

Indian Academy of Pediatrics (IAP)



GUIDELINES FOR PARENTS

Care of a Child with Epilepsy



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10 FAQs on CARE OF A CHILD WITH EPILEPSY

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10. What are the protective measures for preventing seizure-related risks?

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Care of a Child with Epilepsy

Q1

What is epilepsy and what are the factors that cause epilepsy?

Epilepsy is a neurological disorder that causes a child to have recurrent seizures. In epilepsy, normal physiological brain activity becomes abnormal due to various reasons that disrupt normal brain signals, causes seizures, or unusual phenomenon like unusual behavior and/or sensations. When a child has two or more seizures atleast 24 hours apart, this is diagnosed as epilepsy.

General symptoms of a seizure:

- Blank stares and confusion/ unresponsiveness
- Brief jerky movements of arms and legs
- Stiffening of body
- Periods of rapid eye blinking
- Nodding head rhythmically or head drops
- Repeated twitching of the face
- Falling suddenly associated with loss of awareness and consciousness

Associated symptoms:

- Loss of consciousness
- Drooling of saliva or frothing from the mouth
- Loss of bowel or bladder control
- Sleeping or confused after the episode

In more than half of cases, a cause cannot be found.

Causes of epilepsy:

- Structural
- Genetic
- Infectious
- Metabolic
- Immune
- Unknown

Risk factors:

Risk factors which can trigger the seizures in children with certain epilepsies.

- Fever
- Sleep deprivation
- Flashing light pattern
- Fasting

Also, it is better to avoid stress, excessive noise, and excessive screen time.

Q2

Whom to consult and what are the treatment options for epilepsy?

If a child is not a diagnosed case of epilepsy (or this is the first episode of seizure), the child should be taken to the primary care pediatrician. During the active seizure, the child should be taken to emergency medical care. If seizures are recurring, then consultation with a pediatrician is required.

The first line of treatment for epilepsy is medicines that control the seizures. These are commonly known as anti-epileptic drugs (AEDs) or anticonvulsant drugs. The new nomenclature for drugs that control seizure is “*antiseizure medications*”. There are many types of anticonvulsant medicines. Sometimes, a child may require only one medicine for his seizures, but in some cases, child may require more than one AED. However, it sometimes takes time to find the one that works best for the child as not every child responds to treatment in the same way. In case, routine medications do not work, take opinion from a specialist (pediatric neurologist).

Antiseizure drugs in a child with epilepsy are usually required for 2–3 years in most of epilepsies but not all. But, when to taper medication is best decided by the treating doctor.

Q3

Which tests are necessary for the diagnosis of epilepsy?

Before making a diagnosis of epilepsy, the following steps are required:

- Detailed medical history of child including fever, head trauma, headache, breath-holding, etc. Information regarding the mother’s pregnancy, delivery, family history of epilepsy is also required.
- Details of the seizure—like the type of activity, duration, and other associated symptoms.
- *Physical examination*: To assess cardiac, neurological, and mental status.

Test or Investigations

For every child, the diagnostic process is different, but the following tests are usually required to establish the diagnosis of epilepsy.

- *Electroencephalogram (EEG)*: EEG is used to diagnose the epilepsy syndrome and to determine the risk of seizure recurrence. In some cases, video-EEG is required to record the seizure, which helps to understand the seizure type.
- *Magnetic resonance imaging (MRI)/CT scan*: These modalities may be required to look for any malformation of brain or any lesion likely to result in epilepsy.
- In specific cases, a genetic/metabolic/autoimmune panel may be required.

Q4

What should I do if the doses are missed?

Missing a seizure medication can increase the chance of having breakthrough seizures and seizure-related problems such as falls, injuries, etc.

<i>Steps to ensure "not missing the dose"</i>	<i>What should do if I miss?</i>
Fix a specific time for taking medicines	If you still miss the dose and the medicine was taken, once a day—then give/take the forgotten dose as soon as you remember.
Use of pillboxes, putting alarms or reminders, pasting visible schedules at home	Twice a day—take the forgotten dose if you remember within 6 hours of the due time, otherwise just give/take the next dose.

Caution tip: Importantly, if you have missed any dose, **do not** give/take twice the advised dose at the next due time. This can lead to adverse effects such as excessive sleepiness, metabolic derangements, etc.

Q5

What are the side effects of antiepileptic medications?

Different medicines have different side effects, but it is not necessary that all people taking these medicines will have those side effects. Newer medications have fewer and milder side effects. Few side effects are listed here. All of these are not there with all drugs, and this should not scare you from using these drugs.

Rarely, allergic skin rash can occur. Report to your doctor immediately if any rash appears. Medicines taken for other ailments can interact with the ASM and increase or decrease the levels of the drug in the body. Therefore, always consult your doctor before starting other medicines.

