



Epilepsy Explained
Frequently Asked Questions



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Welcome

When you are first told of a diagnosis of epilepsy you may have lots of questions. Although epilepsy is a common condition, there are many types. People with epilepsy may need different types of treatment and support. Often people know little about it at first, so it is good to get the facts. This booklet deals with the most common questions that people ask.

The Brain: A Quick Tour

The brain is the control centre for the body. It has millions of cells called **neurons**. Neurons fire chemical messages to make our bodies work properly. Sometimes neurons may misfire and the chemical message is mixed up. This can cause a seizure. What type of seizure happens depends on where in the brain the misfire happened. To understand, it helps to know the parts of the brain and what they do. Our brains have 2 halves called **hemispheres**, a left and a right one. See Figure 1 below.

Figure 1

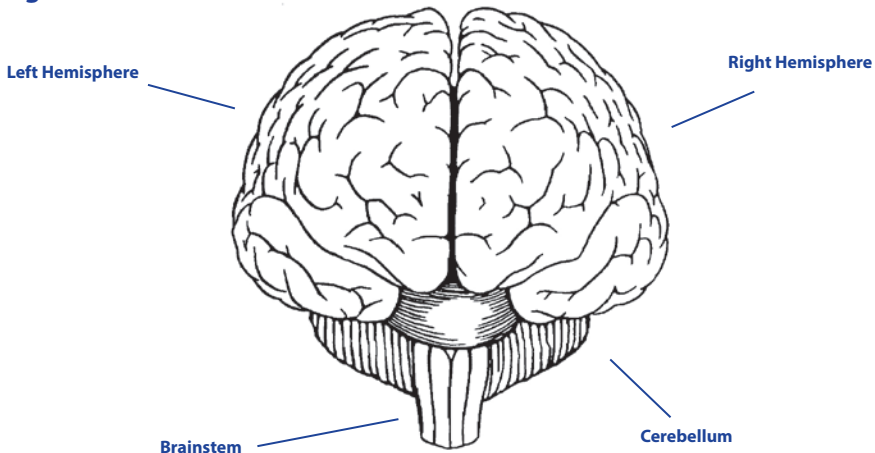
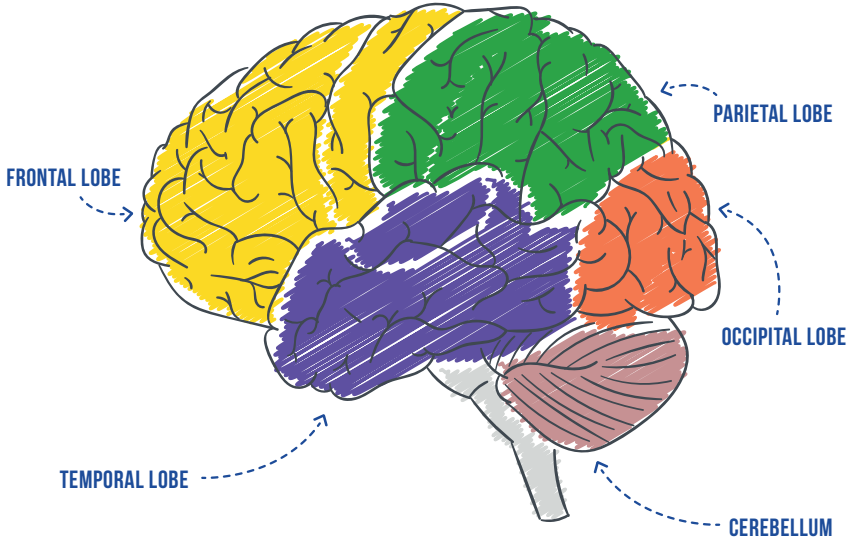


Figure 2

Both hemispheres are divided into lobes: temporal, frontal, parietal & occipital



Lobe of the brain

Temporal Lobe

What it controls & affects

Memory and emotions
Reading and writing
Non verbal processing
Language, speech, visual & auditory skills

Frontal Lobe

Planning and organisation
Judgement and problem solving
Making decisions

Occipital Lobe

Visual perception and attention
Reading and writing

Parietal Lobe

Hand-eye co-ordination
Spatial and direction awareness
Body awareness and touch

About Epilepsy

What is epilepsy?

Epilepsy is a **neurological** disorder which affects the brain. It is a tendency to have repeated **seizures**. This tendency can be long term but the seizures can be controlled, so a person can have epilepsy but they may not have active seizures. Seizures are brief and sudden disruptions to the electrical activity in the brain. Seizures start in a part of the brain or happen in both sides of the brain at once. Nearly **40,000** people in Ireland and at least **50 million** people worldwide have epilepsy. For many people, their epilepsy affects them most while seizures are active. For others, the impact of having epilepsy may be longer term, if their seizures continue.

