Understanding Seizures

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Mother of Madelyn

Seizures are uncommon in children; in fact, only about three percent of all children experience them. However, the occurrence of seizures in children with Cornelia de Lange Syndrome (CdLS) is increased—for unclear reasons—occurring in approximately 15 percent of children with the syndrome.

Although seizures are very frightening to the child and her family, they do not usually cause harm. However, due to the risk of accidental injury, children with seizures, or possible seizures, should not be left unguarded in the bathtub or swimming areas, and should avoid climbing in places where falling might result in injury.

If your child is having a seizure, make sure she is on her side in a safe place where she cannot fall or hit objects. Do not attempt to put anything in her mouth. Keep track of how long the seizure lasts. If it continues more than five minutes, call 911 for help. If the seizure stops on its own but it’s your child’s first seizure, safely take the child for evaluation at your local emergency room.

The first question a medical professional considers is whether the episode was in fact a seizure or some other kind of a spell. In children with CdLS, reflux episodes causing arching may look like seizures. Other spells that mimic seizures include breath-holding, daydreaming and tics.

The next question the physician considers is the cause of the seizure. It’s important to rule out acute malfunctioning of the brain due to illnesses such as meningitis; metabolic disturbances, such as dehydration during a gastrointestinal illness; or bleeding into the brain from trauma.

The initial evaluation of a child with a new seizure looks for acute changes that may have caused the seizure and need to be immediately treated. This procedure often includes laboratory tests and brain imaging by CT or MRI.

Assuming acute causes are ruled out, the next step is determining the type of seizure the child has had. Observers are asked to describe the seizure: where it started in the body and whether
it spread to other parts of the body or started all over the body at the same time. This determines whether it’s a generalized or partial seizure.

Some seizures are easy to recognize, such as grand mal or generalized tonic clonic seizures. These are very dramatic. Sometimes the child will bite her tongue or urinate during the seizure. The child experiencing this kind of seizure will be very sleepy and disoriented for a while afterwards. This is called the postictal state and is not actually part of the seizure.

Petit mal or absence seizures are much more difficult to recognize. These may occur many times a day—sometimes as many as 50 times—and last a few seconds with mild facial movements, such as eye blinks. It does not leave the child sleepy afterward. One way these seizures can be differentiated from daydreaming is that they interrupt the child’s activity—stopping her while talking, sipping from a glass or walking across the room.

Sometimes seizures are partial seizures, affecting only one part of the brain. These are notoriously difficult to diagnose, as they may be motor, with one hand jerking, or sensory, with the child experiencing a funny smell or flashing lights. These sometimes turn into more typical, generalized seizures.

There are various types of seizures, and some tend to occur at certain ages (e.g., absence seizures in childhood and juvenile myoclonic epilepsy during adolescence). Some types don’t require treatment, such as simple febrile seizures or a type of seizure that runs in families and may occur only at night (benign epilepsy of childhood with centrotemporal spikes).

If the physician feels that the episode represents a seizure, she may perform an electroencephalogram (EEG), a non-painful test involving the application of electrodes to the head to record brain waves. EEGs are not performed unless there is a strong clinical suspicion of a seizure disorder. It is performed to guide treatment, not diagnose the seizure.

Since it’s often difficult to tell if a particular episode is a seizure, family members may be asked to keep a record of the events for a few weeks, and even videotape the activity they are concerned about. A follow-up is then scheduled with the neurologist.

It’s important that medication not be used until it’s clear that the child is experiencing seizures. All seizure medicines may have side effects and are not worth the risk of taking if not needed.
If seizures are diagnosed, the physician often orders further testing, including a brain MRI and possibly metabolic testing—if not performed during the acute evaluation—to determine the cause of the seizure.

While the type of seizure and age of the child guides the choice of medication, convenience and expense for the family should be considered. All seizure medications have potential side effects, including changes in mood, activity level and learning. The newer antiepileptic drugs, such as Keppra and Topamax, are less likely to have these effects than the older antiepileptic drugs, such as Depakote, Tegretol, and especially Phenobarbital. However, some types of seizures may respond better to the older medications. Every family should ensure that they have been thoroughly informed regarding the benefits and risks of the medicine being prescribed for their child.

The seizure type and underlying neurological problems determines how long the child needs to be on medication. Generally, it’s more difficult to be weaned off medication if there are underlying neurologic problems. Even in typically developing children, the physician waits two to four years after the last seizure before weaning the medication.

Questions regarding the right medication and when to cease medication should be discussed with the child’s neurologist. It’s helpful to find a neurologist familiar with children with CdLS when possible.

For more information on seizure disorders, visit [www.medhomeportal.org](http://www.medhomeportal.org), [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org) or [www.epilepsy.com](http://www.epilepsy.com).