National Neuroscience Institute

SingHealth

UNDERSTANDING EPILEPSY

A GUIDE FOR PATIENTS AND FAMILIES

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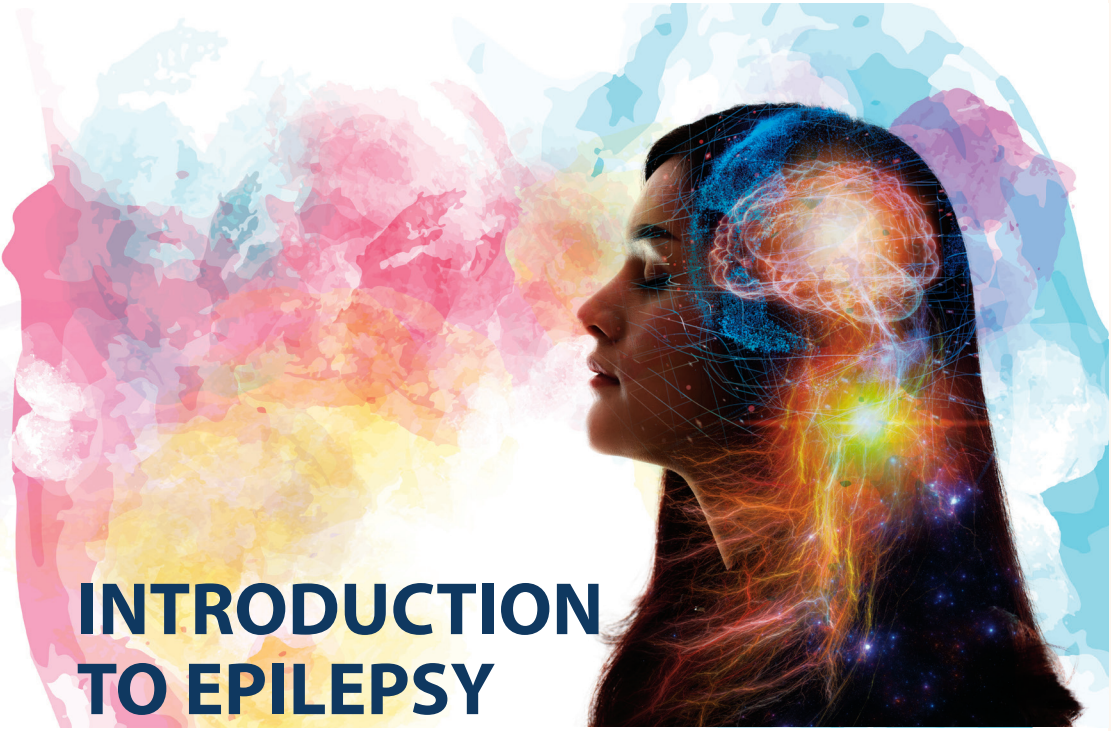


INTRODUCTION TO EPILEPSY

Epilepsy is a medical condition where a patient has a predisposition to having recurrent seizures.

What causes seizures in patients with epilepsy?

Under normal circumstances, the brain transmits electrical signals via brain cells known as neurons. These neurons work together to control and regulate motor movements, sensations, thoughts and emotions.

Occasionally, there is an abnormal electrical discharge in a group of neurons, which may spread to other areas of the normal brain, giving rise to fits, otherwise known as seizures. A person with predisposition to recurrent seizures has a diagnosis of epilepsy.

Who gets epilepsy?

Epileptic seizures can sometimes look frightening but they rarely cause any permanent damage to the brain.

About 0.5 - 1% of the population have had, or will have a seizure at some point in their lives.

Epilepsy can develop at any time, but many new cases begin in childhood, particularly in early childhood and around the time of adolescence.

What causes epilepsy?

In about two thirds of all cases, there is no single cause that can be found. However, causes have been attributed to damage of the nerve cells in the brain which leads to electrical disturbances. They include head trauma, brain tumour, stroke which causes interruption of blood flow to the brain, poisoning such as lead poisoning and infections such as meningitis, mumps and measles.

In some cases, epileptic seizures can be triggered by external factors:

- Alcohol consumption
- Flashing lights
- Lack of sleep
- Loud noises

Hence, it is important for the patient to recognise the factors which trigger seizures for them and avoid these factors in their daily life.

Is epilepsy an inherited condition?