Did you know?

- **1 in 115** people in Ireland have epilepsy
- That's over **37,000 men, women, and children** over age 5
- It is estimated that more than **10,000** are children and about **10,000** are women of childbearing age
- Rates of epilepsy are rising among the **over 65's**
- **Anyone** can develop epilepsy at **any age**
- More than **50 million people** worldwide have epilepsy
- **Diagnosis** is based on the medical history
- Diagnosis is usually based on **2 or more unprovoked seizures**
- But a person can be treated with medication after their **1st seizure** in some cases
- Many people have **normal tests** and **scans** but epilepsy can still be diagnosed
- In **about 50%** of cases the cause is not known
- Where **causes** are known they can include brain injury, brain infections, strokes, genetic factors
- **70%** of people can have their seizures controlled by medication
- **30%** have difficult to control epilepsy
- Epilepsy medication is **free on the Long Term Illness Scheme**
- **Epilepsy surgery** is an option for some people and can be very successful
- Some seizures **affect awareness** but others don't

- **Signs** can range from a déjà vu feeling to falls with shaking of limbs
- There are **over 30** epilepsy syndromes
- The main seizure groups are **generalised, focal** and **unknown onset**
- Certain **trigger factors** can make seizures more likely, such as missed medication, missed sleep, stress, missed meals, alcohol, illness, hormones, flashing lights
- Most people with epilepsy **work** at what they choose
- Some jobs are **restricted** (pilot, train driver, defence forces)
- People who are **seizure free for 12 months** can **drive a car, light van, tractor or motorbike**
- Exceptions to the 12 month seizure freedom driving rule apply to certain seizure types
- Epilepsy can be considered a **disability** if it impacts on a person's normal functioning but not everyone feels it affects them this way

How is epilepsy diagnosed?

A diagnosis of epilepsy is made by a consultant taking account of descriptions of seizures and also test results. Results of tests can help support the diagnosis and even pinpoint the seizure type. **Tests** include the routine awake EEG, sleep and sleep deprived EEG and either CT brain scan or MRI. A normal test result does not rule out epilepsy. Routine blood tests may be ordered. **Witness accounts** are important. Try to get as much information as possible from anyone who saw the seizure. **Videos** can be extremely helpful. Epilepsy is generally diagnosed when there have been two or more separate and unprovoked epileptic seizures.

What if I have only had one seizure?

When you first had a seizure you may have been taken to hospital. If it was your only seizure you may not have got a diagnosis of epilepsy then. This is because 1 in 20 people will have a single seizure and most never have another, while 1 in 115 will have more seizures and may be diagnosed with epilepsy then. Sometimes a person can be treated with medication after the first seizure if their tests suggest epilepsy and their doctor feels there is a risk that they will have more seizures.

What information will the doctors ask for?

When you see a doctor they will take a **history** or an account of what happened. It helps if you can get people who witnessed the seizure to write down what they saw. You can give these descriptions to the doctor to put in your chart. They need to describe what happened before, during and after the seizure in as much detail as possible. A video is useful if someone is able to record it on their phone. Witness accounts are helpful as it is likely you won't recall the seizure yourself if your awareness was affected.

What is an EEG?

The main test for epilepsy is the **EEG** or **Electroencephalogram**. This test measures electrical activity, or brainwaves, in your brain. It is a painless test. Electrodes are placed on your head with sticky pads so your hair must have no spray or gel in it. You will be awake and need to keep still for around 30 minutes. A computer records the results.

What if nothing shows up on the EEG?

Often an EEG is normal as the person is not having seizure activity at the time. This does not mean they don't have epilepsy. Many people with epilepsy have had normal EEG's. If nothing shows on the EEG the doctor may order a sleep EEG or sleep deprived EEG too.

Why are lights flashed during the EEG?

This is to check if you have **Photosensitive Epilepsy (PSE)**, a response to flashing lights, which affects only 3-5% of people with epilepsy. See our website www.epilepsy.ie for more details on PSE.

Sleep EEG

During sleep our brainwave patterns are different to waking so sometimes a sleep EEG may be ordered. A sedative may be given so the person will sleep for the test. This test can help identify certain seizures in young children.

Sleep-deprived EEG

For a **sleep deprived EEG** you may need to sleep less the night before the test, or not sleep at all. This way you are more likely to fall asleep during the test which is what the doctor hopes will happen. Lack of sleep is a trigger for seizures so you may be more likely to have a result on this test. The test lasts 1-2 hours.

