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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. Sometimes, what we believe about epilepsy might be based on someone we knew in the past so it is good to get the facts. This booklet deals with common questions 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.
Both hemispheres have 4 lobes: temporal, frontal, parietal & occipital

<table>
<thead>
<tr>
<th>Lobe of the brain</th>
<th>What it controls &amp; affects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Temporal Lobe</td>
<td>Memory and emotions, Reading and writing, Non verbal processing, Language, speech, visual &amp; auditory skills</td>
</tr>
<tr>
<td>Frontal Lobe</td>
<td>Planning and organisation, Judgement and problem solving, Making decisions</td>
</tr>
<tr>
<td>Occipital Lobe</td>
<td>Visual perception and attention, Reading and writing</td>
</tr>
<tr>
<td>Parietal Lobe</td>
<td>Hand-eye co-ordination, Spatial and direction awareness, Body awareness and touch</td>
</tr>
</tbody>
</table>
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 start in a part of the brain or happen in both sides of the brain at once. Nearly 40,000 people in Ireland have epilepsy as do 50 million people worldwide. 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 nearly 37,000 men, women, and children over age 5
• More than 10,000 are children, 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 EEG, CT, MRI, other tests, medical history
• Diagnosis is usually based on 2 or more unprovoked seizures
• But can be diagnosed on 1st seizure in some cases
• Many people have normal tests and scans but can be diagnosed
• In over 50% of cases the cause is not known
• Most people have no family history
• Causes can include brain injury and brain infections, strokes, genetic factors, developmental disability
• Causes are different to triggers which can make seizures more likely
• 70% of people have their seizures controlled by medication
• But 30% have difficult to control epilepsy
• Epilepsy medication is free on the Long Term Illness Scheme
• Surgery is an option for some people and can be very successful
• Some seizures affect awareness but others don’t
• Signs can range from slight tremors to falls with shaking of limbs
• There are over 40 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
• 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. Often tests are normal but a diagnosis can still be made. Routine blood tests may be ordered. Witness accounts are important. Try to get as much information as possible from anyone who saw your seizure. Videos can be extremely helpful.

Is epilepsy always diagnosed on the first seizure?
Not always. 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 diagnosed after the first seizure if their tests confirm epilepsy and their doctor feels it is likely 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 was 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 to see if it is normal. 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 EEGs. If nothing shows on the EEG your 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
If you have a normal routine EEG or seizures in sleep your doctor may want you to have an EEG done while you are asleep. This is because during sleep brainwave patterns are different from waking. You may be given a sedative to help you sleep and the test will last 1-2 hours. This test is often helpful to pinpoint certain seizures in young children and older people.
**Sleep-deprived EEG**
For a **sleep deprived EEG** you may need to get up very early on the morning of 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 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 scans will my doctor order?**
**CT scan:** The doctor will usually order a brain scan to look for or rule out structural faults in the brain. These could be very small like a misshaped vein, any area that’s grown abnormally or piece of scar tissue. Most people with epilepsy do not have such structural faults. 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. This is **Idiopathic** epilepsy.

Some causes are **inborn or developmental** such as genetic abnormalities or structural problems in the brain like malformed veins or areas which have not developed normally. Genetic factors can be unique to the person or hereditary. Most 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.
Acquired epilepsy results from harm to the brain such as:
- 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. Surgery can be very successful and may cure epilepsy in some people. When someone is seizure free and off medication for many years their epilepsy can be considered resolved. However, resolved does not mean the same as cured as there is no guarantee that seizures would never return.

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.
About Seizures

Up to 2017, seizures were described using such terms as Generalized or Partial, complex or simple. In 2017, the International League Against Epilepsy revised how seizures are classified. Now 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 old and new terms alongside some of the outdated terms in less common use.