Scientists believe that susceptibility to seizures is sometimes inherited. With some people this susceptibility is low and in others, it is higher. However, many people with high susceptibility may never develop epilepsy unless something happens to them that injures the brain. Epilepsy will often develop without family history of the condition.

Is there a cure for epilepsy?

Some forms of epilepsy occur only in childhood and the person may outgrow the seizures. Medication can only help to control seizures. Sometimes, surgery to remove the part of the brain in which the seizures originate can produce a complete and permanent stop to seizures.

DEALING WITH A TONIC-CLONIC SEIZURE

What to do during a tonic-clonic seizure

The first and most important step is to STAY CALM if you witness a seizure. Next, take note of the following:

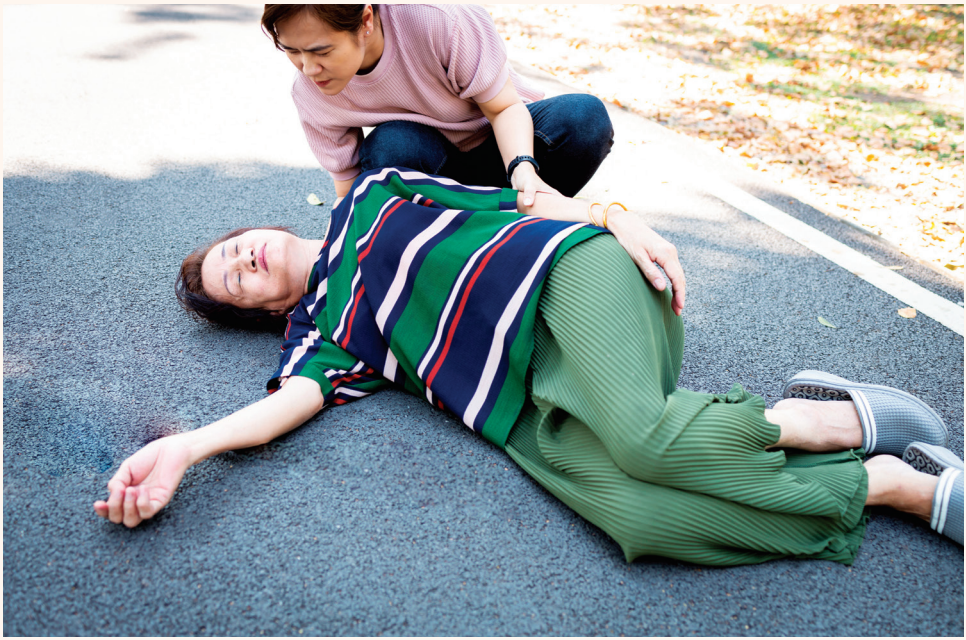
- Time the seizure.
- Place something soft under the head and loosen any tight neckwear.
- Remove any sharp or hard objects that may be nearby.
- Turn the person on his/her left side (recovery position) if he/she vomits or when the seizure is over.
- Stay with the person for at least 15 - 20 minutes after the seizure to ensure the breathing has normalised and he/she has regained consciousness.

What to avoid during a seizure

- DO NOT put any object in the person's mouth.
- DO NOT restrain the person.
- DO NOT move the person unless he/she is in danger (e.g. in the middle of the road).
- DO NOT apply CPR or mouth-to-mouth resuscitation until the jerking has stopped (if resuscitation is necessary).

When to call an ambulance

- The seizure lasts longer than usual for that person.
- The seizure lasts longer than five minutes, if you do not know how long the seizure will normally last for that person.
- Repeated seizure without gaining consciousness.
- It is the person's first seizure.
- Injury occurs during seizure or the seizure occurs in water.
- The person is pregnant.
- The person has difficulty breathing after the seizure is over.



TREATMENT FOR EPILEPSY

Epilepsy affects people in different ways. Your doctor will recommend a treatment plan based on your age, symptoms and other medical conditions.

1. Anti-Epileptic Drugs (AEDs)

AEDs are the most common treatment for epilepsy. Although they do not cure epilepsy, they prevent recurrent seizures. The goal of treatment is to control the frequency and severity of the seizure without burdening the patients with unpleasant side effects. There are a number of AEDs available but different AEDs control different types of seizures. The effectiveness of AEDs vary from person to person. Thus, the specialist will choose the appropriate AED based on the diagnosis of the patient.

