

Your Child's Seizures: Questions, Options, and Next Steps

A guide for parents and caregivers of children with drug-resistant seizures

When seizures continue, it can be exhausting to keep trying new medications while wondering what else may be possible. You deserve clear answers, an individualized safety plan, and access to every appropriate treatment option – including surgery.

To help #StopSUDEP, we encourage people to ask for a surgical evaluation.

About SUDEP

The seizure type most closely linked to SUDEP (Sudden Unexplained Death in Epilepsy) is the tonic-clonic seizure. This is the seizure where the whole body stiffens and jerks. The risk of SUDEP goes up when these seizures happen often, and especially when they happen at night while a child is asleep. Children who have three or more of these seizures a year face about a 15 times higher risk of SUDEP than children who don't. Nighttime tonic-clonic seizures raise that risk on their own, and the risk climbs even further if a child doesn't have someone nearby overnight (sharing a room, using a baby monitor, or another way of being checked on).

These two things – *tonic-clonic seizures*, and *seizures at night* – are the risk factors doctors are most confident about.

Kids whose epilepsy doesn't respond to medication (drug-resistant epilepsy) are at higher SUDEP risk than kids with epilepsy overall, simply because their seizures tend to be more frequent and harder to control. About 1 in 4 children with epilepsy fall into this drug-resistant group. Studies estimate that somewhere around 1 to 1.5 out of every 1,000 of these children will experience SUDEP each year, and among children followed at specialized epilepsy surgery centers, where seizures tend to be the most severe, that number is higher: roughly 6 to 9 out of every 1,000 children per year. For comparison, the Epilepsy Foundation puts the overall risk for all children with epilepsy at about 1 in 4,500 per year. This means that drug resistance and frequent tonic-clonic seizures meaningfully raise a child's individual risk above that general number.

The short version: the fewer tonic-clonic seizures a child has, and the more controlled their epilepsy is, the lower their SUDEP risk. That's part of why getting to seizure freedom or seizure reduction, including through a surgical evaluation, matters so much.

A referral for an epilepsy-surgery evaluation does not mean your child will have surgery. It means a specialized team can take a closer look at your child's seizures, testing, development, and treatment history to help your family understand the full range of options available.

You are not “giving up” on medication by asking for a surgical evaluation. You are asking to understand every appropriate treatment option for your child.

This toolkit is educational and does not replace medical advice from your child's treating team.

Start with These Questions

Bring this list to your child's next neurology appointment. Circle or highlight the questions that matter most to your family.

About Seizures and Diagnosis

- What type or types of seizures is my child having?
- ***Does my child have generalized tonic-clonic seizures, seizures during sleep, or other features that may affect SUDEP risk?***
- How confident are we in my child's diagnosis and seizure classification?
- Could my child's seizure pattern suggest a specific epilepsy syndrome or a structural cause in the brain?
- Could prolonged EEG monitoring, a new MRI, genetic testing, or another test provide clearer answers?
- Are some events that look like seizures possibly something else?
- How are seizures affecting my child's development, learning, behavior, sleep, mental health, and daily life?

About Treatment Response

- Which antiseizure medications has my child tried, at what doses, and for how long?
- Were those medication trials considered appropriate and adequate for my child's seizure type?
- Has my child achieved sustained seizure freedom on any treatment?
- ***Does my child meet the definition of drug-resistant epilepsy?***
- What are the realistic benefits, risks, and side effects of trying another medication compared with a comprehensive epilepsy-center evaluation?
- Are medication side effects affecting my child's quality of life, development, behavior, appetite, sleep, or ability to learn?
- ***Are there dietary therapy, neurostimulation, surgery, clinical trials, or other treatments options we should discuss?***

About SUDEP and Safety

- ***What is my child's individualized risk of SUDEP?***
- ***Are my child's seizure type, seizure frequency, or nighttime seizures factors that may increase risk?***
- What is our plan for reducing seizures, especially convulsive seizures?
- What should we do during and after a seizure?
- When should we call 911 or seek emergency care?
- Should our family discuss nighttime supervision, monitoring, or seizure-detection tools? What are their benefits and limitations?
- Can we update our seizure action plan for home, school, child care, and respite caregivers?

