

Comprehensive Epilepsy Center

A multidisciplinary
approach to
epilepsy care for
children with
seizures and
seizure disorders



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Improving seizure care for children in North Texas is a top priority for the team at the Comprehensive Epilepsy Center at Children's Medical Center Dallas.

With this goal in mind, the center's pediatric epilepsy specialists have developed an online CME module and companion toolkit to assist primary care providers in management of new onset seizures, counseling patient and families on seizure safety, and coordination of care with an epilepsy center. We recognize the central role primary care providers play in the initial evaluation and treatment of seizures and as partners in the care of children with more complex epilepsy.

There are three sections to the CME:

Care After the First Unprovoked Seizure	Seizure Safety Counseling for patient & family	Partnering with the Epilepsy Center at Children's Medical Center
Presented by: Deepa Sirsi, M.D.	Presented by: Rana Said, M.D.	Presented by: Susan Arnold, M.D.
		
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We hope that the educational materials provided in this toolkit will assist you in managing children with seizures in your practice, and in coordinating care with epilepsy providers. We see primary care providers as essential partners in our efforts to reduce seizure-related injuries and achieve seizure freedom for the children of our region.

Sincerely,

Susan T. Arnold, M.D.

Associate Professor of Pediatrics and Neurology - UT Southwestern Medical School
 Director, Comprehensive Epilepsy Center - Children's Medical Center Dallas

Care After the First Unprovoked Seizure

Key Questions	
Could the seizure have been due to a non-epileptic cause?	<ul style="list-style-type: none"> • Usually Benign - Breath-holding spells, sleep myoclonus or simple motor tics • Requiring further evaluation – TIAs, syncope or psychogenic seizures
Was the seizure associated with a fever?	<ul style="list-style-type: none"> • Simple febrile seizures are usually benign, but the family should receive seizure safety and first aid teaching
What is the age of the child?	<ul style="list-style-type: none"> • Children less than a year old require more comprehensive evaluation
Is the child's neurological examination normal?	<ul style="list-style-type: none"> • Children with abnormal examination have higher risk of seizure recurrence and require more comprehensive evaluation
Has the child experienced staring spells or myoclonic jerks?	<ul style="list-style-type: none"> • Children with an apparent first seizure may have had prior unrecognized seizures • Staring spells could be generalized or partial seizures • Myoclonic jerks suggest generalized epilepsy.

When to Order an EEG	When to Order Neuroimaging (MRI preferred)	Other Testing for New Onset Seizures
<ul style="list-style-type: none"> • First or recurrent unprovoked, non-febrile seizure • A complex febrile seizure lasting more than fifteen minutes or with focal features • More than three febrile seizures per year, especially with a low-grade fever. 	<ul style="list-style-type: none"> • A first seizure with focal features or postictal focal deficit (Todd's paresis) • Recurrent unprovoked seizures • Abnormal EEG <ul style="list-style-type: none"> ◦ Except primary generalized epilepsy (e.g. 3 Hz spike and wave EEG pattern) • Unprovoked seizure in a child less than 1 year old • Significant cognitive or motor impairment of unknown etiology • Unexplained abnormality on neurological examination 	<ul style="list-style-type: none"> • Consider in acute evaluation if history suggests an abnormality: <ul style="list-style-type: none"> ◦ Blood tests – calcium, sodium, glucose, BUN or arterial blood gas ◦ CSF studies (if meningitis suspected) ◦ Toxicology screen • Obtain ECG if "seizure" could be due to cardiac arrhythmia • Request psychiatric evaluation if event is determined to be psychogenic in origin

Risk of Seizure Recurrence

After a First Unprovoked Seizure	For a Child With Idiopathic Seizures, a Normal Examination and Normal EEG	For a Child With an Abnormal EEG, +/- Remote Symptomatic Etiology and +/- Abnormal Neuro Exam
<p>50% overall risk for recurrence</p> <p>Risk increases with:</p> <ul style="list-style-type: none"> • Abnormal EEG • Abnormal neurological examination • Focal seizure or Todd's paralysis • Remote symptomatic etiology (e.g. known structural brain lesion) • Seizure arose from sleep • Age < 3 years 	<p>20-30% risk of a second seizure</p>	<p>60-90% risk of a second seizure</p>

Medication - Medications used for partial seizures differ from those used for generalized seizures.