<table>
<thead>
<tr>
<th>New Term</th>
<th>Older Term</th>
<th>Outdated term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generalised Onset Motor</td>
<td>Generalised Tonic Clonic</td>
<td>Grand Mal, Major Motor, Convulsion</td>
</tr>
<tr>
<td>Unknown Onset Tonic Clonic</td>
<td>Generalised Tonic Clonic</td>
<td>Grand Mal, Major Motor, Convulsion</td>
</tr>
<tr>
<td>Generalised Onset Non-Motor</td>
<td>Generalised Absence</td>
<td>Petit Mal</td>
</tr>
<tr>
<td>Focal Aware Motor</td>
<td>Simple Partial/Aura</td>
<td>Jacksonian</td>
</tr>
<tr>
<td>Focal Aware Non-Motor</td>
<td>Simple Partial/Aura</td>
<td></td>
</tr>
<tr>
<td>Focal Impaired Motor</td>
<td>Complex Partial</td>
<td>Psychomotor Temporal Lobe</td>
</tr>
<tr>
<td>Focal to Bilateral Tonic Clonic</td>
<td>Secondary Generalized</td>
<td>Grand Mal, Major Motor, Convulsion</td>
</tr>
<tr>
<td>Focal/Generalised Myoclonic</td>
<td>Myoclonic</td>
<td>Minor Motor</td>
</tr>
<tr>
<td>Focal/Generalised Atonic/Tonic</td>
<td>Atonic/Tonic Drop Attack</td>
<td></td>
</tr>
<tr>
<td>Focal/Generalized Clonic/Tonic</td>
<td>Clonic/Tonic</td>
<td></td>
</tr>
</tbody>
</table>
**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?

<table>
<thead>
<tr>
<th>ILAE 2017 Classification of Seizure Types Basic Version</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Focal Onset</strong></td>
</tr>
<tr>
<td>- Aware</td>
</tr>
<tr>
<td>- Impaired Awareness</td>
</tr>
<tr>
<td>- Motor Onset</td>
</tr>
<tr>
<td>- Nonmotor Onset</td>
</tr>
<tr>
<td>- Focal to Bilateral</td>
</tr>
<tr>
<td>- Tonic-clonic</td>
</tr>
<tr>
<td><strong>Generalized Onset</strong></td>
</tr>
<tr>
<td>- Motor</td>
</tr>
<tr>
<td>- Tonic-clonic</td>
</tr>
<tr>
<td>- Other motor</td>
</tr>
<tr>
<td>- Nonmotor (Absence)</td>
</tr>
<tr>
<td><strong>Unknown Onset</strong></td>
</tr>
<tr>
<td>- Motor</td>
</tr>
<tr>
<td>- Tonic-clonic</td>
</tr>
<tr>
<td>- Other motor</td>
</tr>
<tr>
<td>- Nonmotor</td>
</tr>
<tr>
<td>- Unclassified</td>
</tr>
</tbody>
</table>

**Why change the names of seizures?**

The new descriptions describe seizures more accurately than words like “partial” or “secondary generalised”. It is hoped the new terms will make discussion of seizures clearer for healthcare professionals and patients. Your doctor may use the new 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 new system.

**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** staring spells last only seconds but consciousness is lost briefly.
• **Tonic-clonic** seizures have 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 always 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** this is 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** (Complex Partial) – awareness is affected to some extent, 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:** 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

<table>
<thead>
<tr>
<th>Focal Onset</th>
<th>Generalized Onset</th>
<th>Unknown Onset</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AWARE</strong></td>
<td><strong>Motor</strong></td>
<td><strong>Motor</strong></td>
</tr>
<tr>
<td>Impaired Awareness</td>
<td>tonic-clonic</td>
<td>tonic-clonic</td>
</tr>
<tr>
<td><strong>Motor Onset</strong></td>
<td>clonic</td>
<td>clonic</td>
</tr>
<tr>
<td>automatisms</td>
<td>tonic</td>
<td>epileptic spasms</td>
</tr>
<tr>
<td>a tonic</td>
<td>myoclonic</td>
<td>Nonmotor</td>
</tr>
<tr>
<td>clonic</td>
<td>myoclonic-tonic-clonic</td>
<td>(Absence)</td>
</tr>
<tr>
<td>epileptic spasms</td>
<td>myoclonic-atonic</td>
<td>typical</td>
</tr>
<tr>
<td>hyperkinetic</td>
<td>atonic</td>
<td>atypical</td>
</tr>
<tr>
<td>myoclonic</td>
<td>epileptic spasms</td>
<td>myoclonic</td>
</tr>
<tr>
<td>tonic</td>
<td></td>
<td>eyelid myoclonic</td>
</tr>
<tr>
<td><strong>Nonmotor Onset</strong></td>
<td><strong>Nonmotor (Absence)</strong></td>
<td><strong>Unclassified</strong></td>
</tr>
<tr>
<td>autonomic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>behaviour arrest</td>
<td></td>
<td></td>
</tr>
<tr>
<td>cognitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>emotional</td>
<td></td>
<td></td>
</tr>
<tr>
<td>sensory</td>
<td></td>
<td></td>
</tr>
<tr>
<td>focal to bilateral</td>
<td></td>
<td></td>
</tr>
<tr>
<td>tonic-clonic</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Are all seizures due to epilepsy?

