



National Institute of Mental Health & Neurosciences

(Institute of National Importance), Bengaluru-560029

राष्ट्रीय मानसिक स्वास्थ्य एवं तंत्रिका विज्ञान संस्थान, (राष्ट्रीय महत्व का संस्थान), बेंगलूर -
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ರಾಷ್ಟ್ರೀಯ ಮಾನಸಿಕ ಆರೋಗ್ಯ ಮತ್ತು ನರ ವಿಜ್ಞಾನ ಸಂಸ್ಥೆ, (ರಾಷ್ಟ್ರೀಯ ಪ್ರಾಮುಖ್ಯತಾ ಸಂಸ್ಥೆ), ಬೆಂಗಳೂರು-

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FAQ on Epilepsy

What is Seizure?

Seizure is a general term and people call their seizures by different names – such as a fit, convulsion, funny turn, attack or blackout. It can happen due to variety of reasons like low blood sugar, liver failure, kidney failure, and alcohol intoxication among others. A person with epilepsy can also manifest with seizure.

What is epilepsy?

Epilepsy is a neurological disorder of the brain (not mental illness) where in patients have a tendency to have recurrent seizures. Seizure is like fever – due to various causes; while epilepsy is a definite diagnosis like fever due to typhoid, malaria.

How many people have epilepsy?

Epilepsy is the one of the most common neurological condition and may affect 1% of the population. Which means there are at least 10 million epilepsy patients in our country.

What causes epilepsy?

Anyone can develop epilepsy; it occurs in all ages, races and social classes. It is due to sudden burst of abnormal electrical discharges from the brain. In a great majority of patients, one does not know the cause for this.

The causes of epilepsy can be put into three different groups: a) *Symptomatic epilepsy*: when there is a known cause for a person's epilepsy starting it is called symptomatic epilepsy. The reasons can include head injury, infections of the brain, stroke, or a scar in the brain. b) *Idiopathic epilepsy*: There is no clear cause for the seizures and is thought due to having a low seizure threshold. The person usually has no other disabilities. c) *Cryptogenic epilepsy*: When it is not clear if epilepsy is symptomatic or idiopathic and is due to a reason yet to be found. In great majority the cause is not known.

Is it hereditary?

In a vast majority of patients, it is not a hereditary condition. Certain types of epilepsies and those with positive family history have a greater chance of familial predisposition

Is epilepsy contagious?

Of course not. This does not spread by any close contact such as shaking hand, kissing or living together or by sharing food from the same plate.

How is a diagnosis made?

The diagnosis is entirely on the information given by patient and more important by the on lookers who have observed the seizure.

Are there different types of epilepsy?

There are different types of seizures. A) *Partial or Focal seizures*. i) Simple partial seizures: consciousness is not impaired and the seizure may be confined to either rhythmical twitching of one limb or part of a limb, or it can be like unusual tastes or sensations such as pins and needles in a specific part of the body. ii) Complex partial seizures: consciousness is affected, and seizures may be characterized by a change in awareness as well as automatic movements such as fiddling with clothes or objects, mumbling or making chewing movements, or wandering about and general



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confusion. The person may respond if spoken to. Complex partial seizures most often involve the temporal lobes of the brain, in which case the person may be said to have 'temporal lobe epilepsy'.

iii) Secondly generalized seizure: For some people either of these partial seizures may spread to involve the whole of the brain and he/she will lose consciousness.

B) Generalized seizures: In these seizures the whole of the brain is involved, and consciousness is lost. The seizure may take one of the following forms: **i)** The most recognized type of seizure is the generalized tonic-clonic convulsive seizure, sometimes called a 'grand mal' seizure. In the first part of the seizure the person becomes rigid and may fall. The muscles then relax and tighten rhythmically causing the person to convulse. At the start of the seizure the person may bite their tongue or cry out. Breathing may become laboured and they may be incontinent. After the seizure the person may feel tired, confused, have a headache and may need to rest to recover fully. **ii)** Absence seizures: occur commonly in children and are often referred to as 'petit mal'. The person experiences a brief interruption of consciousness, unresponsive with blinking of eye lids lasting 5 – 15 seconds **iii)** Juvenile Myoclonic Epilepsy (JME): This is usually seen in young persons aged 10-12 years and consists of sudden jerky movements of the hands resulting in dropping of objects like tooth brush, coffee cup etc and at times jerky movements of legs resulting in abrupt fall to the ground. This usually occurs within an hour or two after waking up; sleep deprivation precipitates this type of epilepsy. Sometimes these patients develop generalized epilepsy at a later date.

