



Epilepsy Ireland
249 Crumlin Road, Dublin 12
Tel: 01- 4557500
Email: info@epilepsy.ie Web: www.epilepsy.ie

FREQUENTLY ASKED QUESTIONS

1. What is Epilepsy?

The word 'epilepsy' is derived from the Greek word meaning 'to be seized, to be overwhelmed by surprise'.

To have epilepsy is to have a tendency to have recurring seizures. Anyone can have a seizure, if the brain is exposed to a strong enough stimulus. We know that about 1 in every 20 people will have a single seizure at some time during their lives.

In 2009 Epilepsy Ireland commissioned the UCD Centre for Disability Studies, School of Psychology, University College Dublin to determine the prevalence of epilepsy in Ireland. The study is the first nationwide prevalence study of anywhere in Europe and provides previously unavailable data on epilepsy in Ireland. The results estimated there are up to 36,844 people over the age of 5 living with epilepsy in Ireland.

The significance of having a tendency to have seizures will vary from person to person, and will depend on many things; for most people, epilepsy, will only affect them for a short period in their lives. For some, however, the consequences can be more lasting.

2. What causes a person to develop epilepsy?

In more than half of all cases, no cause can be found. The person with epilepsy is apparently healthy in every respect and there is no underlying illness, disease or damage causing them to have seizures. This kind of epilepsy is sometimes called idiopathic epilepsy. It would seem that some of us just have a greater propensity than others to have seizures.

Sometimes a cause for the epilepsy can be found. Anything that damages or injures the brain can result in epilepsy. Some of the common causes are head injuries, strokes brain infections e.g. meningitis or encephalitis and birth defects. Other more rare causes are brain tumours and some genetic conditions like tuber sclerosis

3. Is epilepsy an inherited condition?

In many cases, there is no family history of the condition at all. However, it would seem that some types of epilepsy do tend to occur more frequently in some families. Recent research has discovered that some forms of epilepsy have been linked to the inheritance of specific genes.

For example, Juvenile Myoclonic Epilepsy is linked to a gene, which has been located on chromosome six. It is possible to inherit this gene and not have a seizure, which would suggest that even where a person may have a genetic disposition to epilepsy, it does not necessarily mean that epilepsy will develop.

4. Is epilepsy ever contagious?

No. There is no way you can catch epilepsy from another person.

5. What is a seizure?

Epilepsy is the collective term for a large group of anatomical and functional disorders of the brain that are characterized by repeated seizures.

In simple terms a seizure happens when ordinary brain activity is suddenly disrupted.

A seizure can be described as an internal electrical storm. It is the consequence of abnormal, excessive discharges of nerve cells. It is this sudden unexpected loss of control that accounts for many of the misconceptions and the prejudice associated with epilepsy. Seizures are the symptoms of the disorder they are not the disorder itself.

- **How the brain works.**

The brain is the control center for the body. It is made up of millions of cells, called neurons, which are constantly transmitting and receiving messages enabling our bodies to work properly. If some of these brain cells malfunction, for any reason, the messages can become disorganized and a seizure may result. The type of seizure a person has will depend on where in the brain the malfunction occurs. The seizure may take the form of a loss of consciousness, involuntary movements, a change in behaviour or a combination of all these.

- **Types of seizure**

There are many different kinds of seizures but they are usually divided into two categories:

1. Generalised - If a seizure is generalised it means that the whole brain is affected by the malfunction and the person invariably loses consciousness. Tonic-clonic and Absences are examples of generalised seizures.
2. Partial - If only part of the brain is affected, the person may remain conscious throughout the seizure or their consciousness may be impaired in some way. What the person does or experiences during the seizure will very much depend on what part of the brain is malfunctioning.

6. What is a Tonic-Clonic seizure?

A Tonic-Clonic seizure is a major convulsive seizure. It is what most people think of when they think of epilepsy and used to be called "grand-mal".

