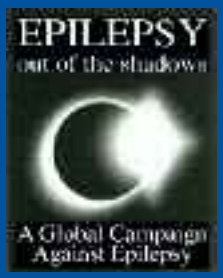
Shedding Light on Epilepsy

A Nurse's Information Pack



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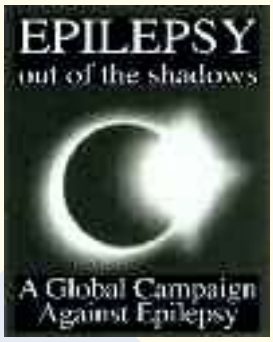

The Global Campaign Against Epilepsy "Out of The Shadows", is a joint initiative by the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and the World Health Organisation (WHO). It was launched in Dublin at the 22nd International Epilepsy Congress in June 1997. The joint mission is to improve the acceptability, treatment, services and prevention of epilepsy worldwide. Brainwave, as the Irish Member of the International Bureau for Epilepsy, is playing its part in promoting the Global Campaign against Epilepsy.

The campaign objectives may be summarised as follows:

- To increase public and professional awareness of epilepsy as a universal treatable brain disorder
- To raise epilepsy on to a new plane of acceptability in the public domain
- To promote public and professional education about epilepsy
- To identify the needs of people with epilepsy on a national and regional basis
- To encourage governments and departments of health to address the needs of people with epilepsy, including awareness, education, diagnosis, treatment, care, services and prevention

To achieve these objectives, the campaign has to set up a new Global Campaign task Force in 2010 which aims to achieve the following goals:

1. Improve the visibility of epilepsy and the activities of the Global Campaign in all countries
2. Promote activities of epilepsy projects at a country and regional level
3. Assess and strengthen health care systems analysis for epilepsy by acquiring a better understanding of the conceptual model, magnitude and scope of the coverage gap including the treatment and knowledge gap measuring the burden of epilepsy and methods for conducting country resource assessments
4. Increase partnership and collaboration with other organisations
5. Develop the necessary infrastructure and resources to achieve the expanded goals of the campaign

IBE International Bureau for Epilepsy

World Health Organisation

International League Against Epilepsy

Authors

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About Epilepsy

What is Epilepsy?

Epilepsy is a tendency to have recurrent unprovoked seizures. It is the most common serious chronic neurological condition in the world. A recent epidemiological study shows that in Ireland there are 37,000 people with epilepsy. **(Linehan et al., 2009)***

What is a Seizure?

A seizure is a sudden, paroxysmal, synchronous and repetitive discharge of cerebral neurons that interrupt brain function. In someone with epilepsy, seizures may be triggered by a range of provoking factors such as missed or delayed medication, excessive alcohol, stress, tiredness, illness, menstruation, medication interactions or skipping meals.

Classically, two patterns of epileptic discharge have been recognised:

- Those arising from focal cortical disturbance causing **partial seizures**
- Those characterised by generalised synchronous spike-wave discharges causing **generalised seizures**

Diagnosis

A diagnosis is made by gathering the clinical history, including an eyewitness description of the seizure. Other conditions are excluded such as cardiac syncope (an ECG should be performed), panic attacks and cerbrovascular attacks. Usually a routine EEG is performed; however studies have shown that up to 50% of EEGs show no abnormalities. However a normal EEG does not out rule a diagnosis of epilepsy. An EEG may help to localise the epileptogenic focus. All patients with a suspicion of non epileptic attack disorder (NEAD) require video EEG. Neuroimaging (MRI/CT) is carried out to detect lesions or subtle congenital malformations.

Causes/ Different types of Epilepsy

Many causes of epilepsy have been identified. Epilepsies associated with Central Nervous System (CNS) pathology are labelled as symptomatic localisation related or partial/ focal. Such causes are CNS infections, cerebral vascular disorders, brain tumours, congenital abnormalities or brain trauma. The generalised epilepsies are idiopathic (with gene foci) or symptomatic (a mixed set of clinical syndromes).

Symptomatic Or Partial/ Focal Epilepsy

In this type of epilepsy, abnormal electrical disturbance is initially localised to one part of the brain. The disturbance may stay confined to an area or it may spread to involve the whole brain i.e. become generalised (secondary generalised). Consciousness is lost late in the seizure, if at all, and the person may have a recollection of the seizure starting. The part of the seizure that the person remembers is called an "aura" or a warning. It should be noted that this "aura" is itself seizure activity.

Generalised Epilepsy

In this type of epilepsy, the whole brain is affected by abnormal electrical disturbance, and the seizures may be major convulsive (Tonic Clonic) or minor (Absences). Consciousness is lost early in the seizure and the individual will have no recollection of what happened during the seizure.

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Nurses Response To Seizures

- Assess Airway, Breathing, Circulation
- Administer oxygen, if cyanosed or experiencing breathing difficulties, suction secretions as required
- Monitor pulse, breaths/min
- Administer prescribed medication, as per care plan
- Maintain a safe environment:
  Protect head and limbs from injury, but do NOT restrain
  Alert other staff members for support
  Pull up cot sides and use padded material on cot sides
  Do not move the patient during a seizure
- When the seizure has terminated, place the patient in the recovery position, record vital signs, observe the patient until fully conscious
- Observe characteristics of the seizure. If semi-conscious, interact with the patient to elicit memory and speech function e.g. hold an object in front of them asking them to name it, give them a code word to remember e.g. 'Red Bus'. Record their responses
- **It is important to document the seizure accurately,** recording any provoking issues, duration of seizure, how the patient felt prior to the onset of the seizure, response to medication and post ictal recovery

General Treatment Options

The goal of treatment is to be seizure free on the minimum amount of medication with no side effects. Approximately 50-60% of patients respond to a first line drug, approximately 10-20% will require a second line drug with the remainder of patients becoming refractory/resistant to medication. **(Brodie et al., 2005)****

Refractory patients with partial/ focal epilepsy will be assessed to see if they may benefit from a resective surgical approach.

Those who are unsuitable for resective surgery may benefit from the insertion of a vagus nerve stimulator. This is a generator that is placed into the chest with a lead coiled around the vagus nerve which is electrically stimulated to reduce neuron excitability and reduce seizures. Half of VNS patients can expect a 40-50% reduction in the frequency of seizures. Patients with generalised epilepsy who do not respond to medication may also benefit from VNS therapy.

Non-Epileptic Attack Disorder (NEAD)

also known as Non Epileptic Seizures (NES)

What is Non-Epileptic Attack Disorder (NEAD)?

Non-Epileptic Attacks look similar to epileptic seizures but are not caused by abnormal electrical activity in the brain. People with NEAD may experience different types of episodes including simple "day dreaming" episodes and more complex types with whole body shaking. These events can be variable in length.

What causes NEAD?

NEAD are caused by various factors, including psychological distress or emotional trauma which may have occurred in the past. Often a person will not be consciously aware of such events so it is not always possible to pinpoint the exact cause. However, this is not essential for successful treatment.

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How common is NEAD?

NEAD is not uncommon. About 1 in 5 people attending services for difficult epilepsy are found to have NEAD. A small percentage of people have both NEAD and epilepsy. It is common for a person to be first diagnosed with epilepsy and, over time, for the diagnosis to be changed. About 80% of patients with NEAD are first diagnosed with epilepsy.

Management

NEAD is managed by a neuropsychological approach. AEDs will not control these types of events. AEDs are usually weaned gradually under the care of a neurologist.