What are febrile seizures?

It is commonly seen in children (6 months to 5 years) and is always accompanied by fever. Child is normal in between and has normal development. It is a benign condition and generally does not require long-term prophylaxis with anti-convulsants.

What is hot water Epilepsy?

This is peculiar reflex epilepsy occurring in south India. It occurs immediately following hot water especially head bath. One should avoid hot water bath to prevent it and then consult a neurologist.

What should be done during a fit?

Convulsive seizures cannot be stopped or altered, so the best thing to do is to follow these guidelines.

1. Try to stay calm
2. Check the time to monitor how long the seizure lasts, as prolonged seizures may require emergency medical help.
3. Prevent others from crowding around.
4. Put something soft under the person's head - such as a jacket or cushion - to prevent injury; loosen tight clothes around neck: tie, collar, necklaces etc.
5. Only move the person if they are in a dangerous place, for example at the top of a flight of stairs or in the road. Move things away from them if there is a risk of injury.
6. Do not attempt to restrict or restrain the convulsive movements as this may cause injury to the person or yourself
7. Do not put anything in the person's mouth. There is no danger of them swallowing their tongue during a seizure and you may damage their teeth.
- 8 Don't give any iron rods, keys to hold as it may injure him/her.
- 9 If the person is known epileptic and the seizure lasts longer than 5 minutes or repeats without full recovery, call the ambulance.
- 10 If it is the first seizure, call the ambulance.
- 11 Video record the onset of the event in mobile phone



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What to do once the convulsions have stopped?

1. Roll the person onto their side
2. Wipe away any excess saliva and if breathing is still labored, check that nothing is blocking the throat such as dentures or food.
3. Do all you can to minimize any embarrassment. If the person has been incontinent deal with this as sensitively as possible.
4. Stay with the person giving reassurance until they have fully recovered.
5. Do not give the person anything to eat or drink until they are fully recovered.

What are common tests?

A number of investigations, including blood tests, an electroencephalogram (EEG) and scans such as Computerized Tomography (CT) or Magnetic Resonance Imaging (MRI) may provide additional information. However, these tests cannot confirm or rule out a diagnosis of epilepsy.

I have had seizures, but the EEG and brain scan are normal. Why have I been diagnosed with epilepsy?

Diagnosis of epilepsy is based on history. While tests such as EEGs and brain scans can be useful, they cannot, on their own, say if someone has or doesn't have epilepsy. Electrical activity in the brain may be normal between attacks in about 40%. The brain scan looks for structural abnormalities within the brain. It does not diagnose epilepsy but may help to explain why seizures are happening. If it is negative, this means that no cause for the seizures has been found. It does not mean that.

What is the treatment for epilepsy?

About 75% of people with epilepsy will have their epilepsy controlled with anti-epileptic drugs (AED). AEDs prevent seizures from happening, but don't cure epilepsy. There are many AEDs, and choice of AED depends on the type of seizures. The first line AEDs are: Phenytoin, Phenobarbitone, Carbamazepine, Sodium valproate. When seizures are not controlled with these AEDs, newer AEDs are used like: clobazam, lamotrigine, topiramate, vigabatrin, levetiracetam, tiagabine etc.

Does it matter when I take my medication?

To work properly, medication needs to be taken regularly as prescribed.

If my seizures get worse, can I take extra medication?

No one should take extra medication unless advised to do so by the doctor.

What are the side effects of epilepsy medications?

As is true of all drugs, the medications used to treat epilepsy have side effects. The occurrence of side effects depends on the dose, type of medication, and length of treatment. The side effects worsen with higher doses but tend to be less severe with time as the body adjusts to the medication. Anti-epileptic drugs are usually started at lower doses and increased gradually to make this adjustment easier.

Side effects of epilepsy drugs can include blurry or [double vision](#), [fatigue](#), sleepiness, unsteadiness, stomach upset, [skin rashes](#), low [blood](#) cell counts, [liver](#) problems, swelling of the gums, [hair loss](#), [weight](#) gain, and tremor. Inform your doctor to address the side effects.



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What are the precautions that I should follow while on medication for epilepsy?

Must not miss the medication even once.

Must be regular with the timing of the medication.

Must have at least 6-7 hours of sleep.

Must not consume alcoholic beverages.