Most patients will be treated with only one drug. If the drug is ineffective, the doctor may increase the dose until the seizures are controlled or the side effects are intolerable. If the seizures still persist, the doctor may substitute with, or prescribe another AED.

Side effects of AEDs

All drugs can cause side effects, however reactions of the individual to the medications may vary from person to person. Other common side effects may include double vision, unsteadiness and headaches. These effects can be alleviated when the dose of AED is reduced. However, most people may develop tolerance to these side effects after taking the AED for some time.

> Most AEDs can cause drowsiness and dizziness, so it is important that you do not operate any heavy machinery after taking AEDs.

TIP If you experience any allergy such as rashes, mouth ulcers, swelling of the eye/lips or breathlessness, inform the doctor immediately.

These are commonly used AEDs to manage symptoms of seizures:

TIP Always take your medication on time

TIP Consult your doctor if any unusual or concerning symptoms appear

TIP Please note that the list of side effects is not exhaustive

Anti-convulsants	Common side effects
Carbamazepine	Blurred vision Dizziness Double vision Drowsiness Dry mouth Headache Lethargy Stomach upset Nausea/vomiting Unsteadiness
Remarks: • The slow release (chrono) preparation allows less frequent dosing • DO NOT chew or crush the preparation • Inform the doctor if you experience abdominal pain, pale stools, fever, sore throat, mouth sores, unusual weakness or fatigue, bleeding or bruising	
Clobazam Clonazepam	Tiredness Problem with coordination Difficulty speaking or swallowing Drooling Change in appetite Vomiting Constipation Cough Joint pain
Remarks: • Clobazam may increase the risk of serious or life-threatening breathing problems, sedation, or coma if used along with certain medications • Tell your doctor if you are taking or plan to take: antidepressants; medications for anxiety; mental illness; sedatives; sleeping pills; opioids such as codeine, fentanyl, morphine or oxycodone or tranquilliser • Call your doctor or seek emergency medical care if you develop any of the following symptoms: unusual dizziness, light-headedness, extreme sleepiness, slowed or difficulty breathing or unresponsiveness	
Gabapentin	Dizziness Drowsiness Dry throat Fatigue Nausea/vomiting Tremor Unsteadiness Weight gain

Anti-convulsants	Common side effects	
Lacosamide Lamotrigine	Dizziness Drowsiness Blurred/Double vision Nausea Vomiting	Tiredness Loss of balance Difficulty walking Tremor Memory problem
Levetiracetam	Diarrhoea Dizziness Double vision Fatigue Headache Insomnia	Nausea Sleepiness Unsteadiness Low mood Irritability
Perampanel	Abnormal gait Aggressive behaviour Balance impairment Dizziness Drowsiness	Falling Ataxia Fatigue Irritability Hostility
Phenytoin	Anemia Confusion Double vision Drowsiness Folic acid deficiency Gum overgrowth Headache	Increase in body hair Lethargy Nausea/vomiting Slurred speech Stomach upset Unsteadiness Vitamin D deficiency
Remarks: • Maintain good oral hygiene • Increase intake of food high in Vitamin D and supplement with folic acid • For patients on tube feeding, avoid feeding two hours before and after phenytoin administration		
Phenobarbitone Primidone	Confusion Constipation Depression Dizziness Drowsiness "Hangover effect" Headache	Impaired judgement Lethargy Nausea/vomiting Nervousness Nightmares Poor memory

Anti-convulsants	Common side effects	
Topiramate	Stomach upset Unsteadiness Fatigue Impaired concentration Confusion Language problem (difficulty in choosing words)	Tremor Hot flushes Weight loss Muscle pain Weakness
Remarks: • Topiramate can cause kidney stones. Hydrate adequately		
Sodium Valproate/Valproic Acid	Change in menstrual cycle Impaired judgement and co-ordination Hair loss Stomach upset	Nausea/vomiting Swelling of ankles Drowsiness Tremor Weight gain
Remarks: • The slow release (chrono) preparation allows less frequent dosing • DO NOT chew or crush the preparation • Inform the doctor if you experience jaundice, fatigue, drowsiness, repeated vomiting and abdominal pain or menstrual changes, sore throat, fever, bruising or bleeding that is severe or that persists		

Monitoring of AEDs

This involves monitoring of seizure frequency and side effects of the treatment. Thus, patients need to maintain a seizure diary and communicate with the physician at each visit. Blood tests are required sometimes to monitor the liver function, components of the blood and drug level.