The whole brain suddenly malfunctions and the person loses consciousness immediately and falls to the ground. Sometimes the person may appear to cry out as he or she falls to the ground. This noise is caused by air being forcefully expelled from the lungs. The body stiffens briefly, (the tonic phase) and then starts jerking (the clonic phase). Breathing may be shallow and even stop for a few moments causing the skin to turn a bluish colour. Saliva may gather in the mouth and, occasionally, bladder or bowel control may be lost.

The jerking movements slow down and the seizure usually ends naturally after a few minutes. On returning to consciousness, the person may feel confused and sleepy but many people are able to resume their normal activities after resting for a short while.

7. What is an Absence?

An Absence is another type of generalised seizure. It looks like a short staring spell that lasts for a few seconds. This type of seizure is most often seen in children.

The child is momentarily completely unaware of what is going on around him or her, but very quickly, returns to full consciousness without falling or loss of muscle control. Some children will stumble and fall if they have this kind of seizure while running around at play.

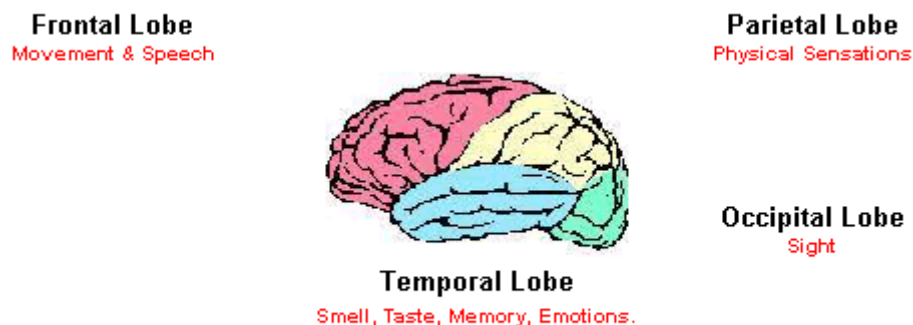
These seizures happen so quickly that they can go unnoticed for some time. Often parents and teachers think that the child is just being inattentive or is daydreaming. Because of this and because absences can occur very frequently, sometimes many times a day, they can adversely affect a child's learning. Once detected, they are usually quite easily treated.

8. Can you remain conscious and have a seizure?

Yes, if you have a simple partial seizure. During this kind of seizure a person may experience jerking in an arm or leg, which they cannot control, but they know what is happening and are aware that they are having a seizure.

9. What is a Complex Partial seizure?

This type of seizure usually results from malfunction in the part of the brain known as the temporal lobe. It is also sometimes called a temporal lobe or psychomotor seizure.



LOBES OF THE BRAIN

A typical complex partial seizure can start with a strange sensation - a feeling of fear, a sick feeling in the stomach, seeing or hearing something that is not really there.

The person may stare blankly and make chewing movements. They may make strange gestures, pull at clothing and walk around in what appears to be a dazed state. Although not aware of things and people around them, a person having this type of seizure may follow simple instructions if they are given in a calm, friendly voice.

It may be some time before the person returns to full awareness and they will still have no memory of what happened or what they did during the seizure.

The manifestation of the type of seizure varies from person to person, but each seizure the person has usually follows a similar pattern.

10. Can someone die from epilepsy?

Yes is the short answer, just as it would be for asthma, diabetes and many other conditions often assumed to be 'benign'. In fact, there are 70 to 80 epilepsy deaths in Ireland each year. Drowning, head injury and road traffic accidents account for many of these deaths. Likewise, status epilepticus, which is a prolonged seizure or series of seizures from which the person does not recover consciousness, cerebrovascular diseases and chest infections are also common causes of death. Suicide too is 2 -- 3 times higher with epilepsy than the rest of the population.

All of the above deaths together account for around 50% of epilepsy deaths. They would be greatly reduced if the seizures of the people dying in these ways were fully eliminated. This is also true for the biggest single cause of epilepsy deaths, which accounts for at least half of them. It is sudden unexpected death in epilepsy (SUDEP).

These premature deaths of otherwise healthy people with epilepsy have no obvious explanation. Usually, the person is found dead without any warning and routine autopsy fails to establish the cause of death. It must be stressed that SUDEP is a non-traumatic death for the person with epilepsy but the effect on his or her loved ones can be devastating.