Photosensitive Epilepsy

Photosensitive epilepsy (PSE) describes sensitivity to flashing or flickering lights, at certain frequency, as well as certain geometric patterns and glare. Only 3-5% of people with epilepsy are photosensitive. Most have idiopathic generalised epilepsy, but photosensitivity is also a feature of progressive myoclonic epilepsies, and can occur in acute symptomatic seizures due to alcohol or drug withdrawal. Photosensitive epilepsy usually begins before the age of 20 years, although it is most common between the ages of 7 and 19. Girls (60%) are more often affected than boys (40%), although seizures are more frequent in boys because they are more likely to be playing video games.

Most people with photosensitive epilepsy are sensitive to 16-25 Hz (Hz = flashes per second), although some people may be sensitive to rates as low as 3 Hz and as high as 60 Hz. Photosensitivity is diagnosed by an EEG test and precautionary measures are advised to affected persons. In almost all cases the person on exposure to a trigger, will immediately experience a generalised tonic-clonic seizure in which they lose consciousness, fall and convulse for typically 1 – 3 minutes.

Photosensitivity can be triggered by flicker; glare; patterns; and saturated red in an image. Television, computer games and electronic displays sometimes are sources of these triggers though newer generation devices such as LCDs and plasma screens are flicker free. Natural light can also trigger seizures, e.g. sunlight shining on water; through leaves of trees; through railings etc. Geometric patterns with strong contrast (bars, stripes, grids, swirls etc.) may also provoke this reaction in some, especially if combined with motion. Prescribed polarised sunglasses, preferably with side shades, can help some people to reduce the effects. Often it helps for the person to cover one eye with one hand to reduce the risk as the provoking image needs to be seen with both eyes to provoke a seizure.

Overall, the condition of photosensitive epilepsy is relatively rare and should not lead to undue restrictions for people with epilepsy as a group.

Guidelines for viewing TV, attending clubs and using VDUs are available from the Brainwave website www.epilepsy.ie

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Sudden Unexplained Death in Epilepsy (SUDEP)

What is SUDEP?

If a person with epilepsy dies suddenly and no other cause of death is found, this is called SUDEP. About 60 - 80 people die from epilepsy each year in Ireland. Accidents and status epilepticus (an uncommon type of severe seizure) account for some of these, but the most common cause of death is SUDEP.

What causes SUDEP?

SUDEP is connected to seizures but what exactly causes SUDEP is unknown. The most likely explanation is that a seizure interferes with the part of the brain that controls breathing or the heart.

Who is at risk?

The risk of SUDEP varies from low to very low (about 1 in 1000 people with epilepsy), but for a small number of people the risk may be higher. It is important to understand the person's particular type of epilepsy and how best to manage it.

The most significant risk factor for SUDEP is the occurrence of seizures (particularly tonic-clonic). Therefore the better epilepsy is controlled, the more the risk is minimised.

Common sense precautions include avoiding binge drinking and taking recreational drugs which may trigger seizures. Other risk factors include:

- having seizures during sleep
- being a young adult
- SUDEP is rare, but can happen in children under 16
- frequent seizures
- having seizures when no-one is around to help
- untreated epilepsy
- abrupt changes in epilepsy medication
- not taking medication as prescribed

Advising patients on reducing risk:

- Clarify what type of epilepsy they have and any specific risks associated with it
- Be knowledgeable of what triggers the seizures and to what extent these triggers can be avoided
- If they are not seizure-free, suggest they seek a referral to a neurologist
- Advise they keep taking the medication and never make changes or stop medication without discussing it with their doctor or epilepsy specialist nurse first
- Advise that their doctor will need accurate ongoing information about the number, frequency and type of seizures and any medication side effects
- If seizures occur in sleep, advise the person about getting a seizure alarm
- Advise about sufficient sleep
- Advise about the risks of binge drinking and recreational drugs

It is advisable that patients raise any concerns about SUDEP with their consultant or epilepsy specialist nurse.

Advise carers that they can do the following to reduce the risk of SUDEP:

- Put them into the recovery position when the seizure has finished. Moving the person could encourage breathing to restart if it has stopped
- Remain with the person for about 20 minutes after the seizure has finished and check their breathing is regular and their colour is back to normal

Formulate a plan with the Doctor or Epilepsy Team which will be followed in the event of a prolonged seizure.

Reasons to call an ambulance can include:

- **If you know it is the person's first seizure**
- **The seizure continues for more than five minutes**
- **One seizure follows another without the person regaining awareness between seizures**
- **The person is injured during the seizure**
- **You believe the person needs urgent medical attention**
- **If the person is a pregnant woman**
- **If in doubt**

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Status Epilepticus

A single epileptic seizure of > 30min duration or a series of epileptic seizures during which function is not regained between ictal events in a > 30min period.

What are the signs and symptoms of Status Epilepticus?

Importantly symptoms may not always include convulsion but are varied:

- Person may appear dazed
- Muscle contractions and spasms
- Loss of consciousness
- High blood pressure
- Irregular heartbeats

What is the treatment for Status Epilepticus?

It is a medical emergency requiring **urgent** hospital admission. Should a seizure

a. Last longer than five minutes or if
b. Multiple seizures occur

send for an ambulance **immediately**. It is critical that rapid treatment is given as soon as possible.

Rescue Medication

Rescue medication may be used to:

1. Stop acute seizures, preventing progression to status epilepticus in those at risk.
2. Prevent repeated seizures that may be short lived but these clusters may lead to injury etc.
3. Terminate seizures with cyanotic episodes.
4. Prevent seizures that occur at specific events, cycles or situations.

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Diazepam is effective via oral, rectal and intravenous routes. It is easy and safe to administer with an appropriate license for use in epilepsy.

Midazolam is effective via buccal, intranasal, intravenous and intramuscular routes. The buccal route is where the medication is placed against the side of the gums and cheek. The medicine is directly absorbed into the bloodstream. Midazolam is unlicensed via buccal and intranasal route.

Brainwave runs a one day training course for Health professionals in the administration of Buccal Midazolam. More information is available on the Brainwave website www.epilepsy.ie

Midazolam Buccal Liquid (EPISTATUS) this is an unlicensed product and is prescribed on a named patient basis. It is for the treatment of potentially life threatening tonic clonic seizures, which are likely to progress to status epilepticus, and is administered via the buccal route.

Lorazepam (Ativan) is effective via oral, intravenous or sublingual routes. It may be used for short term treatment of clusters or repeated/breakthrough seizures where the individual can take oral medication. It is effective in the management of status epilepticus.

Clonazepam (Rivotril) is effective via oral and intravenous routes. It is effective in the management of repeated or breakthrough seizures when given orally and can also be used in status epilepticus.

Clobazam (Frisium) is only available as an oral preparation. It is effective in the management of breakthrough or repeated seizures when given orally.

Where the individual is conscious, a choice of oral medications exists and should be used. When the individual is unconscious, Rectal Diazepam remains the standard but Midazolam has potential. Please note that all individuals affected by epilepsy are different and may require individual care.