AEDs and compliance

Compliance is defined as taking the prescribed medication according to the instructions given. This will help to prevent recurrent seizures and maintain a certain concentration in your blood.

- Take your medication regularly as missing a dose can lead to a seizure.
- If you miss a dose, take it as soon as you remember.
- DO NOT take the missed dose if it is too near the next dose, instead just skip the dose and continue with your next dose.
- DO NOT double the dose, inform your doctor if you miss a dose.
- DO NOT share your medication with others.
- Avoid taking alcohol with your medication. Alcohol will increase the sedative effect of AEDs and may interfere with the metabolism of some AEDs.

Stopping AEDs

Certain patients may need to take AEDs for life. However, if a patient

- Has been seizure-free for 2 – 5 years;
- Has no underlying structural lesion;
- Does not have a genetic condition;
- Has normal EEG and normal results on neurological examination, the doctor may consider tapering down the dosages and discontinuing the AEDs. A decision on whether to stop the AEDs should be discussed with the neurologist after weighing the risks. These include the possibility of having another seizure after the medication has been withdrawn.

2. Surgery for epilepsy

Patients who have seizures that are not controlled despite adequate trials of AEDs are candidates for surgery. The reasons for considering this alternative are the prospects of facing a lifetime of ineffective drug therapies and severely compromised social, intellectual and professional functioning resulting from repeated seizures.

However, like all medical treatments, surgery is not suitable for everyone. Thus, it is important to discuss the risks and outcome of the surgery with the neurologist and neurosurgeon.

3. Avoiding trigger factors

In many patients, the seizure frequency can be reduced by avoiding certain trigger factors as follows:

Alcohol

Drugs that act on the brain, like anti-epileptic medication, are likely to be more sensitive to the effects of alcohol. Alcohol can make seizures more likely to occur. In addition, the unwanted effects of the alcohol will be increased and it may worsen the side effects of anti-epileptic medications. Excessive or heavy drinking is likely to increase the risks of seizures and lead to other health problems.

Stress

Stress, lack of sleep, depression and mood swings may increase the seizure frequency. Counselling, relaxation exercise, stress management and/or aromatherapy may help to reduce stress and thus prevent a seizure from occurring.

Television, computers, video games

For some people with epilepsy, seizures can be triggered off by flickering or changing patterns of lights such as watching television. Chances of occurrences may increase if you get too close to the television screen or when you are tired.

- If you are affected or are feeling uncomfortable (e.g. dizziness, blurred vision, muscle twitching), turn away from the source of flickering light and cover one eye with your hand until the lights stop flashing.
- Always make sure you get regular breaks away from the screen and watch the television in a well-lit room, about 2.5m or more from the television.
- Do not watch if the picture becomes unstable because of poor reception.

Complementary Treatment

There are various types of complementary treatments, which may or may not help in epilepsy. To date, there is no scientific evidence to suggest that any type of complementary treatment is successful in controlling or 'curing' epilepsy.

It is therefore, important to discuss with your doctor first before attempting any form of complementary treatment. In addition, it is not advisable to reduce or stop any AED without consulting your doctor.

LIVING WITH EPILEPSY

Living with epilepsy is a lifelong process. Most people with epilepsy can do almost everything that people without epilepsy can do, be it work or social activities. However, there are certain lifestyle changes and some social implications that need to be noted.

Driving

Under the current Singapore Road Traffic Act, persons suffering from epilepsy are not allowed to drive.

Patients should discuss further with their physician regarding driving issues. The law in Singapore requires one to disclose his/her epilepsy diagnosis when applying for a license.

Employment

Most people with epilepsy are able to hold full time jobs. However, jobs that involve driving, operation of machinery, caustic chemicals, working underwater or at high heights are prohibited for patients with epilepsy. These jobs usually involve substantial risks which may be life or limb threatening should a seizure occur and thus are strictly not recommended.

All patients with epilepsy have an obligation to inform their employers about their medical condition as it could affect their performance ability or their safety, especially if the seizures are likely to affect the job performance severely. However, it is important to not over-emphasize on the condition as there may be prejudice by the employers, which usually stems from a lack of understanding and knowledge of the condition.