Ongoing generalized tonic-clonic seizures and higher seizure frequency are important SUDEP risk factors. Your child's clinician can help your family understand what that means for your child specifically.

Source: [Medscape — SUDEP risk factors](#)

About Evaluation and Referral

- ***Has my child tried two appropriate antiseizure medications without sustained seizure freedom?***
- Is it time to refer my child to a comprehensive pediatric epilepsy center for an epilepsy-surgery evaluation?
- What information can an evaluation give us even if surgery is not recommended?
- Which level 4 pediatric epilepsy center would you recommend, and why?
- Does the center have a multidisciplinary pediatric team with substantial epilepsy-surgery experience?
- Can you send the referral today and help us obtain the records the center will need?
- What testing may be part of the evaluation?
- What support is available for travel, insurance authorization, lodging, school absences, and family navigation?

Expert consensus recommends offering a surgical evaluation as soon as drug resistance is identified; the recommendation applies regardless of seizure type, epilepsy type, duration of epilepsy, or comorbidities.

Source: [PubMed — pediatric epilepsy surgery consensus](#)

How to Ask for a Referral

A Simple Script

Say this:

"My child has continued to have seizures despite trying two appropriate antiseizure medications. I would like a referral to a comprehensive pediatric epilepsy center for an epilepsy-surgery evaluation so that we can understand all appropriate treatment options. Can we begin that referral today?"

If You Are Unsure Whether Two Medications "Count"

Say this:

"Can we review my child's medication history together? I want to understand whether their medication trials were considered appropriate and whether my child meets the definition of drug-resistant epilepsy."

If Your Child's Neurologist Suggests Waiting

Say this:

"I understand that you may want to try another treatment. I would still like a referral now for a comprehensive evaluation. My understanding is that an evaluation is not a decision to have surgery. It is a way to get specialized information and review all options. Can you help us make that referral?"

If You Are Told Your Child Is "Not a Surgery Candidate"

Say this:

"I understand that surgery may not be the right treatment for every child. I would still like my child evaluated at a comprehensive pediatric epilepsy center so a multidisciplinary team can review their seizures, testing, and options. What is the process for requesting that referral?"

If Your Child's Neurologist Will Not Refer

Say this:

"Please document in my child's medical record that I requested a referral for a comprehensive epilepsy-surgery evaluation and the reason it was not made. I would also like a copy of my child's records so we can seek a second opinion."

Then Consider Asking

- Your child's primary care clinician to refer directly.
- Your insurance plan which pediatric epilepsy centers are in network and whether out-of-network authorization is possible.
- A comprehensive epilepsy center whether its intake team accepts self-referrals or can advise your family on the referral process.

Families may reach a surgical evaluation through more than one route, and parent advocacy can be especially important when timely referral has not occurred.

Source: PMC — parent advocacy and referral pathways

What an Evaluation Means

An Evaluation Is Not Surgery

An epilepsy-surgery evaluation is a detailed assessment by a specialized team. It may help your family:

- Confirm the diagnosis and seizure type.
- Identify where seizures begin, if possible.
- Review medication, dietary, device-based, surgical, and other treatment options.
- Understand potential benefits, limitations, and risks of each option.
- Assess how seizures and treatment affect development, learning, language, memory, movement, behavior, and quality of life.
- Build a more complete plan even if surgery is not recommended.

Testing May Include

Every child's evaluation is individualized. Depending on your child's needs, testing may include:

- Detailed medical and seizure history.
- Review of medication trials and treatment response.
- Long-term video EEG monitoring.
- High-quality epilepsy-protocol MRI.
- Neuropsychological or developmental assessment.
- PET, SPECT, MEG, functional MRI, genetic testing, or other specialized studies.
- Discussion by a multidisciplinary epilepsy team.

MRI and EEG are common early components of pediatric surgical evaluation, but no single test decides whether a treatment is appropriate.

Source: *Children's Health — Surgical Epilepsy Program*

Possible Outcomes

- A recommendation for surgery intended to stop or substantially reduce seizures.
- A recommendation for a less invasive treatment, such as laser ablation or neuromodulation, when appropriate.
- A medication, dietary, or other non-surgical treatment plan.
- More testing before a decision is made.
- A decision that surgery is not recommended at this time.