What other EEG tests are there?

Most people only have the routine or sleep deprived EEG's unless the doctor needs more information. An **ambulatory EEG** is a portable EEG worn during daily activities. **Video telemetry** is done in a special unit with an EEG linked to a video camera for 24 hours or more. This is usually for surgical or complex cases.

What routine scans might my doctor order?

CT scan: A brain scan to look for or rule out structural problems in the brain. These could be very small like a mis-shaped vein, any area that's grown abnormally or a piece of scar tissue. Most people with epilepsy do not have such structural problems. The CT (Computerised Tomography) scan x-rays the brain to give a 2-D image of the brain structure.

MRI scan: The MRI (Magnetic Resonance Imaging) scan uses strong magnetic force to take images in sections across the brain and build up a 3-D picture. You will need to keep still during the test.

What causes epilepsy?

In half of cases there is no known cause. The person has no illness, disease or damage to explain epilepsy. Some causes are **structural** such as genetic abnormalities or developmental problems in the brain like malformed veins or areas which have not developed normally. Genetic factors can be unique to the person or hereditary. Many people with epilepsy have no family history of it but some epilepsies are more common in some families. A **low seizure threshold**, which can reduce the brains resistance to a seizure, may run in families.

Other causes can include:

- head injuries
- strokes
- metabolic disorders
- brain infections such as meningitis or encephalitis
- brain tumours
- lack of oxygen due to difficult birth or accident
- damage due to alcohol and substance abuse

Epilepsy is not contagious, you can't spread or catch it

Can epilepsy be cured?

Typically we talk about control of seizures which in most cases is achieved with medication. Epilepsy surgery can be very successful and may cure epilepsy in some people. When someone is seizure free for 10 years and off seizure medication for 5 years their epilepsy can be considered resolved. A person who has an age dependent epilepsy syndrome but who is now past the applicable age, can also be considered to have resolved epilepsy.

What is a seizure diary?

A seizure diary is a written or electronic record of your seizures. It is important in epilepsy care to help you see if there are any patterns to your seizures and find possible triggers. It can also help your medical team track changes in your epilepsy. Phone apps such as the Epilepsy Ireland App help you to record and track your seizures over time. See www.epilepsy.ie for more information.

About Seizures

Before 2017, seizures were described using such terms as Generalized or Partial, complex or simple. Since 2017 they are classified first by **area of origin (Onset)** and then by levels of **awareness (Aware/Impaired)** and by **movement (Motor/ Non Motor)**. The chart below compares the newer and older terms alongside some of the outdated terms in less common use.

Newer Term	Older Term	Outdated term
Generalised Onset Motor	Generalised Tonic Clonic	Grand Mal, Major motor, Convulsion
Unknown Onset Tonic Clonic	Generalised Tonic Clonic	Grand Mal, Major Motor, Convulsion
Generalised Onset Non-Motor	Generalised Absence	Petit Mal
Focal Aware Motor	Simple Partial/Aura	Jacksonian
Focal Aware Non-Motor	Simple Partial/Aura	
Focal Impaired Awareness	Complex Partial	Psychomotor Temporal Lobe
Focal to Bilateral Tonic Clonic	Secondary Generalized	Grand Mal, Major Motor, Convulsion
Focal/Generalised Myoclonic	Myoclonic	Minor Motor
Focal/Generalised Atonic/Tonic	Atonic/Tonic Drop Attack	
Focal/Generalized Clonic/Tonic	Clonic/Tonic	

Explanation of New Terms

- **Onset:** Where in the brain the seizure starts from
- **Generalised onset:** both sides of the brain involved
- **Focal onset:** starts in part (area or lobe) of the brain
- **Unknown onset:** unclear where the seizure starts
- **Onset** is subdivided by **awareness** and **movement**
- **Awareness level:** is awareness impaired or not?
- **Motor or non motor:** is movement involved or not?