Home Activities

Most home activities are generally safe for patients with epilepsy. But it would be wise to take actions to minimise the risks of certain activities. For example:

- Showers are preferred to baths. If a bath is taken, the water level should not be too high and someone should be informed. The bathroom door should also remain unlocked.
- Fragile ornaments should not be placed on tables or any high shelves. They should be placed inside a display cabinet, which has a cover to prevent items from falling.
- A microwave oven is preferred to pots and pans or to a cooker. Open fires are not advisable either.
- There are alarms available in the market for persons with epilepsy living alone or who may need help if they fall.

Recreation

Exercise is generally good to help strengthen the body, relieve stress and improve self-esteem. Nearly all people with epilepsy are able to engage in some sort of physical activity. However, basic safety procedures should be undertaken while doing sports. For instance, anyone who is actively having seizures should not swim without the presence of a friend immediately close at hand or a lifeguard who has been warned of the risk.

Contact sports and other high-risk sport with a likelihood of injury are not advisable either. Examples include boxing, mountain climbing, sky diving, rock-climbing, surfing, hang gliding, scuba diving and water skiing. A protective helmet is advisable for patients who fall frequently due to poorly controlled epilepsy.

In general, the rule of thumb is moderation. Do not over exert yourself during exercise and always make an effort to notify the team leader of any activities that you have epilepsy.

Travel and holidays

People with epilepsy can enjoy traveling just like anyone else. Below are some points that you may want to take note.

- Do ensure that you have enough medicine for your entire trip. It is always better to carry a little extra.
- Always carry your medication in your hand luggage instead of storing in your check-in luggage and keep it in its original packaging. This is because some epileptic medications do not keep well if taken out of their original packaging. This also helps to avoid confusion at the customs.
- Ask your pharmacist for the chemical or generic name of the drug you take (drugs have different trade names in different countries).
- Ask your doctor to write a memo for you, stating your diagnosis and the drugs you require. This memo would be useful while at customs and would help medical staff should you require treatment abroad.
- Flying does not cause seizures, but missing sleep and exhaustion can be a trigger factor in some people.
- Where possible, take your medication at the recommended times. Your doctor can help you plan any adjustments you may need to make for changes in time zones.

Everyone needs a social life. There is no need to let epilepsy stand in your way as long as you are sensible and make sure that you do not put yourself or others in danger.

WOMEN AND EPILEPSY

Pregnancy

Women with epilepsy generally have higher rates of reproductive and endocrine disorders than the general population which may lead to problems of infertility. Always discuss with your neurologist or gynaecologist if you have a history of epilepsy or are on anti-epileptic medications and plan to get pregnant.

Women with epilepsy can become pregnant, have normal children and participate fully in parenthood. Pregnancies are higher risk for women with epilepsy, because of the seizures and the anti-epileptic medications. Birth defects have been reported in women on AED. While the 'normal' state of birth defects is 2 - 3% in women on AED, women with epilepsy who are not taking medication have a slightly higher risk of developing foetal malformations. Women on a single medication have a risk of about 3 - 5%. Multiple drug combination drastically increases the risk. Hence, in general, monotherapy (one AED rather than many) is preferred during pregnancy.

Seizures may even be more frequent during pregnancy and may harm both the baby the mother. Therefore, it is important to ensure that the mother does not stop taking the anti-epileptic medication while pregnant.

A doctor may decide to change or reduce a woman's medication if she plans to become pregnant. In some cases, however, the doctor may recommend that the risks of pregnancy are too great for the mother and child. Any changes in medication must be considered carefully, and a woman should never adjust her own medication without consulting her doctor.

Most neurologists may prescribe folic acid supplements for women who might become pregnant while on anti-epileptic medications. The best dose is not known, but the usual dose may range from 1 - 5 mg per day. The supplements should be taken everyday, since most women are not even aware that they are pregnant, and folic acid is needed for spinal formation of the foetus which takes place in the first six weeks of pregnancy.

Contraception

Some seizure medication can lead to failure of oral birth control pills. Alternative forms of family planning/contraception may be required if trying to avoid pregnancy.

Breastfeeding

Breastfeeding is beneficial, and the benefits usually outweigh the risks from trace amounts of seizure medicine present in the milk (with the exception of mothers on phenobarbitone). The mother should recognise that the child already has been exposed for nine months to the medicine in the placental bloodstream.

TIP Always check with your doctor if you are on AED and plan to breastfeed.

ACKNOWLEDGMENTS

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Note:
This information is given as a guide only and does not replace medical advice from your doctor. You should seek the advice of your doctor before starting any treatment or if you have any questions related to your health, physical fitness or medical condition.

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