Must not do swimming, mountain climbing, other dangerous activities.

Must always tell the treating physician about the epilepsy medication, while receiving a drug for another ailment.

Does epilepsy or the drugs used for epilepsy cause brain damage?

Certainly not. Epilepsy by itself does not cause brain damage, in fact it is other way round. Children born with various degrees of brain damage have retarded brain development as well as epilepsy. The antiepileptic drugs per se do not cause brain damage.

Does epilepsy disappear on its own without any treatment?

Yes, it does. It is reported that in 15-20% of epilepsy has spontaneous remission. This means without any treatment the epilepsy may stop on its own. Such cases are often quoted claiming a cure by alternate methods of treatment. However, the difficulty is to identify who will have spontaneous remission and who will not, so everyone gets treated.

How long will I have to continue to take my medication?

The length of time will depend on the type and duration of epilepsy. If a person has not had seizures for more than 2 years, the neurologist may discuss, to withdraw medication gradually depending on cause and type of epilepsy.

What is refractory epilepsy?

Refractory epilepsy means that the person's seizures cannot be controlled with medication. It is also called "drug-resistant", "intractable", or simply "uncontrolled". Some of them do well with epilepsy surgery.

What is Epilepsy surgery?

About 20% of patients with epilepsy may not respond even to multiple drugs. These patients need to be worked up for epilepsy surgery. About 50% of these patients may benefit with specialized surgical treatment. If selection of patients is good, more than 50% have seizure free post-operatively.

Can people die from epilepsy?

Epilepsy by itself does not cause death but accident due to seizure may result in death (e.g. road traffic accident)

Is there anything I can do to help reduce my seizures?

Taking anti-epileptic medication regularly as prescribed helps to get the best possible control of seizures. It is also helpful to try to identify factors, which may trigger seizures, such as lack of sleep or too much alcohol, and to avoid these where possible.



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Is it safe for me to use a computer and watch television?

Most people with epilepsy, can safely use a computer and watch television. Only when epilepsy is “photosensitive”, which means that their seizures are triggered by flickering or flashing lights it is advised to avoid triggers.

My son has epilepsy. Is it safe for him to have vaccinations?

Current knowledge suggests that there is no connection between the vaccine and epilepsy.

I am finding it harder to remember things since I developed epilepsy. Why is this?

Neither epilepsy nor AED affect memory, only if seizures are very frequent or higher dosage of AED is used, memory may be effected temporarily.

Would complementary treatments help my epilepsy?

The most successful treatment for epilepsy is anti-epileptic medication. Other treatments are normally seen as additional to, rather than an alternative, to medication. At the moment there is little evidence for the effectiveness of complementary therapies.

How about driving?

If you have active epilepsy you should not drive. As per current Motor Vehicle Act in India, people with epilepsy cannot get a driving license. However, in the western countries if a person is free from seizures for six months to two years even while taking Anti Epileptic Drugs driving license is issued to drive personal vehicle.

I have just been diagnosed with epilepsy. Will I be able to get and keep a job?

Nearly all jobs are open to people with epilepsy and most people with epilepsy can work in any area they choose. There are restrictions in the armed services, for people who are still having seizures or are taking medication for seizures. Work involving unguarded machinery, heights, open water or fires is not recommended if seizures are not controlled.

Are there any food restrictions?

Absolutely Not. None of the food items vegetarian or non-vegetarian food, fruits or vegetables have any role to play in controlling or exaggerating epilepsy.

Can a patient with epilepsy play games and take part in any kind of sports?

The answer is YES, in a large number of patients. As a basic principle patient with epilepsy should avoid such activities wherein if the person gets an attack, his/her life should not be in danger due to accident. So obviously activities like swimming, motor racing, rock climbing are avoided. Even here if the patient is fit free for a couple of years one can participate in the sports. All other games like football, cricket can be played without any problem. There are very famous international sports persons living with epilepsy.

Epilepsy and marriage

Can a person with epilepsy get married?

Of course, yes. They can get married, have normal sexual life and children. AEDs should be continued. The future partner should be well informed about illness and emphasize, the need to continue AEDs.



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Epilepsy and Oral Contraceptives

Some type of AED may interfere with contraceptive pills, hence you should consult your doctor when taking oral pills.

How can preconception counseling help?