No. Some seizure-like episodes are not epileptic. Febrile seizures 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 may need to be admitted for video EEG monitoring in hospital. Seizures due to medical conditions with metabolic 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 control the number of seizures you have by changing your lifestyle.
Managing Seizures

What first aid is needed for seizures?

**Generalised Onset Seizure with Motor Features (Tonic-Clonic, Tonic, Clonic, Atonic)**
- Stay calm and time the seizure
- Don’t restrain the person - unless they are in danger
- Let the seizure run its course
- Put nothing in the mouth (you can wipe saliva)
- Protect the head if necessary
- Turn the person on their side after the seizure stops
- Stay with them until they recover and respond fully

**Focal Impaired/Complex Partial Seizures**
- Stay calm and time the seizure
- Don’t restrain (unless the person is in real danger)
- Let the seizure run its course
- Guide the person away from danger
- Don’t agitate them
- Speak gently and reassure them
- Stay with them until they recover and respond fully

**Absences, Minor Seizures, 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

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, more seizures follow without recovery, the person is injured or you are in any doubt.
Treatment and Medication

How is epilepsy treated?
The main treatment for epilepsy is Anti-Epileptic-Drugs or AEDs for short. The
AED prescribed will depend on the seizure type. Sometimes more than one
AED is needed. AEDs 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 Treatment Options booklet for more details.

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 on www.epilepsy.ie

Medical Card (PCRS) and Long Term Illness Scheme (LTIS)
Epilepsy medication is free on the medical card (PCRS card) or the Long Term
Illness Scheme. If you have a medical card (PCRS) your AEDs will be covered but
you will have to pay prescription charges. However, medical card holders can
also have their epilepsy medication on the Long Term Illness Scheme and avoid
paying the prescription for it charges in this way. Medical cards are issued to
people below certain income limits. There are 2 types, the full medical card and
the GP visit card. For more information see www.medicalcard.ie

If you don’t have a medical card then AEDs are free to all people with epilepsy
on the Long Term Illness Scheme (LTIS). You can apply for the Long term
Illness Scheme through your local health office or from www.hse.ie. Your GP,
pharmacist, specialist nurse or Epilepsy Ireland Community Resource Officer
can advise about applying for this scheme.
Work, Family and Living with Epilepsy

Can I drive a car?
In most cases a person can drive provided they have been free of seizures for one year and are certified fit to drive by a doctor. There are exceptions to the one year rule regarding first unprovoked seizures, sleep seizures, provoked seizures and seizures with awareness. These exceptions can mean either a reduced seizure freedom period or permission to continue driving. In certain cases a neurological opinion is needed. Under the guidelines issued to doctors from the Road Safety Authority regarding Driver Licencing and Medical Conditions, drivers are required to notify the RSA when any condition develops or recurs. For details see www.rsa.ie and discuss with your doctor. See Epilepsy Ireland’s Driving Booklet for more details.

Can I work with epilepsy?
Many people with epilepsy can work at what they choose. Whether a job is suitable depends on the seizure type and the type of work. If seizures continue it may mean having to make changes at work. When seizures are controlled more choices open up. People with epilepsy can work in most careers. Some jobs may be less safe especially if they involve heights, water, sharp tools or dangerous chemicals. Some careers requiring high levels of physical fitness may be restricted, such as Airline Pilot, Defence Forces and Fire Service.

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 the number of PRSI contributions that you have paid. 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?**
Yes. Most people with epilepsy will be able to have a family if they choose. Good medical care is important especially for women with epilepsy during pregnancy. Most people with epilepsy have no family history but there may be a slightly higher risk of their children having epilepsy. Following safety guidelines will help parents with epilepsy feel more confident about babycare. Contact Epilepsy Ireland if you need more information about women’s issues, pregnancy and epilepsy. Our Women’s Booklet covers all these topics.

**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 details)

**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?**
Most people with epilepsy have no family history of it but some types of epilepsy do tend to run in some 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. A genetic change may be part of the person’s unique genetic makeup but may not affect their family members. Research in genetics and epilepsy is finding more and more genetic bases for epilepsy.
**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 Non Aware seizure (Complex Partial) or a Bilateral Tonic Clonic seizure. (Secondary Generalised). This type of seizure is different to the generalised type where both sides are affected at one time.