This information is a guide only. If you have further questions please contact the person's Neurologist/ GP/ Epilepsy Nurse Specialist/ The Brainwave advice line on 01 4554133

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*Linehan et al. Examining the prevalence of epilepsy and delivery of epilepsy care in Ireland; Epilepsia, Published Online, Dec 1 2009#

**Brodie, M.J., Schachter, S. C., Kwan, P. (2005) Fast facts: Epilepsy 3rd Edition.

Differences between childhood and adult epilepsy

- There are many differential diagnoses to be considered
- There are many epilepsy syndromes, causes, and varied prognosis
- The usual refractory seizure type is generalised rather than partial
- Most causes are idiopathic
- Seizures evolve and change with age
- Not necessarily lifelong condition
- There is potentially an important relationship between seizures, treatment and learning/ behavioural difficulties
- Treatment must take account of educational issues and family dynamics
- Need to consider the effects of AED's on the immature, developing brain

(Appleton & Gibbs, 2004)*

Diagnosis

Parental anxiety is a big issue when treating children newly diagnosed with epilepsy. Support and advice given to parents at diagnosis seems to help with the adjustment and subsequent management of the condition.

Treatment

Anti Epileptic Drugs (AEDs)

Basic principles of treatment are similar for children and adults. However, when choosing an AED for the treatment of childhood epilepsy a few specific things should be considered:

- **Seizure type-** specific epileptic syndromes have specific first line treatments which are guided by research findings
- **Age and licensing-** some drugs are not licensed for certain age groups. This means the drug may not be used as first line treatment in certain ages but may be considered after other drugs have failed to achieve adequate seizure control

- **Titration-** drug doses are calculated on body weight. Doses are increased slowly to avoid dose related side effects and to ensure tolerance
- **Weight-** some drugs can cause weight gain or weight loss. If either of these issues are of concern then careful consideration should be given to drug choice e.g. Epilim can cause weight gain, Topamax can cause weight loss
- **Behavioural problems-** certain drugs and preparations may be avoided as they are known to cause behavioural problems e.g. Epilim syrup can cause hyperactivity
- **Ability to swallow tablets-** syrup, solution or sprinkle preparations may be easier for children to swallow. However, not all children have difficulty with tablets

Other Treatment Options

Diets: Ketogenic diet and modified Atkins diets

Research has shown that both diets have an antiepileptic effect. The reason for this is not clearly understood. These diets are not suitable for everyone. To ensure safety and optimal growth and development, children who are on these diets need to be carefully monitored by hospital doctors and a specially trained dietician.

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- **Ketogenic diet**- is a diet high in fat, provides adequate protein and is very low in carbohydrates. As this is a very restrictive diet it can be unpleasant and difficult to comply with.
- **Modified Atkins**- is a diet high in fat and protein and low in carbohydrate (usually 10g). It is considered less restrictive than the Ketogenic diet and food is considered more palatable.

Surgery (see also Treatment of Epilepsy)

AEDs are considered the mainstay of treatment. However when a child fails to respond to medication, surgery may be considered. The work up for surgery can take time and parents need to be aware of this.

Criteria for surgical consideration usually include:

- Persistent intractable seizures despite trial of 3-4 AEDs at maximum tolerated /recommended doses
- No realistic hope of spontaneous remission of epilepsy
- Evidence of medical, social and educational disability due to seizures
- Acceptable risk-benefit ratio for the proposed surgery
- No indication that the surgery will adversely affect the child

Surgical work up usually includes:

- Detailed clinical history
- Scalp EEG
- Long term video EEG monitoring
- Neuroimaging-MRI
- Psychiatric assessment
- Speech and language therapy
- Occupational therapy
- Neuropsychology – including WADA if old enough **(See Treatment of Epilepsy – Surgery)**
- Subdural electrode recording & SPECT (single-photon emission computed tomography) -sometimes required **(See Treatment of Epilepsy – Surgery)**
- Summary of treatment plan to date should be present at neurosurgical meeting for multidisciplinary team opinion

Psychology

Psychology/ neuropsychology are sometimes needed to help children and parents adjust and cope with the diagnosis of epilepsy

Common Triggers for seizures

The following is a list of common triggers. It is unlikely all of these triggers will affect every child but it is helpful to identify triggers so that they can be avoided or managed:

- Tiredness
- Boredom
- Excitement
- Anxiety or stress
- Poor sleep routine
- Illness
- Constipation
- Flashing lights (only if photosensitive)
- Weight gain
- Growth spurt
- Missed/ skipped meals
- Poor nutrition
- Travelling (change in time zones)
- Heat or humidity
- Hormonal changes
- Change in routine
- Anaesthetic
- Alcohol
- Recreational drugs
- Menstruation

Medication related triggers:

- Missed dose of AED
- Withdrawal of AED
- Late administration of AED
- Medication adjustment (increase or decrease of dose)
- Some antibiotic administration
- Contraceptive pill
- Ritalin
- Some fish oil supplements

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Seizure Diary
Keeping a seizure diary helps identify seizure triggers. Known triggers should be avoided. If this is not possible steps should be taken to manage triggers.

Discharge Planning:
If you are the nurse on duty when a patient is being discharged following a diagnosis of epilepsy please ensure the parents and patient have the following information before discharge:
- Prescription for anti-epileptic medication and understanding of the doses
- Prescription for rescue medication (e.g. Epistatus) and have been informed how to administer this
- Information in relation to their diagnosis or details on how to gain information (Brainwave)
- Contact details for relevant departments i.e. Epilepsy Nurse Specialist
- An application form for Long Term Illness Scheme

Educational Issues:
Most children with epilepsy go to mainstream school and do not have any learning difficulties. However some children may require extra support. The factors that are thought to be important in contributing to cognitive impairment in people with epilepsy include:
- Treatment for epilepsy e.g. medication
- The occurrence of interictal epileptiform discharges
- The underlying cerebral pathology
- Disruption of sleep by seizures
- The occurrence of seizures and their underlying pathophysiology
- Genetic factors
- Psychosocial factors e.g. mood, stigma and educational deprivation

Death in childhood epilepsy (See About Epilepsy – SUDEP)
Certain characteristics are known to be associated with an increased risk of death:
- Epilepsy with onset in first 12 months of life
- Epilepsy which is symptomatic in aetiology (cerebral malformation)
- Severe myoclonic epilepsies of infancy and childhood
- Infantile spasms (related principally to the treatment of spasms-ACTH and steroids)
- Severe developmental delay already present at the onset of epilepsy
(Appleton & Gibbs, 2004)*

Frequently asked questions

Why is blood level monitoring required?
Blood tests may be used to measure the amount of a medication in a child's blood, but not all children require this testing. However, blood level monitoring is necessary when:
- Seizures are uncontrolled despite high doses of medication
- Where non compliance is suspected
- A child has an episode of status epilepticus (convulsive or non convulsive)
- A child appears toxic (i.e. excessively drowsy or lethargic) even on a low dose of medication
- When phenytoin is prescribed

Can illness or infections increase the chance of having seizures?
A child's seizures could increase in number or severity when they have illness or infection. High temperature may well be a triggering factor for some. Gastro-intestinal upset can reduce absorption of anti-epileptic medication so the drugs might not work as well as usual, increasing the risk of more seizures.

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What about the risk of vomiting anti-epileptic medication?
Where medication is in tablet form, the tablets may be seen in the vomitus. In this situation it is safe to repeat the dose once the child's tummy upset has settled. Where medication is in a coloured liquid form, it too may be obvious in the vomit and likewise can be repeated. If however, the child vomits 45 minutes or more after taking the drug, it would not be advisable to repeat the dose.