Partial Seizures	Generalized Seizures
<ul style="list-style-type: none"> • Few evidence-based guidelines for initial drug therapy in children with partial epilepsy • Commonly used first medications <ul style="list-style-type: none"> ◦ Oxcarbazepine (Trileptal, Oxtellar)* ◦ Levetiracetam (Keppra, Keppra XR) • Other medications that may be used for initial therapy <ul style="list-style-type: none"> ◦ Carbamazepine**, Phenytoin**, Valproic Acid** (all have black box warnings) ◦ Topiramate, Zonisamide <p><i>*Clinical studies support use as initial monotherapy in children</i> <i>**Clinical studies support use as initial monotherapy in adults</i></p> <p><i>Glaser et al, Epilepsia, 2006</i></p>	<ul style="list-style-type: none"> • One recent study compared initial monotherapy in childhood absence epilepsy <ul style="list-style-type: none"> ◦ Ethosuximide (Zarontin) was superior to other medications tested ◦ Valproic Acid (Depakote, Depakene) was equally effective but higher incidence of side effects ◦ Lamotrigine (Lamictal) was equivalent in terms of side effects but less effective. • Unfortunately, Ethosuximide is not effective for other forms of generalized epilepsy • Commonly used first medications for generalized seizures (other than absence epilepsy): <ul style="list-style-type: none"> ◦ Levetiracetam ◦ Topiramate ◦ Lamotrigine ◦ Zonisamide ◦ Valproic acid (teratogenic, not recommended for adolescent females) • Some drugs make generalized seizures worse <ul style="list-style-type: none"> ◦ Carbamazepine, phenytoin, oxcarbazepine <p><i>Glaser et al, Epilepsia, 2013</i></p>

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Partnering with the Comprehensive Epilepsy Center at Children’s Medical Center

The comprehensive Epilepsy Center recognizes the central role you play in a child and family’s life. Enlisting your support and participation allows us to provide the best possible care for children with epilepsy.

New Onset Seizures

You can begin the initial evaluation and treatment of epilepsy prior to referral to a neurologist.

- Ordering initial testing (e.g. EEG, MRI if needed)
- Seizure safety and first aid teaching
- Dispelling fears or misconceptions about seizures
- Starting medication if needed and/or arranging neurology care

Follow up care

A routine outpatient visit to a primary care provider offers many opportunities for you to partner in follow-up epilepsy care, following American Academy of Neurology Quality Guidelines.

- Documenting seizure type and frequency
- Discussing and assessing for medication side effects (common adverse reaction are listed in the Antiepileptic Drug Table in this toolkit)
- Epilepsy Safety counseling
- Counseling regarding reproductive health and contraception
- Addressing barriers to medication compliance
- Identifying patients who need escalation to a higher level of epilepsy care
- Sending lab tests to monitor for medication compliance or adverse effects.

<p>Interacts With Oral Contraceptives:</p> <ul style="list-style-type: none"> • Carbamazepine (Tegretol, Carbatrol, etc) • Lamotrigine (Lamictal) • Oxcarbazepine* (Trileptal) • Phenobarbital • Primidone (Mysoline) • Phenytoin (Dilantin) • Topiramate* (Topiramate) <p>*at high doses</p>	<p>No Interaction With Oral Contraceptives:</p> <ul style="list-style-type: none"> • Benzodiazepines • Felbamate (Felbatol) • Ethosuximide (Zarontin) • Gabapentin (Neurontin) • Levetiracetam (Keppra) • Pregabalin (Lyrica) • Valproic acid** (Depakote) • Zonisamide (Zonegran) <p>**not recommended for women of childbearing years</p>
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Barriers to medication compliance

Parents may feel more comfortable discussing reasons for medication compliance with you rather than with a specialist. Often this is the difference between medication failure and success. Is as simple as changing the dosing schedule, medication formulation, or using a pill box. The Antiepileptic Drug Table to the right shows options for different formulations and common side effects.

Barrier	Solution
Fears about medication risks	Education
Cost of medication	Change to less expensive formulation, patient assistance program
Child refuses medicine	Change to a different formulation
Inconvenient dosing regimen	Change to extended release formulation or to a longer acting medication
Forgets to give medicine	Pill reminder box, alarm
Medication side effects	Change dose or regimen, change to a different drug.