Preconception counseling helps women to be fully informed about the effects of their epilepsy and anti-epileptic drugs (AEDs), on themselves and their unborn baby. Women who take AEDs to control their seizures may need to be aware that their medication could affect their baby. They also need to consider the possible effects of not taking medication. If a woman has seizures when she is pregnant, there is a risk of injury to her and to her unborn baby. The doctor will discuss these issues during preconception counseling and try to give minimum dosage of AED. Ideally, epilepsy treatment should be looked at before becoming pregnant. If a woman is still having seizures, her AEDs may be kept on the lowest dose that still gives the best control of her seizures. If a woman has been seizure free for two or three years, she may be advised to slowly stop her AEDs.

What happens if the pregnancy was not planned?

This is most common scenario. If a pregnancy is not planned, there is no opportunity to have preconception counseling. When this happens, it is recommended that the woman carries on taking her AEDs and starts taking folic acid. It is also recommended that she see her doctor as soon as possible.

Does AED in pregnant woman cause birth defects in child?

The baby will be exposed to the mother's AEDs while in the womb and there is a risk that her baby may be born with a birth defect or developmental abnormality. The risk of a major birth defect in normal population about 3%. If she is taking one AED, the risk is around 3- 7% and it rises to around 15% if two or more AEDs on higher doses are taken. At the moment sodium valproate appears to carry greater risks than other AEDs.

If the baby's father has epilepsy, his epilepsy and AEDs will not affect the baby's development

Why is folic acid recommended?

Folic acid is a vitamin that helps a developing baby's spine to form. It is recommended that women take a supplement of folic acid ideally before conception and through pregnancy. This may help to reduce the risk of birth defects.

What is ante-natal screening?

For all pregnant women, ante-natal screening of the baby in the womb is used to check the baby's development. Screening such as ultrasound scans can be done at certain intervals throughout the pregnancy. Some women have an alpha-feto protein blood test to find out the risk of the baby having spina bifida. Pre-natal screening can only identify some types of birth defect or developmental abnormalities but is not 100% reliable.

Why is vitamin K prescribed?

Vitamin K is important for blood clotting. AEDs can sometimes affect the level of vitamin K in the body. It is often recommended to take 10mg of vitamin K1 daily during the last month of pregnancy. This aims to reduce the risk of bleeding problems in the baby during and after labor. .

Can we prevent Epilepsy?

Yes, by preventing brain damage a) during birth with hospital delivery b) avoid road traffic accidents by wearing helmets, seat belts etc. c) prevent brain infections like tuberculosis and neurocysticercosis and d) stroke prevention.



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Famous person list

Many famous and well known people have or did have epilepsy, here is a list of some of these people who suffered epilepsy in their lives: Sir Isaac Newton, Aristotle, Napoleon Bonaparte, Alexander , Alfred Nobel, Leonardo Da Vinci, Martin Luther, Pythagoras , Theodore Roosevelt, [Jonty Rhodes](#).

How can I advocate for epilepsy?

Answer: There are lots of ways! One of the easiest ways is to talk about it. One of the most difficult challenges that people with epilepsy face is the stigma. By helping to spread awareness and educating others, you can help erase the misconceptions that exist about epilepsy. Not only that but voicing your concern – especially to the government – is another big way to advocate for epilepsy.

Can people with epilepsy take COVID-19 vaccines?

Vaccines against COVID19 are currently being approved and becoming available. There is currently no evidence to suggest that having epilepsy is specifically associated with a higher risk of side effects from a COVID-19 vaccine. For people with epilepsy, the risk of COVID-19 infection and potential complications far outweighs the risk of side effects from a COVID-19 vaccine. As with other vaccines however, a fever can develop after a COVID-19 vaccination. This could lower the seizure threshold in some people. Antipyretics (e.g. paracetamol/acetaminophen) taken regularly for 48 hours after the vaccination (or for the duration of fever) will minimize this risk.

Before you receive a COVID-19 vaccine, make sure to let your vaccination provider know that you have epilepsy, as well as any other important medical information, such as:

- Allergies, especially an allergy to any ingredient in the vaccine
- Allergic reactions to prior vaccines (e.g. flu vaccine)
- Current or recent fever or infection
- All medications you are taking, especially medications that suppress the immune system (e.g. immunomodulatory or immunosuppressive medicines) or anticoagulants.
- If you are pregnant or nursing, or plan to become pregnant

As with any vaccine, you should not receive the COVID-19 vaccine if you are allergic to any of its ingredients. You should not receive a second dose if you had an allergic reaction to the first dose.