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| <ul style="list-style-type: none"> • Gastric upset • Excessive sleepiness • Dizziness | <ul style="list-style-type: none"> • Blurring of vision • Behavior or mood problems • Lack of attention | <ul style="list-style-type: none"> • Increased or decreased appetite • Decreased bone mineral density |
|--|--|---|

Q6

How can recurrences of seizures be prevented?

- Taking the medicines as advised by your doctor in correct dosages regularly is the only way to prevent seizure recurrences.
- Missing doses increase the chance of having seizures.
- It is important to follow-up with your doctor regularly.
- Carry all the medicines for every visit and show them to the doctor.
- Some epilepsies can be triggered by certain activities such as taking a bath with hot water, watching TV, listening to loud music, playing video games, fasting, etc. Hence, these activities should be avoided as per directions of the doctor.
- Sleep deprivation can also trigger seizures and thus children should follow a regular sleep schedule.

Q7

What are the changes in general lifestyle measures for my child diagnosed with epilepsy? Is a special diet required?

Child with epilepsy needs to be treated as a normal child as far as possible. Overprotection should be avoided. Child should have good physical exercise, exposure to sunlight, participation in family functions, and social gatherings. Child, siblings, and family should not be isolated or victimized. Epilepsy does not spread from person to person. The family should know about the resources available for treatment and rehabilitation of these children.

There should be no blanket restriction of activities, but if seizures are not well controlled, then activities such as cooking, swimming, and cycling should be under supervision. Teenagers with uncontrolled seizures should not be allowed to ride two-wheelers. The child should keep the door of the bathroom unlatched during bath and toilet activities. Parents should discuss with the treating doctor who will be able to decide about sports activities depending on the disease and the age of the child. Avoid video games in children with photosensitive epilepsy.

No special diet is required. A normal balanced diet is required as per the daily activities of the child. Ketogenic diet is required as a part of treatment for a few uncontrolled epilepsies. This must be carried out under supervision.

Q8

What are the precautions to be taken care at school and which sport can my child play?

Child should attend normal school as far as possible. Parents should inform the teacher about the disease and the medication which the child is taking. Teacher should be trained to recognize seizure, position the child, and provide nasal spray of midazolam if seizure >5 minutes. Medication can be kept in class room or medical room in school. Parents should be informed as soon as possible. All extracurricular activities can be done and child should be encouraged to participate in them. But, care should be taken so the child receives regular medication on time, avoids sleep deprivation, prolonged fasting, or extra screen time. Child may have a decrease in academic performance due to medication or the disease per se. These children may need extra attention and coaching. School trips may be allowed with special precautions.

Sports as dancing, golf, athletics, baseball, basketball, and cricket have no significant additional risk and are permitted if the child is seizure-free for some time. Cycling, gymnastics, skating, and motorsports are moderate-to-high risk. These can be permitted in few cases after permission from the pediatrician otherwise should be avoided.

Q9

What is the prognosis, and will it affect my child’s future in any way?

- About 60–70% of children will have control of their seizures easily with medicines if compliant.
 - Seizure control allows your child to eventually come off antiseizure medications. Talk to your doctor if the child has not had seizures for 2 years.
 - About 30% may have difficulty with seizure control and other problems related to epilepsy such as learning difficulties, behavior and mood problems, and the problems with building social relationships over the long term.

An individual child’s prognosis depends on several factors:

- Results of neuroimaging such as MRI of the brain
- Epilepsy syndrome
- Cause of epilepsy
- Age at which seizures started
- Number of antiseizure medications required for seizure control
- Additional neurological problems

Q10

What are the protective measures for preventing seizure-related risks?

Seizure-related risks	Protective measures
<ul style="list-style-type: none"> Fall from bed and injuries, if seizures are frequent in sleep. Fractures if there are tonic-clonic convulsions and frequent falls. 	<ul style="list-style-type: none"> Keep the bed away from windows. Padding of sharp edges of bedside table.
Head injury if drop attacks are frequent in your child's epilepsy.	Wear a helmet, the helmet that is to be used is a cycling helmet. In case, it is unaffordable, parents can either use a cap with an internal padding, or use a pagri in the village setup.
In children with frequent generalized tonic-clonic convulsions and refractory epilepsy, there is a risk of sudden unexpected death in epilepsy (SUDEP).	<ul style="list-style-type: none"> Strict adherence to medication. Keep a listening device in the child's bedroom. Avoid sleeping in prone position. Self-monitoring Apps on phone for warning.
<ul style="list-style-type: none"> Injuries during sports Seizures and injuries at school/college 	<p>Make sure your child:</p> <ul style="list-style-type: none"> Wears a helmet during sports. Has adult supervision while swimming. At school/college—wears a seizure bracelet. <p>If seizure alert bracelet/chain is not available, a laminated card with name and contact number of patient with doctor name and current drugs and dosages can be kept in child's pocket.</p>



You can wear a Medic Alert bracelet or chain. Keep a Medic Alert badge or pin in your pocket

Ask parents to talk to their doctor about abortive medicines for home use, if the child gets frequent seizures and/or health facilities are far-off (e.g., nasal midazolam).