When Medication Fails

- 60% of children have seizure control with a first antiepileptic drug
- Success rate decreases with each additional medication trial
- 25-30% of childhood epilepsy cannot be controlled with medication alone
- Indications for referral to an epilepsy center
 - o If seizures persist after 12 months of starting treatment
 - o If seizures persist despite appropriate trials of two or more antiepileptic drugs
- Services offered by our epilepsy center that might not be available in a general neurology practice include:
 - o Vagal nerve stimulation
 - o Ketogenic diet
 - o Epilepsy surgery

- You can play an important role in helping parents make difficult decisions regarding treatment options for intractable epilepsy and provide support throughout the course of a child’s care. Good communication between primary care providers and the epilepsy center is essential.

The physicians in the Comprehensive Epilepsy Center encourage PCPs to contact them by phone or email:

- o 214-456-2768 main Neurology number
- o epilepsyprogram@childrens.com Epilepsy Program manager
- o individual physician emails available at utsouthwestern.edu

Antiepileptic Drugs (AEDs)

Generic Name (Brand names)	Form*	Laboratory Monitoring	Black Box Warnings	Common or Serious Side Effects
Carbamazepine (Carbatrol, Epitol, Equetro, Tegretol, Tegretol XR)	T C L E O	Therapeutic Range: 4-12 µg/ml Monitor CBC, LFTs during therapy.	Stevens-Johnson syndrome (SJS) increased risk with HLA-B*1502 allele. HLA screening recommended prior to use. Aplastic anemia and agranulocytosis reported.	Rash, dizziness, drowsiness, unsteadiness, nausea, fatigue, multiorgan hypersensitivity, liver dysfunction, cardiac arrhythmia, aplastic anemia. (Chronic use has been associated with osteoporosis.)
Clobazam (Onfi, Frisium)	T L	Therapeutic Range: Not established No monitoring Recommended	No Black Box Warning	Rash, drowsiness, lightheadedness, confusion, unsteadiness, amnesia, vomiting, irritability, fatigue, sedation, ataxia, cough, aggression, muscle weakness
Clonazepam (Klonopin)	T O	Therapeutic Range: Not established No monitoring Recommended	No Black Box Warning	Drowsiness, fatigue, dizziness, low muscle tone, ataxia, restlessness, confusion, amnesia, depression, behavior problems
Ethosuximide (Zarontin)	C L	Therapeutic Range: 40-100 µg/ml Monitor CBC, LFTs during therapy	No Black Box Warning	Rash, anorexia, nausea, abdominal pain, leukopenia, drowsiness, headache, urticaria, lupus erythematosus, diarrhea
Felbamate (Felbatol)	T L	Therapeutic Range: 30-60 µg/ml Monitor CBC, LFTs during therapy.	Associated with increased incidence of aplastic anemia. Acute liver failure reported. Avoid with history of hepatic dysfunction.	Anorexia, nausea, headache, fever, somnolence, dizziness, insomnia, fatigue, ataxia, constipation, aplastic anemia, liver failure
Gabapentin (Neurontin)	C L	Therapeutic Range: Not established No monitoring recommended	No Black Box Warning	Rash, dizziness, somnolence, fatigue, peripheral edema, behavior change, diarrhea, dry mouth, nausea, headache, ataxia, weight gain, depression, sleep disturbance, headache,
Lamotrigine (Lamictal)	T C E O	Therapeutic Range: 3-14 µg/ml Monitor CBC, LFTs during therapy	Serious life-threatening rash, including Stevens-Johnson syndrome, occurs more often in children than in adults.	Rash and hypersensitivity reactions, dizziness, diplopia, headache, ataxia, blurred vision, nausea, somnolence, diarrhea, abdominal pain, joint pain, blood dyscrasias.
Lacosamide (Vimpat)	T L IV	Therapeutic Range: Not established Monitor ECG if known cardiac disorder	No Black Box Warning (Reports of PR prolongation and cardiac arrhythmias.)	Headache, nausea, diplopia, dizziness, fatigue, blurred vision, somnolence, tremor, prolonged PR interval, diarrhea, balance disorder, ataxia, depression, fatigue.
Levetiracetam (Keppra)	T L E IV	Therapeutic Range: 3-63 µg/ml No monitoring recommended	No Black Box Warning	Somnolence, asthenia, headache, anorexia, dizziness, nervousness, ataxia, irritability, aggression, depression, diarrhea, nausea, blurred vision.
