

Primary Generalized Epilepsy

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Primary Generalized Epilepsy: is a group of several different types of epilepsy syndromes that begin in childhood or adolescence. The most common forms are called:

Childhood Absence Epilepsy
Juvenile Absence Epilepsy
Juvenile Myoclonic Epilepsy
Generalized Tonic-Clonic Seizures Upon Awakening

This group of epilepsies is considered **genetic in origin: The Cause is the brain's own tendency to have seizures** (not brain injury, brain tumor or other brain diseases). So, if your child is diagnosed with one of these disorders, there typically is no need to pursue a brain scan.

The physician makes the diagnosis by learning about the **seizure characteristics**, the presence or absence of **mixed seizure types**, **age of onset**, the child's **cognitive ability**, the child's **examination findings** (typically normal) and the **EEG findings**. The EEG shows similar findings in all these disorders: **Generalized epileptiform activity of various frequencies and character**. These findings show that the whole brain, at times, has unintended electrical activity spreading throughout the brain. Sometimes this activity does not cause a problem (epileptiform activity on EEG without seizure) whereas other times a seizure occurs (clinical manifestation like staring or jerking).

In general, the syndromes nearly always includes absence seizures: staring for a few seconds without memory and without much movement (sometimes eye blinking or lip smacking). Children rarely fall, although they may continue walking and risk injuries such as falling down stairs or walking into objects. The younger the age absence seizures begin, the lower the risk of developing Generalized Tonic Clonic (GTC) seizures (convulsions or grand mal seizures). Absence epilepsies have a high rate (but not 100%) of going away around puberty. Treatments are typically recommended to limit a child's risk of injury and minimize academic disruption.

The older the onset of absence seizures, the more likely that GTC seizures will occur and the lower the rate of spontaneous resolution (growing out of them). Some children actually start having GTC seizures. In Juvenile Myoclonic Epilepsy, the child (more often females) develop mixed seizure types (absence, GTC and myoclonic). The myoclonic seizures are very rapid, brief movements, typically involving the arms and often occurring in the morning ("morning myoclonus").

Treatment is with Anti-epileptic-drugs (AED's) are used to suppress seizures, not cure them. AEDs can decrease seizure frequency and even stop seizures in some people. All these medicines may work for all seizure types except Zarontin which treats absence and some myoclonic seizures (it will not suppress GTC). These medicines are not addictive. They do have potential side effects. know that side effects **do not** happen to everyone taking the medicine. A common side effect may occur in 10-20 % of people taking the medicine and often will go away after a week or two. It is difficult to know which medicine is best for an individual without trying it. Treatment decisions are individually determined based on many issues including ability to swallow pills, cost, personal preference and risk-benefit determination. Medication does not "cure" epilepsy, but response to the medication is usually very good.



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Medications:

Seizures	Absence	GTC	Myoclonic	Characteristics
Zarontin® Ethosuximide	+++	No effect	++	Some GI symptoms: stomach discomfort
Depakote® Depakene ® (liquid) Valproic Acid Divalproex	+++	+++	+++	GI symptoms, weight gain common, pregnancy concerns, tremor, hair loss
Lamictal® Lamotrigine	+++	+++	+++ Could worsen Myoclonic seizures	May worsen myoclonic seizures; Reversible rash (~10%), weight neutral Rare life threatening rash; slow dose increases lowers risk of rash felt relatively safe in pregnancy
Keppra® levetiracetam	++	++	++++	Relatively very safe; some agitation
Zonegran® Zonisamide	++	++	?	“zones” out some people Rare rash, kidney stones
Topamax® Topiramate	+ / ++	++	?	Slow thinking at high doses, some tingling of fingers, alters taste of sodas, reversible glaucoma, kidney stones, heat intolerance

Are there any non-medication treatments available?

Alternative treatments include a special, very strict high-fat low carbohydrate diet called the Ketogenic Diet. There are no known herbs or dietary supplements, biofeedback, chiropractics or acupuncture that helps with epilepsy. Vagus Nerve Stimulator (VNS) may be tried in very refractory cases.

Goal of Treatment: No seizures at all. Sometimes, just controlling the GTC is the main goal and occasional absence seizure seems reasonable instead of having side effects from too much medicine. If a child is 2 years seizure-free, we will discuss weaning off the medicine slowly and under my supervision. Never stop a seizure medicine suddenly, as this may precipitate increase in seizures or a very long seizure requiring emergency care.



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Monitoring: Repeat EEGs, occasional blood tests and routine visits with Dr Siegler at frequencies based on a child's response to medicines. Each child's care is personalized depending on seizure frequency, medication or combination of medications, presence of side effects and level of activity (ie. driving, sports, etc.).

Are there any activities that should be avoided due to seizures?

In general, children are encouraged to engage normally in childhood activities. There are some activities that can promote seizures in persons with JME which includes **staying up very late at night** (not getting enough sleep, sleep deprivation), alcohol or drug use or excessive quantities of coffee and tea which may lead to insomnia and result in sleep deprivation. Only some people may be sensitive to flashing or flickering lights (such as strobe lights or flickering light when driving past trees) and should be avoided. Most video games do not promote seizures but if they do, the seizures should occur during the activity, not minutes later. Certainly, anyone with seizures should avoid potential injuries. Seizures during certain activities are more likely to promote injuries include driving motorized vehicles (4 wheelers, golf carts, go carts, cars), horse and bike riding (potential falls can cause serious injuries), cooking or being near open flames and being in or near water: Showers are preferred over baths (someone should be watching during bath or while in hot tubs or swimming). A "buddy system" (a person watching the patient) and wearing a life vest is recommended when swimming in larger bodies of water that is not clear (ponds, rivers, lakes). Driving is feasible if the patient has been seizure-free on medications for a certain amount of time (in Oklahoma it is 6 months), takes his/her medicine regularly and reports his/her epilepsy to the Department of Public Safety (which issues a **Medical Evaluation Form** to be filled out by your neurologist on a regular basis). If the patient is driving and has a seizure (even if not while driving) the patient is obligated to report the seizure to the Department of Public Safety and his/her neurologist.

Who should I tell about my child's epilepsy?

Be sure to talk with your child about the seizures, explaining that he or she must take the prescribed medicine regularly. Explain that the seizures are related to his genes and not because of something he or she did. If he or she has questions you cannot answer, be sure to discuss these issues with your neurologist during appointments. It is up to you and your child with whom you share medical information. Certainly, sharing with people with whom your child spends a lot of time is a good idea. Having good friends and their families and teachers know what to do in case of a seizure will be helpful. It is best not to treat the diagnosis of epilepsy as a secret or something bad. This would give your child the message that the disorder is too terrible to talk about.

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