The goal is not to “qualify” for surgery. The goal is to make sure your child's care plan reflects the best available information and all appropriate options.

Appointment Preparation Checklist

BEFORE THE APPOINTMENT

- ☐ Keep a current seizure diary, including date, time, duration, seizure type, triggers, recovery, and rescue medication use.
- ☐ Record or bring video of seizures when it is safe and appropriate to do so.
- ☐ List every antiseizure medication your child has tried, including dose, dates, benefit, side effects, and why it was stopped.
- ☐ Gather prior EEG reports, MRI images and reports, genetic test results, hospital discharge summaries, and clinic notes.
- ☐ Bring your child's seizure action plan and emergency medication plan.
- ☐ Write down your top three goals, concerns, and questions.
- ☐ Bring a support person, if possible, or ask whether you may record the discussion for personal use.
- ☐ Request an interpreter or accessibility accommodations in advance, if needed.

AT THE APPOINTMENT

- ☐ Say clearly that you want to discuss drug-resistant epilepsy and referral for a comprehensive epilepsy-surgery evaluation.
- ☐ Ask your clinician to explain unfamiliar terms in plain language.
- ☐ Ask for a written plan before leaving.
- ☐ Confirm who will send the referral, where it is being sent, and when you should expect contact.
- ☐ Ask how to obtain records and imaging files for the referral center.
- ☐ Request the referral order and visit summary through the patient portal.

AFTER THE APPOINTMENT

- ☐ Follow up within one week if you have not received referral instructions.
- ☐ Confirm the receiving epilepsy center has your records and imaging.
- ☐ Ask about insurance authorization, wait times, travel, lodging, and telehealth options.
- ☐ Continue the current treatment and safety plan unless your child's treating clinician tells you otherwise.
- ☐ Contact the epilepsy team promptly if seizures change, increase, last longer than usual, or rescue medication is needed.

One-Page Referral Request

Families can copy, paste, print, or send this message through a patient portal.

Subject: Request for comprehensive pediatric epilepsy–surgery evaluation referral

Dear Dr. [Name],

I am requesting a referral for my child, [Child's Name], to a comprehensive pediatric epilepsy center for an epilepsy–surgery evaluation.

[Child's Name] continues to have seizures despite trials of [number] antiseizure medications: [medication names, if known]. We would like a specialized team to review their diagnosis, seizure history, testing, treatment options, and whether any surgical or non–surgical advanced therapies may be appropriate.

We understand that requesting an evaluation does not mean that surgery will be recommended or chosen. We want to make sure we understand every appropriate option for seizure control, safety, development, and quality of life.

Please let us know:

- Which comprehensive pediatric epilepsy center you recommend.
- Whether you can place the referral today.
- What records, EEG reports, MRI images, and medication history will be sent.
- Who we should contact if we do not hear from the center within [7–10] business days.

Thank you,

[Parent/Caregiver Name]

[Phone number]

[Patient date of birth / medical record number, if needed]

Sources:

On tonic–clonic seizures and nighttime risk:

1. **AAN Practice Guideline: Sudden Unexpected Death in Epilepsy** (American Academy of Neurology / *Neurology*): <https://www.aan.com/Guidelines/home/GetGuidelineContent/852>
2. **Sveinsson et al., "Clinical risk factors in SUDEP"** (*Neurology*, 2020): <https://www.neurology.org/doi/10.1212/WNL.00000000000008741>
3. **"Sudden Unexpected Death in Epilepsy (SUDEP): A Review of Risk Factors and Possible Interventions in Children"** (Pediatric Pharmacy Association, via PMC, 2021): <https://pmc.ncbi.nlm.nih.gov/articles/PMC8372858/>

On drug-resistant epilepsy statistics:

4. **"Cardiac dysfunctions in children with drug-resistant epilepsy"** (*Frontiers in Neurology*, 2024): <https://www.frontiersin.org/journals/neurology/articles/10.3389/fneur.2024.1381293/full>
5. **"Association of hyperventilation-induced heart rate variability and SUDEP in drug-resistant epilepsy"** (PMC, 2024): <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC11531865/>
6. **Epilepsy Foundation New England — "Sudden Unexpected Death in Epilepsy"**: <https://epilepsynewengland.org/knowledge-center/sudden-unexpected-death-in-epilepsy>