To those concerned we would emphasise that good self-care can significantly reduce risks of SUDEP in those with established epilepsy. This means:

- Eliminating seizures
- Compliance with anti-epileptic medication
- Regular sleep and meals
- Learning to relax and manage stress
- Pre-conception counselling
- A sensible approach to alcohol
- Avoidance of street drugs

We in Brainwave also recommend that all children and people with epilepsy should use an anti-smother pillow (or no pillow at all), especially if there is any history of nocturnal seizures. Unfortunately, no research has been carried out to confirm that these pillows can actually protect people from SUDEP.

Family members and carers should be informed of what to do during and following a seizure. In particular, carers, should be advised to stay with a person for 15 - 20 minutes after the seizure to ensure they are breathing easily and to watch that they are not turning blue. An ambulance should be called if the seizure lasts more than five to seven minutes or if they are unduly concerned. Where risk factors of SUDEP are present carers should have a basic knowledge of resuscitation techniques.

Those at most risk from SUDEP are children and people with epilepsy who have other neurological conditions as well as epilepsy, those who are experiencing tonic-clonic seizures, young adults particularly males, people who have seizures during sleep and those people who are experiencing either increasing numbers of anti-epileptic drugs taken at the same time or frequent changes of anti-epileptic drugs. Most recent studies indicate that the lack of seizure control is the greatest risk factor.

The SUDEP risk for children with epilepsy whose seizures are well controlled is small, especially where there are no other complications. However, some children have died of SUDEP even during the child's earliest seizures. Most of the lifestyle advice above will not be applicable to children, most of whom will have excellent habits. The one area where parents may wish to intervene is in the area of sleeping. This can

be done by some form of monitoring either by sleep alarms or periodic checking. It may be possible for the child to be in the same room as his/her parent/s or for an adult to share his/her bed. However, this approach has to be taken in tandem with concerns for the child's independence, especially as s/he gets older.

Taking the steps outlined above can significantly reduce SUDEP risk, particularly if Brainwave members insist on their right of access to specialists and that action be taken to eliminate seizures. However, the other urgent action that needs to be taken is for major research into the causes of SUDEP. Brainwave has been campaigning to have such research carried out in Ireland and we urge you to support this in any way you can.

11. Can certain things cause a seizure to start?

For most people there is no single thing that triggers a seizure - it just happens. However, seizures may happen more often if a person gets very tired or hungry or forgets to take their medication. Commonly, people find that alcohol or getting over-stressed can bring on a seizure but no two people are alike and what affects one may have no effect on another.

About 3-5% of people who have epilepsy are photosensitive and may have a seizure in response to flickering lights e.g. strobe lights, or even the flickering of sunlight through trees.

If you discover that certain things can trigger your seizures, it is advisable to try to avoid whatever it may be. In this way, you may be able to control the number of seizures you are likely to have by adjusting your lifestyle.

12. How is it that some people get a warning of a seizure and others don't?

Some people experience an unusual sensation or an odd smell or taste or maybe a feeling of fear or sickness before they have a seizure. Sometimes, this "aura" lasts long enough for a person to be able to move away from danger or out of the public eye and to lie down in a safe place before they lose consciousness. This warning is, in fact, the start of seizure activity in part of the brain before it spreads to other areas. Sometimes, the seizure activity does not spread and all that happens is the special sensation.

If the seizure is generalised and involves the whole of the brain from the beginning then there will be no warning.

13. How is epilepsy treated by doctors?

In most cases, the family doctor will refer someone who is having seizures to a specialist for examination.

To make the diagnosis of epilepsy, the doctor will need a careful medical history and as much information about what happened when the person had the seizure and what it looked like. A good eyewitness account is very important.

Usually, the person will be asked to undergo an Electroencephalogram (EEG). Sensors attached to the scalp can record the electrical activity in the brain, which can help the doctor decide whether or not the person has epilepsy.

If epilepsy is diagnosed, it is usually treated by a daily drug regime.