Can seizures change as a child gets older?
Yes, particularly if the seizures started early in the child's life. In some cases seizures can resolve (e.g. benign rolandic epilepsy of childhood) whereas in others it continues into adolescence and adult life (e.g. juvenile myoclonic epilepsy). Changes in seizures may also be due to:

- Type of epilepsy the child has been diagnosed with, e.g. some epilepsy syndromes follow a similar course as a child gets older
- Hormonal changes at puberty may cause a change in seizure pattern, usually related to the menstrual period
- Exposure to seizure triggers (see list)

Who needs to be told that the child has epilepsy?
While it is up to the parents to decide who they disclose this information to, there are key personnel who "need to know" and circumstances in which it is vital that they be informed. For example:

- Teachers or Crèche staff who have responsibility for a child's wellbeing in the parents' absence
- All sports coaches, especially swimming instructors
- Baby sitters / child minders
- Other parents who may be in charge of the child during play dates/ sleepovers
- Summer camp instructors and teachers of extracurricular activities
- Scout leaders, student-exchange host families, exam supervisors
- The State Exams Commission (only where the child is applying for Reasonable accommodations in State Examinations) TEL: 090 644 2700

For leaflets to support parents giving an explanation of epilepsy see www.epilepsy.ie

Exactly what do these people need to be told?
Tailor the information to the specific child. Where possible, write down the essential points and make copies. It is important for teachers, childminders and others to be made aware of:

- Type of seizure the child usually experiences, how it starts, how it progresses, parts of body involved etc., so they know what to expect
- How the seizure is normally managed
- How and when to administer first aid
- Whether or not the child gets an 'aura' or warning
- How long the event may be likely to last
- How long the child needs to rest after the event
- How frequent the seizures are
- Is there a pattern to them?
- What the possible trigger factors are e.g. flashing lights, certain computer games etc
- In case of emergency, what action must be taken, who should be contacted, where emergency medication is located and how it is to be administered

*R. Appleton and J. Gibbs, Editors, Epilepsy in childhood and adolescence (third edition), Martin Dunitz, London (2004).
Journal of the Neurological Sciences, Volume 231, Issue 1, Pages 106-106
J.Haller

EPILEPSY AND INTELLECTUAL DISABILITY

It is important to state that people with epilepsy as a group have the same range of intelligence as the general population. Having a diagnosis of epilepsy does not imply an intellectual disability. However, among people with intellectual disabilities the incidence of epilepsy is higher than it is among the general population.

The term Intellectual Disabilities (ID)

The official term "Intellectual Disability" as designated by the Department of Health and Children in Ireland refers to a lifelong condition marked by deficits in understanding new and complex issues, coping with everyday life, and having had a history of notably reduced intellectual ability in childhood. People with ID have a developmental delay that may prevent or delay progress through some of the childhood milestones of human development. The incidence and prevalence of intellectual disabilities is difficult to clarify as children may not be diagnosed at birth or for sometime after. Intellectual disabilities can develop during the prenatal, perinatal or post natal stages and, as with epilepsy, the causes are often unknown.

Dual Diagnosis – people with epilepsy and ID

Some of the most common intellectual disability disorders associated with the development of epilepsy are congenital malformations of the brain, metabolic disorders, trauma, infections of the nervous system and brain tumours. Epilepsy can result due to the nature of the underlying intellectual disorder.

People with intellectual disabilities are diagnosed with epilepsy and treated in the same way as everyone else. Epilepsy can be a difficult condition to diagnose in any person and it can be particularly so with people who also have an intellectual disability. Stereotypical mannerisms, behaviour issues and poor communication skills can often lead to the delay in diagnosing. People with an intellectual disability have similar needs to the whole population. Due to the organic nature of some syndromes, epilepsy may be more complicated and difficult to control among some people with intellectual disability. Those predisposed to having complex needs include people with more severe ID, those with more co-morbid conditions, poorer access to care and reduced communication skills. Getting to know each individual person is essential to understanding and dealing with these complexities.

Specific Epilepsy Syndromes associated with ID

Certain specific epilepsy syndromes are associated with increased levels of intellectual disabilities. Most of these are diagnosed in childhood, examples include:

- Rett syndrome
- Sturge-Weber syndrome
- Lennox Gastaut syndrome
- Landau Kleffner syndrome
- Tuberous sclerosis
- West Syndrome – Infantile Spasms

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People with Epilepsy and ID: Making Choices about Care

People with epilepsy and ID may have reduced ability to

- access a diagnosis
- participate in investigations
- have input into specific management plans
- express their views regarding treatment options
- plan their future
- communicate their needs
- express their choices regarding daily care

Due to these issues their needs may have to be voiced by a nurse or family member who understands the person's preferences. Where more than two disabilities are involved, thoughtful care planning is required to improve quality of life.

Epilepsy–related issues in Developing Care-Plans for People with ID

- There is a higher incidence of sudden unexpected death in epilepsy (SUDEP) among people with ID
- There is a higher incidence of non epileptic attack disorder (NEAD) in people with ID
- There is a higher incidence of complicated and difficult to control seizures
- Certain groups of people are at increased risk of developing epilepsy e.g. people with autism, people with cerebral palsy and, in later life, those with Down's syndrome
- Nursing supervision may be necessary at all times for some people which may curtail their freedom, for example, to live in community settings
- Difficulties with staff availability and staff ratios can impact on the person's participation in activities
- There may also be interaction issues to consider also, such as interaction effects with other conditions as well as between other treatments and anti epileptic drugs

The Role of Nurses working in the Intellectual Disability Context

Nurses working closely with people with epilepsy and ID over a consistent time tend to get to know the person, their family and the multidisciplinary team involved. Experienced nurses will have developed expertise from listening, from observation and monitoring and from communicating with all those concerned with the person's care. In some services, nurses design resources to help the person with ID and epilepsy to communicate their needs, manage their own epilepsy, seek support, manage medication and live a more independent life.

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Behaviour Observation

Epilepsy can be difficult to diagnose and may be misdiagnosed in around 25% of people with intellectual disabilities.

Seizure observation records are vital to helping identify seizure behaviours and to clarify and refine diagnoses. It can be sometimes be difficult to tell some seizures apart from other kinds of behaviours. This is especially true in people with Intellectual Disabilities and related diagnoses.

Observing the behaviours within a context of knowing the person well allows nurses record behaviours, observe commonalities, spot trends and notice particular physical signs evident in the person.

Knowing the person allows us to begin to differentiate their behaviours into epilepsy related behaviour and other categories of behaviour.

How do I know if what I observe is due to Epilepsy, ID or something else?

Commonly observed behaviours among people with intellectual disabilities can arise from several causes. These include typical behaviours as well as epilepsy related and non-epilepsy related behaviours.

Behaviour Observation Chart

The chart over leaf will assist you differentiate between four main categories of observed behaviour.

Behaviour is the action or reaction of a person usually in relation to the environment. Behaviour can be conscious or subconscious, overt or covert, and voluntary or involuntary. The way we behave or act can be attributed to how we control ourselves. The following four types of behaviour may help to view observations differently, as it is sometimes difficult to categorise the problem.

Typical Behaviour
Typical behaviour as opposed to behaviours associated with neurological disorders, can be described as everyday behaviours that people display as they progress through the lifespan.

Epilepsy Behaviour
Epilepsy Behaviours are observable signs from a person's physical and communication behaviours. The signs will be different to the person's usual behaviour.

Intellectual Disability Behaviour
Intellectual disability behaviours are observable behaviours associated with various syndromes or behaviours associated with institutionalised lifestyles.

Autistic Behaviour
Autistic behaviour can include observable physical signs and communication skills typical to autism. These may include people repeating behaviours consistently, poor eye contact or limited interactions with others.