ILAE 2017 Classification of Seizure Types Basic Version

Focal Onset

Aware
Impaired Awareness

Motor Onset
Nonmotor Onset

Focal to Bilateral
Tonic-clonic

Generalized Onset

Motor
Tonic-clonic
Other motor
Nonmotor (Absence)

Unknown Onset

Motor
Tonic-clonic
Other motor
Nonmotor

Unclassified

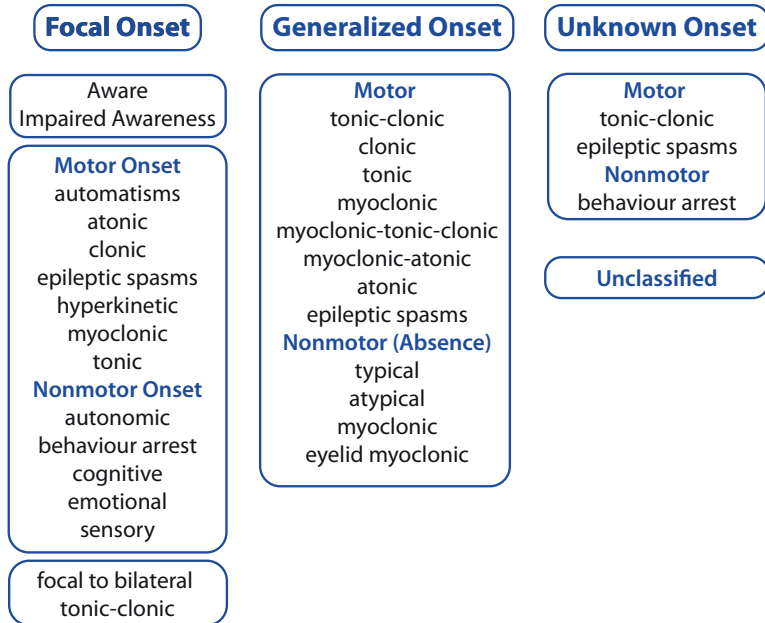
Why change the names of seizures?

The newer descriptions describe seizures more accurately than words like “partial” or “secondary generalised”. It is hoped the newer terms will make discussion of seizures clearer for healthcare professionals and patients. Your doctor may use the newer terms, or you may see them used online, so it is good to know about them. However, you can use whichever term you are comfortable with. There may be overlap between terms at first but you should not be concerned. As with any change, it may take time for everyone to adopt the newer terms.

What happens in seizures?

1. **Generalised Onset seizures** – in these seizures abnormal electrical activity affects both sides of the person’s brain and they may lose consciousness, sometimes so briefly that no one may notice. What symptoms are seen depend on whether it is a **generalised non motor** or **generalised motor seizure**.

- **Generalised Non Motor Seizures** include typical and atypical absences.
 - **Generalised Motor Seizures** include tonic-clonic, tonic, clonic, atonic, and myoclonic.
 - **Absences** are staring spells which last only seconds but consciousness is lost briefly.
 - **Tonic-clonic seizures** involve loss of consciousness and convulsive movements of the limbs. This is the type of seizure that most people think of when they think of epilepsy.
 - **Myoclonic seizures** involve brief jerking of the whole body, or more often the arms or legs, but not normally loss of consciousness.
 - **Atonic seizures** are also known as drop attacks where the body suddenly loses tone, goes limp and falls to the ground.
 - **Tonic seizures** involve stiffening of the whole body and the person will fall if not supported.
 - **Clonic seizures** are the jerking phase of a seizure by itself where the limbs may jerk without the tonic or stiffening phase happening first.
2. **Focal Onset** (Partial) seizures start in one part of the brain. Focal seizures divide into:-
- **Focal Aware** (Simple Partial) – the person may experience a range of symptoms including déjà vu, jerking movements, a taste or smell.
 - **Focal Impaired Awareness** (Complex Partial) – awareness is affected to some extent, and symptoms vary. There may be confused behaviour and wandering.
 - **Focal to Bilateral Tonic Clonic** (Secondary Generalised) – seizures start in one part of the brain and spread to affect both sides to become a full tonic clonic seizure.
 - Focal seizures may or may not affect consciousness (**aware or impaired**) and may or may not affect movement (**motor or non motor**).
3. **Unknown Onset:** Describes where the area the seizure starts in is unknown. These may either have **Motor** or **Non Motor** symptoms.



ILAE 2017 Classification of Seizure Types Expanded Version

Are all seizures due to epilepsy?

No. Some seizure-like episodes are not epileptic.

Febrile seizures (febrile convulsions) are common in young children and linked to fever. These typically fade with age.

Non Epileptic Attack Disorder (NEAD) episodes may look like epileptic seizures but they are different and often have a psychological cause. They are outside the person's control and are treated with psychological support. It is possible to have both epileptic seizures and Non Epileptic Attack Disorder. In order to tell epileptic and NEAD attacks apart a person will need to be admitted for video EEG monitoring in hospital.

Seizures due to medical conditions, such as diabetes and cardiac causes, are not epilepsy and should improve when the underlying condition is treated.