Oxcarbazepine (Trileptal, Oxtellar)	T L E	Therapeutic Range: 15-35 µg/ml Monitor Sodium during therapy	No Black Box Warning (Clinically significant hyponatremia may occur)	Rash, Hyponatremia, dizziness, somnolence, diplopia, fatigue, ataxia, nausea, abdominal pain, confusion, depression, and tremor.
Perampanel (Fycompa)	T	Therapeutic Range: Not established	Unknown, FDA prescribing information not yet available	Dizziness, sleepiness, appetite change, aggression, anxiety, confusion, ataxia, speech difficulties, blurred vision, nausea, fatigue, weight gain.
Phenobarbital (Luminal)	T L IV	Therapeutic Range: 15-40 µg/ml No monitoring recommended	No Black Box Warning	Rash, drowsiness, impaired memory or cognition, respiratory depression, nausea. (Chronic use has been associated with osteoporosis.)
Phenytoin (Dilantin, Epamin)	T C L E IV	Therapeutic Range: 10-20 µg/ml No monitoring recommended	No Black Box Warning	Rash, nystagmus, ataxia, decreased coordination, confusion, dizziness, drowsiness, motor twitching, headache, nausea, gum hyperplasia, hypertrichosis, coarsening of facial features. (Chronic use has been associated with osteoporosis.)
Primidone (Mysoline)	T	Therapeutic Range: 5-12 µg/ml No monitoring recommended	No Black Box Warning	Rash, Ataxia, dizziness, drowsiness unsteadiness, impaired memory or cognition, nausea, , agranulocytosis, red-cell hypoplasia, aplasia. (Chronic use has been associated with osteoporosis.)
Pregabalin (Lyrica)	T L	Therapeutic Range: Not established Monitor CK level, CBC, ECG during therapy	No Black Box Warning (Reports of rhabdomyolysis, PR interval prolongation).	Somnolence, dizziness, peripheral edema, ataxia, weight gain, dry mouth, asthenia, blurred vision, constipation, abnormal thinking/memory, tremor, prolonged PR interval, Thrombocytopenia, rhabdomyolysis
Rufinamide (Banzel)	T L	Therapeutic Range: 3-30 µg/ml (?) Monitor CBC, ECG during therapy	No Black Box Warning (Reports of short QT interval during therapy.)	Rash, somnolence, nausea, headache, fatigue, dizziness, tremor, nystagmus, decreased appetite, ataxia, diplopia, blurred vision. Shortened QT interval, leukopenia.
Tiagabine (Gabitril)	T	Therapeutic Range: Not established	No Black Box Warning (Reports of increased seizures or status epilepticus in some patients)	Rash, dizziness, asthenia, tremor, nausea, nervousness, somnolence, abdominal pain, difficulty with concentration, insomnia, confusion, diarrhea, status epilepticus
Topiramate (Topamax, Trokendi)	T C S E	Therapeutic Range: 5-20 µg/ml Monitor for metabolic acidosis during therapy	No Black Box Warning (Increased risk of secondary angle-closure glaucoma reported, avoid use if known glaucoma)	Rash, anorexia, anxiety, nausea, diarrhea, fatigue, weight loss, cognitive problems, paresthesias, somnolence, mood problems, confusion, hypohydrosis, hyperthermia, glaucoma, metabolic acidosis, kidney stones
Valproic Acid and Divalproex Sodium (Depakene, Depakote, Epilim)	T C S L E IV	Therapeutic Range: 40-125 µg/ml Monitor CBC, LFTs during therapy.	Fatal hepatic failure may occur, risk increased in children <2 yrs, especially if on multiple anticonvulsants, with congenital metabolic disorders. Teratogenic effects and pancreatitis reported	Nausea, diarrhea, abdominal pain, asthenia, somnolence, anorexia, dizziness, hair loss, weight gain hepatotoxicity, pancreatitis, fetal neural tube defects, thrombocytopenia, hyperammonemia. Has been associated with polycystic ovaries and menstrual problems.
Vigabatrin (Sabril)	T O	Therapeutic Range: Not established Monitor CBC, vision assessments during therapy.	Causes permanent vision loss in children, and adults; Risk of vision loss increases with increasing dose and cumulative exposure.	Vision loss/visual field defects, rash, somnolence, irritability, nausea, diarrhea, constipation, sedation, influenza, anemia, aggression, impaired concentration or memory, tremor, weight gain.
Zonisamide (Zonegran)	C	Therapeutic Range: 10-40 µg/ml Monitor for metabolic acidosis during therapy.	No Black Box warning	Rash, somnolence, anorexia, dizziness, ataxia, irritability, difficulty with memory and/or concentration, headache, nausea, abdominal pain, weight loss, confusion, diplopia, hypohydrosis, hyperthermia, , metabolic acidosis, kidney stones.