Examples illustrating Epilepsy Related Behaviour and other behaviours

Typical Behaviour	Epilepsy Behaviours	Intellectual Disability Behaviours	Autistic Behaviours
Absent minded	Staring	Boredom	Atypical gazing
Picking fluff from sweater	Repetitive movements	Finger flicking	Stereotyped behaviour
Stretching	Atonic movements	Stereotyped behaviours	Body positioning
Licking lips	Lip smacking	Mouthing objects	Atypical face movements
Shouting	Pre ictal scream	Ritualistic shouting	Self stimulatory soundings
Fixing clothes	Complex partial seizure	Stereotyped behaviours/complex partial seizure	Stereotyped behaviours/complex partial seizure
Running	Atypical running seizure	Avoiding environment/ Atypical running seizure	Avoidance of feared place/ictal running
Crying	Dacrystic seizure (seizure with crying behaviour)	Upset behaviour/ Dacrystic seizure	Behavioural disinhibition/ Dacrystic seizure
Laughing	Gelastic seizure (seizure with laughing behaviour)	Enjoyment/gelastic event	Idiosyncratic behaviours associated with autism/gelastic event
Drinking a glass of water	Ictal behaviour associated with complex partial seizures	Stereotyped behaviours/ictal behaviour	Stereotyped behaviours/ictal behaviour

Note: “Ictal” refers to the seizure event itself

Women & Epilepsy

In order to enable informed decisions and choice, and so as to reduce misunderstandings, women with epilepsy and their partners must be given accurate information and counselling about issues such as contraception, conception, pregnancy, breastfeeding, caring for young children and menopause.

All healthcare professionals who treat care for, or support women with epilepsy should be familiar with relevant information and the availability of counselling.

Epilepsy, menstrual cycle and fertility

- Catamenial seizures refer to an increase in seizures around the time of the menses, either just before or during the first few days of menstruation
- All women with epilepsy should be counselled about their fertility and the possible side-effects of their anti epileptic drugs (AEDs)
- There is a decreased fertility amongst women with epilepsy (WWE)

Contraception

- In women of childbearing potential, the risks and benefits of different contraceptive methods, including hormone-releasing Intra Uterine Devices, should be discussed
- If a woman taking enzyme-inducing AEDs such as Phenobarbitone, Primidone (Mysoline), Phenytoin (Epanutin), Carbamazapine (Tegretol), Topiramate (Topamax) or Oxcarbazepine (Trileptal) chooses to take the combined oral contraceptive pill (COCP), a minimum initial dose of 50 micrograms of oestrogen is recommended. If breakthrough bleeding occurs, the dose of oestrogen should be increased to 75 micrograms or 100 micrograms per day, and 'tricycling' (taking three packs without a break) should be considered
- The progesterone-only pill is not recommended as reliable contraception in women taking enzyme-inducing AEDs
- Women taking enzyme-inducing AEDs who choose to use depot injections of progesterone should be informed that a shorter repeat injection interval is recommended (10 weeks instead of 12 weeks)
- The progesterone implant is not recommended in women taking enzyme-inducing AEDs
- The use of additional barrier methods should be discussed with women taking enzyme-inducing AEDs and oral contraception or having depot injections of progesterone
- If emergency contraception is required for women taking enzyme-inducing AEDs, the dose of levonorgestrel should be increased to 1.5 mg and 750 micrograms 12 hours apart
- A barrier method of contraception should also be employed particularly if breakthrough bleeding is an issue
- Additional care needs to be taken when Lamotrigine is the AED of choice as the COCP can interfere with Lamotrigine levels

Conception

- All women of child bearing potential with epilepsy should be offered pre-conceptual counselling and advised to plan each pregnancy as much as possible
- Women with epilepsy should be informed about the risk of epilepsy and AEDs in pregnancy and should be advised to contact the Irish Epilepsy and Pregnancy Register for the most up to date information
- The risk of major and minor fetal malformations in any pregnancy is 2%. This risk increases two-three folds in women taking a single AED. Certain drugs and certain combinations of drugs carry higher risks
- Details of major and minor malformations should be discussed to include neurodevelopmental impairments
- A minimum dose of 5mg Folic Acid should be prescribed following the onset of menses or at least 3 months prior to conception. The reason for the increased dose is that certain anti-epileptic medications use up more folic acid already in the body at a faster rate, leaving reduced amounts of the vitamin in the body, which is essential in the early development of a baby's spinal cord

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Pregnancy

- Women with epilepsy need accurate information during pregnancy, and the possibility of status epilepticus and SUDEP should be discussed with all women who stop their AEDs against medical advice
- Women with epilepsy may experience a change in seizure pattern during pregnancy and if this occurs they should be reviewed by their specialist urgently
- Doses of AEDs should not be increased routinely in pregnancy but should only be adjusted on clinical grounds
- Other factors such as non-compliance and vomiting should be considered if seizure pattern deteriorates
- Care of the pregnant woman should be shared between the obstetrician and the specialist
- A detailed ultrasound scan should be performed at 18-22 weeks gestation, to check for any major/minor mal-formations because of history of epilepsy and if taking any AEDs
- Mothers taking enzyme-inducing AEDs should be prescribed oral vitamin K 10mg daily in the last month of pregnancy, to prevent hemorrhagic disease of the newborn as some AEDs may interfere with the clotting function in the newborn

Labour

- Women should be advised to consider devising a birth plan in consultation with her obstetrician and specialist
- Most WWE will have a normal labour and vaginal delivery but stress, pain, sleep deprivation, over-breathing and dehydration increase the risk of seizures in labour
- The usual oral AED medication should be administered in labour and postnatally
- Women should consider the use of a TENS machine; gas and air and epidural anesthesia to aid rest, pain and stress relief. Pethidine should be avoided, as it is metabolized into norpethidine and this may induce a seizure
- All seizures in labour should be stopped immediately with the use of Lorazepam (PO, IV) or as per hospital policy

Breastfeeding

- In general, mothers with epilepsy on AEDs prior to delivery should be encouraged and supported in their decision to breastfeed. However each mother needs to be supported in her choice of feeding

After the birth

- New parents should be advised on simple safety measures that need to be employed such as feeding/ changing the baby on the floor, no bathing the baby unsupervised, and the use of a playpen
- Parents should be advised that the risk of injury caused to the baby by maternal seizures is low (special epilepsy alarms are available for mothers home alone)
- Women should attend their specialist within 6 weeks of delivery to enable a review on her epilepsy and her AED therapy
- Advice on contraception and re-commencing Folic Acid should be discussed

Menopause

- Women should be aware that their seizure pattern may change at this time
- HRT should be prescribed for the same indications as in women who do not have epilepsy
- WWE on long term enzyme-inducing drugs are at risk of developing bone demineralization. This should be investigated and a calcium supplement prescribed
- General advice on bone health to include diet, exercise and smoking should also be addressed

Investigative Procedures

Electroencephalography (EEG)

The EEG is used to support a clinical diagnosis of epilepsy, assist classification of seizure type and syndrome, and to determine whether the patient is photosensitive. The initial EEG would usually be a routine EEG. More than 50% of patients with epilepsy will have a normal trace **(Brodie et al., 2005).***

Activation techniques include hyper-ventilation and photic stimulation. If the initial EEG is unremarkable and the diagnosis remains in doubt, a sleep deprived study is recommended. Alternatively, the patient may have a prolonged inter-icital recording using ambulatory monitoring, preferably for 24 hours.