Key Points about Seizures

- A single seizure may not be epilepsy.
- In seizures, consciousness may be lost fully, partly or not at all.
- Seizures vary greatly between people.
- Most major seizures last from 1-3 minutes.
- Triggers include excess alcohol, skipped meals and missed sleep.
- Absences are staring spells often mistaken for daydreams.
- Some seizures feature wandering, confusion or agitation.
- Prolonged seizures are treatable with emergency medication.
- Seizures occur when normal brain activity is briefly disrupted.
- Our brains work on electrical impulses.
- Too much electricity can lead to seizures.
- Seizures are short and usually stop naturally.
- Not all seizures are the same.
- Not all seizures are due to epilepsy.

Triggers for seizures

For many people a seizure just happens. However, certain triggers can make seizures more likely. Common triggers can include missed medication, too much alcohol, lack of sleep, stress, and illnesses or fevers. Everyone is different and what affects one person may have no effect on another. If you find that certain things trigger your seizures, it is wise to try to avoid whatever it may be. In this way, you may be able to reduce the number of seizures you have.

Managing Seizures - First Aid

Generalised Onset Seizure with Motor Features (Tonic-Clonic, Tonic, Clonic, Atonic)

Do:

- Stay calm and time the seizure
- Protect the head area
- Remove any harmful objects
- Look for epilepsy ID
- Let the seizure run its course
- Turn the person onto their side into the recovery position when the seizure stops
- Stay with the person until they are fully recovered
- Stay with them until they recover and respond fully

Don't:

- Put anything into the person's mouth (you can wipe away saliva)
- Restrain or move the person, unless they are in danger
- Give them food or drink until they are fully recovered

An ambulance should be called if:

- it is the first known seizure
- the seizure lasts over 5 minutes for major seizures (or longer than average for the person's seizures)
- there are concerns about breathing difficulties
- more seizures follow without recovery in between, clusters of seizures
- the seizure happens when the person is in water
- the person is injured, has another medical condition or is pregnant
- you are in any doubt

Focal Impaired/Complex Partial Seizures

Do:

- Stay calm and time the seizure
- Let the seizure run its course
- Guide the person gently from danger
- Speak gently and reassure them
- Stay with them until they have fully recovered

Don't:

- Restrain the person, unless they are in danger
- Agitate the person

When to call an ambulance:

- If the seizure lasts more than 5 minutes, the person has more than one seizure, it is the person's first seizure, the person is injured or you are in any doubt.

Absences, Focal Aware/Simple Partial

Stay calm and time the seizure.

If they wander, guide them gently from danger.

Wait until the person is fully recovered and responsive.

Reassure them and explain what happened.

Medical help is not normally needed. Exceptions to this would include prolonged seizures, injury or repeat seizures without recovery.

Treatment and Medication

How is epilepsy treated?

The main treatment for epilepsy is **Anti-Epileptic-Drugs** or **AED's** for short. The AED prescribed will depend on the seizure type. Sometimes more than one AED is needed. AED's are all designed to stop too much electrical activity in the brain. The goal is to stop the seizures completely on one drug, or the fewest drugs with least side effects. This can sometimes take time to achieve. Seizure control is more likely when you are taking medication as prescribed and not changing it unless guided by your doctor or specialist nurse. Refer to Epilepsy Ireland's Treatment booklet for more details, see www.epilepsy.ie.

Side effects

All medications can have side effects though not everyone will experience these. Any side effects you have should be noted in a diary and should be discussed with your medical team. They may be able to adjust the AED dose or change the drug to avoid the side effect while still keeping your seizures controlled. See AED chart with possible side effects in our Epilepsy Treatment booklet on www.epilepsy.ie.

Medical Card (PCRS)

If you have a full medical card (PCRS) your AED's will be covered on that but you could be asked to pay prescription charges. To avoid prescription charges on epilepsy medication, full medical card holders can apply to get their epilepsy medication on the Long Term Illness Scheme (see below). Medical cards are issued to people below certain income limits. There are two types, the full medical card and the GP visit card. For more information see www.medicalcard.ie

Long Term Illness Scheme (LTIS)

The Long Term Illness Scheme (LTIS) covers free medications for certain specified illnesses or conditions only. Epilepsy is one of these conditions, so anyone diagnosed with epilepsy can get their epilepsy medication free on this scheme. The LTIS is not means tested. Since June 2019 changes have been made to the application process for the scheme, see www.epilepsy.ie. Information on how to apply for the LTI Scheme is available from www.hse.ie/lti or LoCall 1890 252 919.

Work, Family and Living with Epilepsy

Can I drive a car?