14. Will I have to pay for my Medication?

No. People with epilepsy are entitled to get their anti-epileptic medication free of charge, if you do not have a medical card, you can get a Long Term Illness Book through your local health board.

15. Can epilepsy be cured?

Some children who have certain types of epilepsy can grow out of the tendency to have seizures altogether.

Recent research has shown that, in many cases, once a person has been free of seizures for a few years, the epilepsy medication may be withdrawn, slowly, by the doctor and there is an excellent chance of the person remaining seizure free, without medication.

For some people, taking the medication is something that will have to be continued for many years and for some, existing medications do not completely control their seizures. Newer medications, which have recently appeared on the market, will hopefully, help to reduce this number still further.

For those who do not respond to the medication, surgery may be an option. If the abnormal activity causing the seizures is limited to a small area of the brain in the temporal lobe, it may be possible to eliminate, or control, the seizures, by removing part of the brain in an operation called a temporal lobectomy.

Anyone being considered for surgical treatment will have to undergo a long series of investigations, which can take a considerable length of time. These will usually include long-term EEG recordings (including a stay in hospital), psychological assessment and brain scans.

16. Can seizures cause damage to the heart or Brain?

Despite the most violent movements and disturbances at the time of the seizure, the heart is not strained and continues as strong as ever, afterwards. The brain, although temporarily put out of normal function during the attack, does not suffer any lasting effect. There may be rare exceptions but only in the case of the prolonged, severe and frequently repeated seizures.

17. Will having epilepsy affect my employment prospects?

In most cases, it should not. However, the impact of epilepsy on people's lives varies a great deal and decisions on employment should be based on each individual's circumstances.

Most people with epilepsy are perfectly able to work at whatever they choose to do. Others do not have any particular difficulties when placed in the right job, but each person's difficulties and limitations need to be individually assessed.

Anyone with a history of epilepsy, however, will not be able to work in a job that will require them to drive a lorry, bus, train, etc.

18. Will epilepsy affect my ability to take part in sports or other leisure activities?

Again, in most cases, it won't. A lot will depend on the degree of seizure control and the type of sport activity involved.

If there is a possibility that you might have a seizure you should ensure that, for example, when you swim, it is with someone who will recognise a seizure and will be able to keep your head above water if you have one while swimming.

Again, cycling on a busy road should be avoided, unless, you are fairly sure your epilepsy is under control and always remember to wear a helmet.

19. Can people with epilepsy drive a car?

Yes, provided the person has been free of seizures for one year and is certified fit to drive by a doctor.

20. Can I drink alcohol if I have epilepsy?

Heavy drinking is likely to bring on a seizure and should be avoided. Moderate use of alcohol depends on the reaction of each individual. Some people find they can drink without any ill effects, but others can't and find that alcohol increases the likelihood of having a seizure. As a result, some doctors recommend that alcohol is avoided, if possible. You will have to base your decision on your own experience.

21. Will epilepsy affect me having a baby?

The great majority of women with epilepsy have normal pregnancies and healthy babies. If you can, it is a good idea to plan your pregnancy in advance and to discuss the matter with your doctor, who may wish to change your drug regime before you become pregnant. Where as none of the anti-epileptic drugs can be said to be completely safe, some are considered to be safer than others.

However, any drug changes will need to be undertaken well in advance of pregnancy. You should never stop taking anti-epileptic drugs suddenly as this will result in serious withdrawal seizures and could be dangerous.

- **FOLIC ACID**

The Department of Health & Children encourages all women with epilepsy to take increased doses of folic acid when planning pregnancy. Due to the action of some anti-epileptic drugs, women with epilepsy are recommended to take higher doses of folic acid daily, compared with 400mcg recommended for women generally.

Folic Acid reduces the risk of neural tube defects, such as spina bifida. This risk is slightly higher in women with epilepsy so there is a very good reason to stress the importance of the supplement.

However, taking any supplements should occur in consultation with a patient's regular doctor. This is one issue that would be covered in preconception counselling, which is recognised as being important for women with epilepsy.

The Epilepsy pregnancy Register advises women with epilepsy who are pregnant or considering pregnancy.

Contact 1850 320 820