In some cases the patient may be sent for video telemetry which is EEG recording for long periods on equipment remote from the patient, in combination with synchronised video allowing correlation of clinical and electrographic events. Video telemetry is mandatory as part of evaluation for epilepsy surgery, and may be the only way to distinguish epileptic from non-epileptic seizures.

Structural and Functional Imaging

Imaging studies of the brain to look for underlying structural abnormalities are essential for the appropriate diagnostic evaluation of most patients with epilepsy, particularly those presenting with partial-onset seizures.

The imaging modality of choice is Magnetic Resonance Imaging (MRI). It has a higher sensitivity and specificity than Computed Tomography (CT) for identifying structural lesions such as malformations of cortical development, hippocampal sclerosis, arteriovenous malformations, cavernous hemiangioma and low grade gliomas. A CT

scan should be performed if MRI is unavailable, or in patients for whom MRI is contraindicated (e.g. those with cardiac pacemakers, non-compatible aneurysm clips or severe claustrophobia).

Functional imaging can identify focal abnormalities in cerebral physiology even when structured imaging results are normal. Single Photon Emission Computed Tomography (SPECT) can demonstrate increased blood flow in brain regions associated with seizure activity. With Positron Emission Tomography (PET), epileptogenic areas can be detected as hypometabolic regions interictially. Both of these functional neuroimaging techniques are useful adjuncts in the workup for epilepsy surgery.

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Medical Management Of Epilepsy

Anti Epileptic Drugs (AEDs) are mainly used as long-term treatment to prevent the occurrence of seizures. Treatment is indicated following two or more unprovoked seizures but may also be considered in patients after a single seizure if the likelihood of recurrence is considered to be high or when a recurrence might have serious consequences. Providing detailed instructions to the patient and/or relatives about the nature of the treatment, as well as its risks are a prerequisite for successful therapy.

One of the most important principles in the treatment of epilepsy is an individualised approach to both drug choice and dosage. Factors to be considered include type of seizures, epilepsy syndrome, patient age and life situation, risk factors, and the patient having adequate follow-up. The aim of drug treatment is complete prevention of seizures with as few side effects as possible.

Monotherapy is preferred, and the drug chosen is determined by considering the efficacy spectrum and the tolerability profile that is least likely to interfere with the quality of life of the individual patient. Almost 60% of patients with recent-onset epilepsy achieve seizure control with the first or second AED (Brodie et al., 2005).* Polytherapy is used in refractory patients after careful consideration of the balance between seizure suppression and adverse reactions.

Measuring AED serum concentrations can help to ensure compliance, to assess side effects and to establish the most effective concentration in a seizure-free patient. Other tests may include measurements of electrolyte levels, liver and kidney function tests, and blood-cell counts, depending on the patient's history and the type of adverse effects reported with the AED being used.

Surgery

AEDs are considered the mainstay of treatment. However when an individual fails to respond to medication, surgery may be considered. The work up for surgery can take time and individuals need to be aware of this. A person with epilepsy may be suitable for surgery in the following circumstances:

- Antiepileptic drug treatment has been tried but has proven unsuccessful
- The seizures originate from one localised area of the brain
- The person's ability to function normally would not be affected by removing this part of the brain
- The irregular part of the brain is accessible to the surgeon and can be removed without further damage
- The areas of the brain responsible for speech, sight, movement or hearing are not a part of the brain to be removed
- The person is thought to have a good chance of becoming seizure free after surgery
- The person has no other medical problems which would make them unsuitable for the surgery

Criteria for surgical consideration usually include:

- Persistent intractable seizures despite trial of 3-4 AEDs at maximum tolerated/ recommended doses
- No realistic hope of spontaneous remission of epilepsy
- Evidence of medical, social, and educational disability due to seizures
- Acceptable risk-benefit ratio for the proposed surgery
- No indication that the surgery will adversely affect the person

Surgical work up usually includes:

- Detailed clinical history
- Scalp EEG
- Long term video EEG monitoring
- Neuroimaging-MRI
- Psychiatric assessment
- Speech and language therapy
- Occupational therapy
- Neuropsychology – including WADA if old enough

The Wada test looks at language and memory. Language (speech) is controlled by one side of the brain (in most people, the left side). The Wada will confirm which side controls language. Memory can be controlled by both sides of the brain; the Wada helps determine which side of the brain has better memory. If the side that controls language or has better memory is where seizures may be coming from, the surgeon may consider further investigation e.g. MRI or brain mapping before surgery.

- Subdural electrode recording & SPECT (single-photon emission computed tomography) is sometimes required

  SPECT shows the blood flow in the brain. A radioactive compound is injected during a seizure. A comparison of the patterns of cerebral blood flow between and during a seizure assists localisation of the epileptic focus.

- Summary of treatment plan to date should be present at neurosurgical meeting for multidisciplinary team opinion

Surgical procedures usually aim to:

- Remove a mass of epileptogenic tissue e.g. anterior lobectomy
- Remove structurally abnormal tissue e.g. hemispherectomy or lesionectomy
- Separate the epileptogenic cortex from the rest of the brain-disconnection procedures e.g. corpus callosotomy, multiple subpial transection

Vagus Nerve Stimulation therapy

Vagus nerve stimulation (VNS) has been approved as an adjunctive therapy, i.e. a treatment to be used in conjunction with another therapy, usually AEDs. VNS therapy is indicated for reducing the frequency of seizures in children, adolescents and adults with partial onset seizures, with or without secondary generalisation, or generalised seizures that are refractory to antiepileptic medications.

Vagus nerve stimulation requires implantation of a programmable signal generator subcutaneously in the chest. Electrodes carry electrical signals from the generator to the left vagus nerve in the neck. The most common side effects of VNS therapy include temporary hoarseness, cough, a tickling sensation in the throat and shortness of breath. These side effects occur during the stimulation periods and typically decrease over time. There is evidence that VNS may have positive effects on mood, memory and drowsiness.

Complementary Therapies

Although some people find complementary treatments helpful in treating their epilepsy, there is no scientific evidence to suggest that any type of complementary treatment is successful in controlling or curing epilepsy. Because of this lack of scientific evidence, it is recommended that complementary treatment should be used with antiepileptic medication, rather than on its own.

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Acupuncture

Acupuncture involves treating the whole person, body and mind, by using needles, and sometimes heat, to stimulate the nerve endings. The aim is to improve the general state of health, creating a better mental, physical and emotional balance. Very little research has been carried out into the use of acupuncture in epilepsy. However, of the research that is available, there does not appear to be any harmful side-effects relating specifically to epilepsy.

Aromatherapy

Aromatherapy involves the use of pure aromatic oils taken from various plants. General relaxation is one way that aromatherapy can be used and oils such as ylang ylang, camomile and lavender, appear to aid relaxation and may be helpful for some people with epilepsy.

Aromatherapy should only be given by a qualified aromatherapist. This is because some oils can trigger seizures and should therefore be avoided by people with epilepsy. These oils include rosemary, sage, hyssop, fennel (these herbs when used in foods and drinks are perfectly safe). Note- wormwood should be avoided.

Biofeedback

Biofeedback works on the principle that you can learn to control body processes which were previously thought to be entirely involuntary. Using an electroencephalogram (EEG) you are able to see the activity of your brain on a computer screen and through various methods can learn to alter your brain activity.

Although it can certainly be effective for some people, biofeedback training requires a lot of time and dedication from the person with epilepsy and the professionals concerned.