**Can someone die from epilepsy?**

The risk of dying from epilepsy is small but it’s important not to overlook it. It’s best to understand the risk so you can reduce it further. We all face risks in our daily lives. The main risks in epilepsy include seizure related accidents, status epilepticus and SUDEP. See our Safety Booklet 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 booklet contains a personal safety plan to help with reducing risk.

**Status Epilepticus** is a prolonged seizure lasting over 30 minutes, or a series of seizures where the person does not fully regain consciousness. Most seizures stop naturally within a few minutes. A prolonged seizure is a concern as it is a medical emergency. This is why we give a “5 minute guideline” 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 between 21-44 cases per year in Ireland out
of nearly 40,000 people. It’s not yet fully known what happens in SUDEP but much research, including Irish research, is taking place. Risk factors for SUDEP include uncontrolled tonic clonic seizures and sleep seizures.

Seizure 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 Booklet and www.epilepsy.ie for details of alarms and other safety aids such as pillows and helmets.

What support can Epilepsy Ireland offer me?
Epilepsy Ireland offers a range of services such as information and support, free Living Well with Epilepsy Programme for those newly diagnosed, STEPS self management programmes for adults and parents, InnerWise meditation programme, Training For Success FETAC Level 5 pre employment course as well as individual and group support, family fun days, outreach services, emergency medication training, professional education events, seminars, specialist nurse and transition nurse help-lines.
Supporting Someone with Epilepsy
Learn as much as you can about their epilepsy 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 for information

For Parents of Children with Epilepsy
Nearly 1 in 200 children in Ireland have 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 prospects. Epilepsy Ireland run Tookit and Steps programmes for parents see www.epilepsy.ie

Questions Parents Ask
Will my child grow out of their epilepsy naturally?
Certain benign 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 honestly. 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 a separate room or maybe the chance to complete the exam later that day if they have a seizure during it. Career guidance teachers can support a student with epilepsy make a college choice or career choice that is suitable for them.

**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 safe for them. The doctor or specialist nurse can advise on what is safe for a child to do. See Epilepsy Ireland’s Safety 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 school. See www.accesscollege.ie for more information. When a student with epilepsy enrols in college they should also register with the Disability Officer to see what supports the college can offer. Epilepsy Ireland runs a one year full time pre-employment course for people with epilepsy. The course is called **Training For Success** and graduates can also progress to college from this course. For more information see www.epilepsy.ie

**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.

**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.

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**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
Epilepsy Ireland

Web: www.epilepsy.ie
Facebook: facebook.com/epilepsy.ie
Twitter: @epilepsyireland
YouTube: youtube.com/BrainwaveEpilepsy

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Tel.: 01 455 7500
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Specialist Nurse Helpline Tel.: 01 455 4133
Monday 9.30am – 1pm
Transitional Care Advice Line Tel.: 01 455 4133
Monday 2pm – 5pm

North West
Covering: Donegal, Leitrim & Sligo
Community Resource Officer: Agnes Mooney
Letterkenny Office, Grand Central Complex, Floor 2B, Canal Road, Letterkenny, Co. Donegal
Tel.: 074 9168725
Email: amooney@epilepsy.ie
Tel.: 071 9141858

West
Covering: Galway, Roscommon & Mayo
Community Resource Officer: Edel Killarney
Westside Resource Centre, Seamus Quirke Road, Westside, Galway
Tel.: 091 587640
Email: ekillarney@epilepsy.ie

Mid-West
Covering: Limerick, Clare & Tipperary North
Community Resource Officer: Veronica Bon
Social Service Centre, Henry St. Limerick
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Kerry
Covering: Kerry
Community Resource Officer: Kathryn Foley
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Cork
Community Resource Officers:
South Lee & West Cork: Niamh Jones
North Lee & North Cork: Loretta Kennedy
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South East
Covering: Kilkenny, Wexford, Carlow, Waterford & Tipperary South
Community Resource Officer: Miriam Gray
C/o HSE, St. Joseph’s, Waterford Rd, Kilkenny
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Midlands
Covering: Offaly, Longford, Laois & Westmeath
Community Resource Officer: Cliona Molloy
The Charleville Centre, Church Avenue, Co. Offaly
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East
Covering: Dublin, Kildare & Wicklow
Community Resource Officer:
Dublin North, West & Kildare: Edel Curran
Dublin South & Wicklow: Carina Fitzgerald
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North East
Covering: Louth, Meath, Monaghan & Cavan
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Epilepsy Specialist Nurse HELPLINE
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Tel.: (01) 4554133

Transitional Care Information Advice Line
Monday 2pm - 5pm
Tel.: (01) 4554133