that are difficult to get to. Ablation does not use radiation and is done through a very small incision or no incision at all. Two common ablation techniques include:

- Laser interstitial thermal therapy (LITT): A minimally invasive procedure where a thin laser is inserted into the brain through a small tube, using MRI imaging to guide it. The laser heats up and destroys small areas of tissue, such as hypothalamic hamartomas, that are causing seizures.
- High-intensity focused ultrasound (HIFU): A noninvasive procedure that uses focused sound waves to create heat and destroy specific areas of brain tissue. It is sometimes used for conditions like hypothalamic hamartomas, where the goal is to target and eliminate very small, deep areas of abnormal tissue causing seizures. The procedure is guided by MRI, which helps us precisely focus on the right tissue.

2. HEMISPHEROTOMY

This is a surgery that disconnects the side (hemisphere) of the brain causing seizures from the rest of the brain and brainstem through a small incision. This procedure is often used for conditions like hemimegalencephaly, hemispheric malformations, stroke, Sturge-Weber syndrome, and Rasmussen's encephalitis. The goal is to stop the seizures completely by cutting off the connections between the affected side of the brain and the rest of the brain.

3. CORPUS CALLOSOTOMY

This procedure is used to treat tonic or atonic drop attacks, which are sudden, severe seizures that cause a child to lose muscle strength and fall. This surgery involves disconnecting the corpus callosum, the primary bundle of nerve fibers that connect the two hemispheres of the brain. It can be performed using microsurgery (a type of surgery that uses very small, specialized tools and a microscope) or laser ablation.

The procedure does not necessarily eliminate all seizures, but it can significantly lessen the number of drop attacks, improve a child's quality of life and reduce the risk of injury from falls.

4. DEVICES

There are three types of advanced surgical devices that can be implanted in a child's body to monitor brain activity and send signals to the brain to help stop seizures before they occur.

Types of devices include:

- Robotic-assisted responsive neurostimulation (RNS): Used for children with focal seizures coming from areas of the brain that control critical functions such as language, motor skills or sensory processing.
- **Deep brain stimulation (DBS)**: Used to treat focal, multifocal or generalized epilepsy, in which seizures originate from more than one area of the brain.
- Vagus nerve stimulation (VNS): A device similar to a pacemaker that is implanted under the skin in the chest. It sends small electrical pulses to the brain through the vagus nerve in the neck. This treatment is especially helpful for children whose seizures do not come from just one area of the brain.



CHOP pediatric neurologist, Sudha Kilaru Kessler, MD, MSCE, performing a brain scan.

Expert Care, Innovative Techniques, Trusted Outcomes

Our highly skilled team uses their experience and expertise to customize these complex surgical procedures to be as minimally invasive as possible, ensuring the **best possible outcomes**. Our goal is to use the least invasive approach possible to stop seizures from interfering with a child's quality of life. We have a proven track record of successfully disconnecting the seizure onset zone while minimizing the risk of complications.

For example, we can perform corpus callosotomy and hemispherotomy using burr holes through very small incisions. This unique technique utilizes intrinsic brain landmarks to ensure complete disconnection. We are also able to perform innovative minimally invasive techniques to access the brain through small incisions in the eyelid (transorbital) or by inserting surgical instruments through the nose (transnasal).

Our ability to make these kinds of modifications provides many benefits for patients. These include less damage to brain tissue, minimal impact on brain function, less pain after surgery, shorter recovery times, a shorter hospital stay, a lower risk of infection and better overall outcomes.

Our team is actively involved in clinical research trials to improve epilepsy surgery procedures. This helps us create better outcomes for patients and develop personalized treatment plans.

How do you determine which epilepsy surgery technique is right for a child?

At our Neuroscience Center, families can expect a balanced opinion regarding treatment. Children go through a detailed evaluation to see if they are a good candidate for epilepsy surgery. This evaluation involves a team of specialists, including experts in epilepsy, electroencephalogram (EEG), brain imaging, psychology, neurogenetics, neurosurgery and anesthesia. We include ongoing input from the patient and their family throughout the process.

The initial evaluation for epilepsy surgery typically includes:

- Detailed history of the nature of the seizures
- Brain magnetic resonance imaging (MRI) scan
- Brain magnetoencephalogram (MEG) scan
- Video electroencephalogram (EEG) recording of some seizures in our specialized Epilepsy Monitoring Unit (an inpatient unit)
- Robot-assisted stereoelectroencephalography (sEEG), a minimally invasive diagnostic surgical procedure in which electrodes are implanted into the brain to pinpoint the precise location of seizure activity

Additional tests may also include positron emission tomography (PET) scan, functional MRI (fMRI), transcranial magnetic stimulation (TMS), and the WADA test. After a child's evaluation is complete, our team meets with families to discuss the surgical options available and the risks and benefits they can expect with each. We will also help provide families with <u>ideas for how to talk with your</u> <u>child</u> about epilepsy surgery. We collaborate with families to determine which option will deliver the best chance of improving the child's symptoms and reducing seizures. We then customize the surgical technique to each child's unique circumstances and anatomy.



Our highly skilled team uses their experience and expertise to customize complex surgical procedures to be as minimally invasive as possible.

When seizures are not controlled by medication, surgery is often the most effective way to improve both brain development and overall quality of life. Rather than thinking of surgery as a 'last resort,' we encourage families to view it as one of the best options for helping their child reach their full potential.

-Dr. Benjamin Kennedy



Dr. Kennedy and his team include ongoing input from patients and their families throughout their care journey.

What advice would you give to parents who are hesitant about surgery for their child?

Deciding whether to pursue epilepsy surgery can be a challenging and emotional decision for families. As parents, you want what is best for your child, and so do we. We all share the same goal: to help them grow and develop to their full potential.

Surgery is not something we take lightly, and we understand the fear that comes with it. However, when seizures are not controlled by medication, surgery is often the most effective way to improve both brain development and overall quality of life. We have a strong track record of successful and safe surgeries, and many children see great results.

Rather than thinking of surgery as a "last resort," we encourage families to view it as one of the best options for helping their child reach their full potential. Research shows that children who undergo surgery earlier — before they have had seizures for too long — tend to have better developmental outcomes and fewer seizures over their lifetime. In many cases, this leads to a better quality of life, much sooner, for both the child and the family.

How can I get a second opinion for my child with epilepsy?

Pediatric neurologists and neurosurgeons at CHOP's Neuroscience Center are available to consult with you or your physician. We work with families and clinicians from all over the country and around the world to establish and confirm diagnoses, provide education, and make treatment recommendations so you can make informed decisions.

Our Epilepsy Surgery Nurse Navigator offers personalized support for families considering epilepsy surgery for their child. Acting as a central point of contact, the nurse navigator helps to coordinate all aspects of care. This includes scheduling appointments, arranging imaging, and ensuring seamless communication between all medical professionals involved.

Our goal is to provide a smooth, streamlined experience for families throughout the entire process.

For more information, visit **chop.edu/second-opinions**.

To schedule an appointment or speak to a member of the CHOP Neuroscience Center team, call 215-590-2780.





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