Most people with epilepsy can drive once they are 12 months seizure free and certified fit to drive by a doctor. Exceptions apply to first unprovoked seizures, seizures occurring in sleep only, seizures which don't affect consciousness or ability to act at any time, seizures due to withdrawal of anti-epileptic medication and provoked seizures. These exceptions can mean a reduced seizure freedom period or a licence issued subject to conditions. Some cases require a neurological opinion. The Medical Fitness to Drive guidelines require drivers to notify the National Driver Licence Service (NDLS) and their insurance provider about any condition that may affect driving safely. See the booklet *Epilepsy, Seizures and Driving* at www.ndls.ie and discuss with your doctor.

Can I work with epilepsy?

Having epilepsy doesn't necessarily prevent a person from following their chosen career and many people with epilepsy do just that. However, whether a job is suitable depends on the seizure type, pattern and frequency and the type of work involved. If seizures continue it may mean having to make changes at work and there are supports available to employers to help make the work place safer. Some jobs by their nature may be less safe, especially if they involve heights, water, sharp tools or dangerous chemicals. Careers requiring high levels of medical fitness may be restricted too. Health and safety considerations can mean you can't work at a job which would put your safety or that of others at risk. Factors such as pattern, as with sleep seizures, as well as triggers and the work environment need to be considered. Jobs involving shift work, care or supervision of children and vulnerable adults and lone working may need careful consideration. An individualised assessment of the seizures and the work environment is important. Driving regulations will impact on eligibility for transport related work while seizures are ongoing but when seizures are controlled more choices open up. While becoming an airline pilot may not be possible for someone with a history of epilepsy, obtaining a C or D licence to drive a large vehicle is possible when a person is 10 years seizure free without medication.

What am I entitled to if I can't work?

If you cannot work you may be eligible to apply for a welfare payment such as Disability Allowance, Disability Benefit or Invalidity Pension. The conditions attached to each payment vary. All will require a medical assessment. Disability Allowance is means tested while the rest are based on PRSI contributions. For more details see www.citizensinformation.ie

Am I entitled to Free Travel?

Currently Free Travel is attached to certain welfare payments and is only available to people on those payments. These include Disability Allowance, Invalidity Pension, Blind Pension and Carers payments. See www.citizensinformation.ie for more details about Free Travel.

Can I have a family?

Most men and women with epilepsy will be able to have a family if they choose. However, certain medications have been linked to lower fertility in some women and men so if you are having difficulties conceiving it would be important to discuss this with your GP and specialist nurse. For women with epilepsy access to good medical care is important before and during pregnancy. Most women with epilepsy have normal pregnancies and healthy babies. Folic acid at the higher dose of 5 mg is recommended for women and girls with epilepsy of childbearing age and this must be prescribed. This must be taken for at least 3 months prior to conception and continued until 14 weeks into pregnancy. If you are planning a pregnancy it is important to discuss your medication with your doctor or medical team to see if changes need to be made as some anti-epileptic drugs can put the baby at risk of birth defects or developmental problems. The highest risks are associated with sodium valproate (Epilim) but other epilepsy drugs also increase the risks and no anti-epileptic drug can be considered risk-free. Currently there is no evidence of increased risk from sodium valproate, or other AEDs, in babies of men with epilepsy. If you are a woman and you are concerned about your medication do not stop taking it, as seizures can also pose significant risks to women and unborn babies, but do follow your GP or epilepsy specialists' guidance. For more information on women's issues, pregnancy, safety and baby-care you can download this booklet from epilepsy.ie or contact your local Epilepsy Ireland office for a copy.

Can someone with epilepsy live an active life?

Yes. Most people with epilepsy can live a full and active life working, playing sport, socialising, travelling and taking up hobbies. If seizures continue some changes may be needed for safety reasons but it is still important to keep up as normal a lifestyle as possible. See www.epilepsy.ie for more information.

Will flashing lights, computers and TV affect me?

Only a small number of people with epilepsy (3-5%) are photosensitive and may have seizures due to flickering lights like strobes or flicker of sunlight through trees. This is diagnosed on an EEG. If you aren't sure if this applies to you, you can ask your medical team. See www.epilepsy.ie for more information.

Is epilepsy inherited or genetic?

Not everyone with epilepsy will have a known family history of it but some types of epilepsy do tend to run in families. The tendency to develop epilepsy can be described as a low seizure threshold and this may be inherited but seizures might not affect everyone. Some epilepsies are genetic but may not be inherited. Research in genetics and epilepsy is finding more and more genetic bases for epilepsy syndromes, which could, in time, lead to new therapies.