Herbal Treatments

There are different types of herbal treatments available, for example, general herbal medications and Chinese herbal medicines. Herbal treatment uses plants as a cure to treat the whole person. Limited research has shown that herbal treatments may be helpful as a complementary treatment for epilepsy.

However, certain herbal remedies may trigger seizures for some people or interact with anti-epileptic medication. Therefore it is advisable that the person with epilepsy discusses any herbal remedies with their doctor or pharmacist before starting the herbal treatment.

Yoga

Stress is often a precipitating factor for seizures. Yoga is believed to induce relaxation and stress reduction, as it is said to help people become balanced in mind and body. Various studies carried out in the past involve small numbers of patients. A Cochrane Database Systematic Review (2000) of clinical trials into use of Yoga in Epilepsy revealed that “no reliable conclusions can be drawn regarding the efficacy of yoga as a treatment for epilepsy. Further studies are necessary to evaluate the efficacy of yoga in the treatment of epilepsy.”

There are different types of yoga available. Strong pranayama (breath exercises) and trataka, (gazing at a meditation object) should be avoided by people with epilepsy, as they could trigger a seizure. More information about yoga is available from the Irish Yoga Association www.iya.ie and the British Wheel of Yoga (the governing body for yoga in Great Britain).

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*Brodie, M.J., Schachter, S. C., Kwan, P. (2005) Fast facts: Epilepsy 3rd Edition.

Helping Your Patient Get the Most out of Neurology Appointments

When a diagnosis of epilepsy is made the person may be unsure of what they need to know and you can help them prioritise what is important for them and help identify their support and information needs. Other issues can be discussed with their epilepsy nurse, GP or Brainwave representative at other times.

Preparing for the appointment with the neurologist

- **Before the appointment**

  Appointments are made months and even years in advance. The patient can programme the time and date into a calendar on a mobile phone to ensure they remember. Some health insurers operate an email reminder service also.
  A good witness account combined with an accurate seizure diary is important. Clinics may use slightly different protocols for observing seizures. The Brainwave website has a leaflet on recording seizures. Ask the witness to describe what they saw rather than trying to interpret the seizure type.
  Before the seizure - what was the person doing, was there a trigger or a warning?
  During the seizure – what was observed; what parts of the body were involved; was consciousness lost, if yes, how long did it last; did the seizure differ from previous seizures, if yes, how?
  After the seizure - Were they sleepy; confused; upset? How long did the recovery take?
  Additional relevant details should be included as necessary.

- **On the day of the appointment**

  Clinics operate timed allocation appointments so it is important to be there at the allotted time for check in. If there is a delay en route let the clinic secretary know.
  Busy clinics may run late. Tests may be ordered or the patient may see other team members at the Consultants discretion. Adequate time needs to be allowed for this.

Checklist for the consultant appointment - be sure to bring the following:

- The appointment letter
- Their anti epileptic medication – so it can be reviewed and discussed
- A support person who has witnessed the seizures and can describe them
- A list of relevant questions i.e. what do they most need to know?
- A copy of the seizure diary for their file
- Copies of all current prescriptions
- Documents which require the doctor's signature
- Recordings of seizures on CD/ DVD/ Mobile phones
- A notebook to take notes of guidance given (the support person might do this). Before leaving review these notes with the doctor to ensure accuracy

LONG TERM ILLNESS SCHEME (LTIS)

All persons with epilepsy are entitled to anti-epileptic medication **FREE OF CHARGE** through the Long Term Illness Scheme. Where an applicant is eligible for the Primary Care Re-imbursement Scheme (PCRS was formerly the GMS or Medical Card) this covers medication also. The LTIS is granted irrespective of means to all persons **NOT** entitled to a P.C.R.S Card. For the LTIS apply to your health board for a form to be completed by the applicant and a doctor/consultant.

Epilepsy & Lifestyle

A diagnosis of epilepsy can have implications for the person's lifestyle on several levels.

Driving

A diagnosis of epilepsy can have implications for the person's lifestyle on several levels. In Ireland, the law currently requires that a person with a diagnosis of epilepsy must be 12 months seizure free before being eligible to drive. Licensing for a person with a history of epilepsy currently applies to categories A1, A, B, EB, M or W (motorcycle, car light van, work vehicles). A doctor's certification will be required to verify that the person is seizure free for driving purposes.

A person with a history of epilepsy cannot currently be licensed to drive in category C1, C, D1, D, EC1, EC, ED1 or ED (heavy goods vehicles, bus, etc). However a forthcoming EU Directive to be enacted by the end of 2010 will alter this ruling in relation to those more than 10 years seizure free. The EU Directive will also change the rules in relation to certain Group 1 exceptions which presently exist in Ireland. For details of these exceptions and further information on driving regulations, see Brainwave's website "Rights & Entitlements" www.epilepsy.ie.

Leisure & Travel

Restrictions may be advised in respect of certain leisure and sport activities but every case needs individual assessment depending on seizure control, seizure type and degree of supervision. Extreme sports are usually inadvisable e.g. Bungee jumping, paragliding, parachuting etc. Contact sports require individual assessment but any involving blows directly to the head (e.g., boxing) are inadvisable. Swimming is possible in a pool (not open current e.g. sea, lake, river) under supervision, with a qualified pool attendant; it is advisable for visibility to wear a brightly coloured swimming cap. Cycling depends on seizure type and frequency – it is not advisable for those with frequent drop attacks. Helmets must always be worn. People with epilepsy may travel by air, bus and rail but preparation is important as is good seizure management in these situations. Travel insurance is essential in conjunction with the EHIC card (for European travel). Plans for lone or extended travel should be discussed with the person's doctor in advance. For detailed travel advice see the Brainwave website; www.epilepsy.ie.

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WHAT YOUR PATIENT AND THEIR CARER NEED TO KNOW

This chart is a quick reference guide by age and gender; it highlights some of the many issues people with epilepsy have to deal with at various stages in their lives. The impact of each issue will vary depending on the person's age and degree of seizure control.

CHART KEY	FURTHER INFORMATION
EPILEPSY ISSUES	MEDICAL TEAM & BRAINWAVE
MEDICAL/TREATMENT ISSUES	MEDICAL TEAM
PSYCHO-SOCIAL ISSUES	BRAINWAVE
EMPLOYMENT & EDUCATION	BRAINWAVE
PHYSICAL	MEDICAL TEAM & BRAINWAVE

OLDER PEOPLE
- LIFESTYLE & TRIGGERS
- LOSS OF INDEPENDENCE
- MEMORY ISSUES
- INCREASED VULNERABILITY
- BONE HEALTH
- FALLS
- INCREASED SAFETY RISKS
- COMMUNITY CARE
- SUPERVISION

PRE SCHOOLERS
- MILESTONES
- EARLY INTERVENTIONS
- ASSESSMENT
- DEVELOPMENT

ALL
- TESTS/INVESTIGATIONS
- SEIZURE TYPE
- SEIZURE PATTERN
- SEIZURE MANAGEMENT
- MEDICATION SIDE EFFECTS
- SUDEP
- SAFETY

SCHOOL CHILDREN
- EDUCATIONAL PLACEMENT
- ACHEIVEMENT & PROGRESS
- LEARNING
- SUPPORT NEEDS
- PEER PRESSURE
- SOCIAL ACCEPTANCE
- LEISURE/SPORT

ADULT MALES

- CAREER PROGRESSION
- BONE HEALTH
- LIBIDO
- SEXUALITY
- FERTILITY
- DRIVING SAFELY
- RELATIONSHIPS
- EMOTIONAL SUPPORT
- RELATIONSHIPS
- LIFESTYLE & TRIGGERS