*Available Forms: T:tablet, C:capsule, S: sprinkle capsule, L:liquid, E:extended release, O:other, IV: intravenous
(Sources include the British National Formulary for Children, PDR.)



Read Ella's story at
[childrens.com/Ella](https://www.childrens.com/Ella)

Things to Know About Seizures

- A person having a seizure cannot swallow their tongue; don't put anything in their mouth.
- Most seizures end after a minute or two without harm and do not cause injury to the brain.
- CPR is not usually recommended or necessary during a seizure.
- Confusion or sleepiness after a seizure is normal and does not mean the brain has been injured.
- It's normal for a child not to remember what has happened.

Seizure Safety Counseling for Patient & Family

Fewer than 20% of primary caregivers referring children to the Comprehensive Epilepsy Center document any form of seizure safety education in their office notes. The risk of injury from a seizure is much higher than the risk of sudden death due to epilepsy. Safety counseling can help reduce this risk and protect children.

Safety Precautions & Counseling

Safety counseling varies with age, but all families should know basic safety measures.

- Bathing or swimming only when supervised
- Showers are safer than baths
- Leave the bathroom door unlocked
- Wear a life jacket around all water activities
- Wear protective gear when bicycling, skating, etc.
- No climbing higher than 10 feet
- No driving or operating heavy machinery (unless cleared by physician)
- Consider a medical alert bracelet
- Other things to consider may include cooking, ironing, babysitting, overnight trips and staying home alone

Sports Safety

- Assess the risk of injury with sports activities
- No contact sports if seizures are not controlled
- Always use protective equipment
- Encourage families to discuss precautions with sports coaches

Prohibited sports and activities include scuba diving, rock climbing, sky diving or any activity where the risk outweighs the benefit.

Patients should check with their states's regulations for drivers with epilepsy.

Recognizing a Seizure Emergency

Most seizures in people with epilepsy are not medical emergencies because they end within a minute or two without harm; however, it's important for families to know what to do and when to call for help.

Seizure First Aid

- Time the seizure.
- Don't put anything in the mouth.
- Look for medical alert identification.
- Turn the person on their side and cushion their head.
- Loosen tight clothing and remove glasses.
- Don't grab or hold the person down.
- Explain to others what is happening.
- Speak calmly and offer help as the seizure ends.

See the patient education handout enclosed in the back of this booklet.

Reasons to call for emergency help include:

- A seizure in someone without known epilepsy or who does not have seizure identification
- A seizure that lasts more than five minutes
- A second seizure without full recovery of consciousness
- Pregnancy or any sign of a medical diagnosis
- Difficulty breathing or cyanosis
- Significant injury related to the seizure

Find digital copies of these materials at
[childrens.com/epilepsy](https://www.childrens.com/epilepsy)

Patient Education and Referral

These handouts are designed to help you manage children with seizures in your practice.

- First Aid for Seizures (English & Spanish)
- General Information About Seizures
- Living with Seizures: Be Safe and Have Fun
- Referral Forms
 - Epilepsy Center and EEG Request
 - To request an MRI, visit [childrens.com/radiology](https://www.childrens.com/radiology)

Learn more about the Comprehensive Epilepsy Center at [childrens.com/epilepsy](https://www.childrens.com/epilepsy).



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A special thanks to Lundbeck for providing the grant to produce this educational resource.



Earn CME credits through our online Epilepsy course at childrens.com

Quick Reference to refer a patient:
Call **214-456-2768**
Email epilepsyprogram@childrens.com



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