Can someone be conscious in a seizure?

Yes, in a focal aware (simple partial) seizure a person is fully aware.

Why do some people get warnings?

Warning or auras before seizures are Focal Aware (Simple Partial) seizures. These start in one area and may spread to affect more functions and awareness. In this way a person is aware at first before going on to have a more involved seizure such as a Focal Impaired Awareness seizure (Complex Partial) or a Bilateral Tonic Clonic seizure (Secondary Generalised).

Can someone die from epilepsy?

Everyone, whether they have epilepsy or not, faces some risk in daily life. While the risk of dying from epilepsy is small, it's important not to overlook it. It's best to understand the risk so you can reduce it further. The main risks in epilepsy include seizure related accidents, status epilepticus and SUDEP. See our Safety and Seizures Booklet at www.epilepsy.ie for more information.

Seizure related accidents and injuries can be reduced or prevented by taking special care around water, heat, heights, in the home and out and about. Seizures with falls are a particular concern for older people with epilepsy and for those with bone health issues. People with frequent seizures have higher rates of soft tissue injuries, fractures and even burns injuries. There is much you can do to reduce your own personal risk. Epilepsy Ireland's Safety and Seizures booklet contains a personal safety plan to help with reducing risk, see www.epilepsy.ie.

Status Epilepticus is a prolonged seizure lasting over 5 minutes, or a series of seizures where the person does not fully regain consciousness. Most seizures stop naturally within a few minutes. If a seizure lasts longer than 5 minutes it should be treated as a medical emergency and this is why we give a "5 minute rule" for calling an ambulance. Emergency medication helps prevent Status Epilepticus. You should talk with your doctor or specialist nurse about when emergency medication should be given.

SUDEP (Sudden Unexpected Death in Epilepsy) is a sudden death which is often not witnessed. It is rare with an estimated incidence of 1 death per 1000 adults and 1 per 4,500 children with epilepsy per year. It's not yet fully known what happens in SUDEP but it is thought that breathing or heart rhythm may be affected. Risk factors for SUDEP are thought to include, but may not be limited to: frequent seizures, uncontrolled tonic clonic seizures, sleep seizures, not taking medication as prescribed, unwitnessed seizures, being a young adult, male gender, earlier onset and longer duration of epilepsy, having intellectual disability, reduced seizure control during pregnancy and infrequent medical reviews. Sudep risks can be reduced by improving seizure control, avoiding or reducing known triggers including alcohol, monitoring ongoing seizures, having regular medical reviews and monitoring sleep seizures. More information about SUDEP is available in our Safety and Seizures booklet at www.epilepsy.ie.

Alarms and Safety Aids

Seizure alarms can help detect certain kinds of seizures with signs of movement, breathing and heart rate changes, saliva and urine. Some detect sleep seizures and others can be worn during waking. Some can dial out for help or alert a carer in the home. See our Safety and Seizures Booklet and www.epilepsy.ie for details of alarms and other safety aids such as pillows and protective headwear.

What support can Epilepsy Ireland offer me?

Epilepsy Ireland offers a range of services such as information, training and support. Our services for people with epilepsy and their families are free and our core programme is the Living Well with Epilepsy Programme (Toolkit) for newly diagnosed adults and for parents and carers. Further free programmes include STEPS self management programmes for adults and parents, and InnerWise meditation programmes. In addition, we also run Training For Success, a QQI Level 5 access course (see below). We provide individual and group support, school talks, family fun days, outreach services, emergency medication training, professional education events, seminars and conferences.

Training for Success

Training for Success is Epilepsy Ireland's one year full time access programme based in the Institute of Technology, Sligo. The programme is at QQI level 5 in the National Framework of Qualifications. No Leaving Certificate is required and student intake is from all over Ireland. All eligible students receive a training and accommodation allowance from the Mayo, Sligo and Leitrim Education and

Training Board. The course is the only one of its kind in Europe specifically for students with epilepsy to identify goals, build confidence and decide on a career of their choice. For more information see www.epilepsy.ie or contact the Course Manager at 071-9155303.