AGES

- COMPLIANCE
- STIGMA
- COGNITION
- MEMORY RETENTION
- INSURANCE
- EMOTIONAL ISSUES
- ENTITLEMENTS
- LONG TERM ILLNESS SCHEME

ADULT WOMEN

- CAREER PROGRESSION
- CONTRACEPTION
- FOLATES
- PREGNANCY
- CHILDBIRTH
- BONE HEALTH
- BABY CARE
- MENSTRUATION
- FERTILITY
- SEXUALITY
- DRIVING SAFELY
- EMOTIONAL SUPPORT
- RELATIONSHIPS
- LIFESTYLE & TRIGGERS

TEENS

- VOCATIONAL ISSUES
- EXAMS
- PEERS
- RISK TAKING
- INDEPENDENCE
- LIFESTYLE & TRIGGERS
- SOCIAL ISSUES
- DATING
- SEXUALITY

YOUNG ADULT

- CONTINUING EDUCATION
- EARLY SCHOOL LEAVING
- EMPLOYMENT
- TRAINING
- CAREER OPTIONS
- PEERS
- RELATIONSHIPS
- DRIVING
- LEISURE & TRAVEL
- INDEPENDENT LIVING
- LIFESTYLE & TRIGGERS
- SEXUALITY

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Safety in Home

In the kitchen

- Use cordless appliances and use a microwave rather than a conventional cooker to reduce the risk of burns. Avoid the use of sharp knives, particularly carving.
- Use a trolley to move pots and hot dishes rather than carrying them, and keep water levels in kettles at the minimum to reduce scalding risks

In the bathroom

- Showers are preferable to baths; use a shower chair but not a shower curtain which can lead to entanglement. Hard floor surfaces can cause injury – carpet is better. Avoid glass shelving

In the bedroom

- Top bunks should be avoided and if sleep seizures occur, a ventilated pillow (supplied free to new Brainwave Members) is recommended (or no pillow at all), instead of soft pillows which may pose a hazard
- Freestanding furniture and fittings should be secured in case of seizures involving wandering

In the living room

- Trailing flexes should be bundled together or tacked to skirting boards
- TV's and other equipment should be secured or preferably wall mounted. Avoid glass tables and glass door panels. Open fires need a surround fireguard as used for young children
- Radiators with sharp edges can be covered with guards with curved hoods
- Ground level accommodation is safest. Where there are stairs it may be wise if the person has frequent seizures for them to have a downstairs bedroom and bathroom or at least to limit their use of stairs so as not to make to unnecessary use of them. For more detailed advice see www.epilepsy.ie

Lifestyle Management

Lifestyle triggers for seizures include stress, skipped meals, missed sleep, alcohol, missed medication, or a combination of these, especially when a person is out of their usual pattern at weekends, holidays and travelling to different time zones. Other triggers may include street drugs and energy drinks which contain large amounts of caffeine. A combination of healthy diet with regular meal breaks, adequate sleep and a programme of relaxation and stress prevention is always advisable. Physical triggers may be less avoidable; these include illness, fever, pain, periods, some medication interactions, and flicker and glare for those who are photosensitive.

Education

In respect of state examinations young people with epilepsy may be eligible for reasonable accommodations in examinations which may entail the use of a separate room if required and which also means the person would not be penalized for having a seizure during the exam. This provision must be applied for in advance of the June exams and may not come into play unless a seizure occurs. See the State Examinations Commission site www.sec.ie. No account is taken of time missed from school or the cognitive effects of seizures and medication on memory and learning.

Brainwave in partnership with the Institute of Technology, Sligo runs a 1 year Pre-employment Training programme Training For Success (TFS). To enter you must be a person with epilepsy, be registered with FÁS and be capable of independent living. For further information on TFS contact Honor or Maire at 071 9155303. This programme is funded by FÁS.

Employment

Employment prospects are enhanced by good seizure control. There are only a few areas currently not open to people with a history of epilepsy, these include becoming a professional pilot, HGV driver (due to change soon), and train or bus driver. Admission to the armed forces and emergency services may be difficult also. While most people do manage to work at what they choose, the degree to which their seizures are controlled is important. A person whose seizures are well controlled may have no difficulty working as a child care worker or teacher but there could be supervision issues in the case of a person whose seizures are uncontrolled.

Living Independently

In conjunction with sensible precautions, lifestyle management and safety guidelines, there are some additional measures the person can take to maximise their independence. For adults living alone there are alarms which can detect seizures with movement and wandering both around the house and also in sleep. These may be linked to a monitoring centre or may dial pre-programmed numbers of key holders nearby who can come to the person's assistance. When out and about, it is advisable to wear an epilepsy identity bracelet which is supplied free to new Brainwave members and is linked to a 24 hour confidential bureau which keeps details of the person's treatment, next of kin and other relevant details which may be required by casualty staff.

Brainwave The Irish Epilepsy Association

Aims and Objectives of the organisation

Brainwave The Irish Epilepsy Association is the National member led charity for people with epilepsy in Ireland. Brainwave has offices located throughout the country.

Vision

Brainwave's vision is to achieve a society where no person's life is limited by epilepsy

Mission

Brainwave The Irish Epilepsy Association is committed to working for, and meeting the needs of everyone with epilepsy in Ireland and their families and carers

- To provide support, information and advice to people with epilepsy
- To provide information and advice to health professionals in dealing with epilepsy
- To improve public understanding of epilepsy (in order to eliminate fear and prejudice) through awareness campaigns and education programmes
- To undertake, encourage and assist research into the causes of, cure for and management of epilepsy and into the social and psychological effects of the condition
- To promote legislative and civil rights for people with epilepsy and to campaign to eliminate all discriminatory practices and policies affecting them
- To assist in the development of support groups for people with epilepsy in the area of training and employment
- To provide information on issues related to driving: insurance, changing legislation
- To provide practical aids to people with epilepsy (pillows, bracelets)
- To operate as a public forum and an advocate for the condition of epilepsy
- To raise funds to support its work in an awareness-creating manner

Resource List:

International Bureau for Epilepsy (IBE) - www.ibe-epilepsy.org

Joint Epilepsy Council of UK and Ireland (JEC) – www.jointepilepsycouncil.org.uk

International League Against Epilepsy (ILAE) – www.ilae-epilepsy.org

The Republic of Ireland Epilepsy and Pregnancy Register – www.epilepsypregnancyregister.ie

Epilepsy Action UK – www.epilepsy.org.uk

The National Society for Epilepsy UK (NSE) – www.epilepsynse.co.uk

The National Centre for Young People with Epilepsy UK (NYCPE) – www.nycpe.org.uk

Epilepsy Scotland – www.epilepsyscotland.org.uk

Epilepsy Bereaved UK – www.sudep.org

Epilepsy Foundation USA – www.epilepsyfoundation.org

Neuroscience for Kids – http://faculty.washington.edu/chudler/neurok.html

Beyond Epilepsy – www.livebeyondepilepsy.com

Matthew's Friends – www.matthewsfriends.com

Neurological Alliance of Ireland – www.nai.ie

EpilepSy Nurses Association UK (ESNA) - www.esna-online.org.uk

International League Against Epilepsy UK (ILAE) – www.ilae-uk.org.uk

Beaumont Hospital Epilepsy Research Group – www.epilepsyprogramme.ie

IrishHealth.com Epilepsy Clinic - www.irishhealth.com/clin/epilepsy

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