For Parents, Family, Friends and Carers

Supporting Someone with Epilepsy

Learn as much as you can about their seizure type

Listen and let them know you support them

Offer practical support, like lifts if they can't drive

Include, don't exclude or let them feel isolated

Foster independence and avoid overprotection

Understand if they are tired, stressed or down

Encourage them to seek support for themselves

Reassure them that they are as valued as always

Allow for seizures to disrupt plans

Contact Epilepsy Ireland for support or information

For Parents of Children with Epilepsy

Many people had their first ever seizure in childhood or in their teens. Most will go on to enjoy full active lives and only some will continue to have seizures as adults. For many children with epilepsy, AED's work well to control seizures. The best outcome can be achieved by getting the best level of seizure control possible for the child and this can limit the effects of epilepsy on their social, education and career choices. Epilepsy Ireland run Toolkit and Steps programmes for parents, see www.epilepsy.ie

Questions Parents Ask

Will my child grow out of their epilepsy naturally?

Certain syndromes carry a high chance the child won't have seizures into the future. However, in most cases the best outcome is to control seizures fully, as happens in 70% of cases. Your child's doctor will explain what they expect to see happen for your child.

How do I explain epilepsy to my child?

Your child's questions need to be answered with explanations appropriate to their age. This helps them to become more confident and understand their epilepsy better. There is a range of child friendly resources available from Epilepsy Ireland which may help explain epilepsy to children. Your Epilepsy Ireland Community Resource Officer can discuss how best to approach telling children about their epilepsy.

Who needs to know about my child's epilepsy?

Anyone who takes responsibility for your child at any stage needs to know. This includes teachers, childminders, close family, sports coaches and anyone taking your child for extra-curricular activities or camps. Other parents who might be supervising your child on playdates, parties and sleepovers may need to know. The more information they have the better prepared they are to handle any seizures. Even if seizures are controlled teachers should know that the child is on medication for epilepsy. The teacher needs to be made aware of any side possible effects of medication on concentration or behaviour.

What about school and learning?

Most children with epilepsy are as academically capable as their peers. Those attending mainstream school can often fulfil their potential as much as any child. If a child has concentration or memory problems they may need some extra support. Teachers will need to know about the child's needs so they can offer school based supports. In state exams like the Junior or Leaving Certificate a student can apply to the State Examinations Commission to have **Reasonable Accommodations in Certificate Examinations** made for them. This may mean having a separate room or rest breaks, see www.sec.ie for an explanation of reasonable accommodations. Career guidance teachers can support a student with epilepsy to make a college choice, perhaps through the Disability Access Route to Education (DARE) Scheme if they are eligible, or, a career choice that is suitable for them. Epilepsy Ireland has produced an Education Information Pack for schools and colleges, see www.epilepsy.ie for details.

Can they take part in sports and leisure activities?

Most children with epilepsy can take part in most sports and hobbies as long as safety guidelines are followed. It is important to encourage the child to continue with activities that are safe or can be made safer for them. The doctor or specialist nurse can advise on what is safe for a child to do. See Epilepsy Ireland's Safety and Seizures Booklet for more details.

Can they go to college?

Epilepsy is not a barrier to going to college. Many young people with epilepsy go on to third level study. Students with ongoing epilepsy may be eligible to apply for the **Disability Access Route to Education (DARE)** scheme as part of their CAO application. This scheme has a percentage of places in the major colleges which can be accessed on a reduced points basis. The scheme is for students with disabilities whose condition has impacted on their learning or attendance at secondary school. See www.accesscollege.ie for more information. When a student with epilepsy enrolls in college they may also register with the Disability Officer to see what supports the college can offer.

Epilepsy Ireland runs a one year full time QQI Level 5 Access course for people with epilepsy. The course is called **Training For Success** and it is based in the Institute of Technology, Sligo. See page 18 for details.

How can I help my child live with epilepsy?

Having an upbeat approach will help you and your child cope best. Make sure you get the right information about your child's epilepsy. Talking about epilepsy openly with your child will help them understand it better. Using child friendly resources like Epilepsy Ireland's children's books will help you explain to even quite young children. There are publications for parents and families on childhood epilepsy, school and communicating about epilepsy. For young adults there is a booklet called Moving Forward.

Tips for Parents and Guardians

Do accept your child for themselves. They are a unique person who happens to have epilepsy.

Do encourage them to think of themselves this way.

Do focus on what they can do rather than what they can't do.

Don't encourage them to see epilepsy as a barrier to doing something or to see themselves as "less able".

Don't restrict your family life unduly because of your child's epilepsy.

Are you a Member?

Epilepsy Ireland relies on people to join as members to help us to have a voice for Epilepsy in Ireland.

If you are not already a member, please contact us on (01) 455 7500 or check our website for details - www.epilepsy.ie



Web: www.epilepsy.ie

Facebook: facebook.com/epilepsy.ie

Twitter: [@epilepsyireland](https://twitter.com/epilepsyireland)

YouTube: youtube.com/BrainwaveEpilepsy

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