Epilepsy – definitions, diagnosis and treatment

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The word epilepsy comes from the Greek word epileamabanien which means to seize or attack. It is the most common neurological disorder (after migraine) affecting 50 million people worldwide. Irish prevalence figures would suggest there are 36,844 people (over the age of 5) in Ireland affected by the disorder.1 An estimated 10,000 of whom are women of childbearing potential.2

It is a condition associated with a great deal of stigma, which is recognised by the people with the condition. Epilepsy occurs in all social groups. People with epilepsy are often made to feel very different and as a result are very reluctant to reveal their illness. The health service is now beginning to recognise the need for more intervention to educate and support those affected by the condition.

THE ROLE OF THE COMMUNITY EPILEPSY NURSE

This new role was brought about by the partnership of the Health Services Executive, Brainwave – The Irish Epilepsy Association and Beaumont Hospital. The result was the appointment of the first Clinical Nurse Specialist in Community Epilepsy Services in the country and to date there are now three specialist epilepsy nurses working with Brainwave.

I commenced the post of Community Epilepsy Nurse on the 10th June 2002. One of the primary aims of this post was to improve the links between Beaumont Hospital and the primary health care sector, including general practitioners, public health nurses, practice nurses, pharmacists and other allied health professionals as proposed by the National Health Strategy 2002.

The overall aim is to improve patient care and increase awareness of the services provided by Brainwave.

DEFINITION OF EPILEPSY

Epilepsy is a clinical condition characterised by recurrent unprovoked seizures. It is classified by both syndromes and seizures. One seizure does not constitute epilepsy. It is a very common condition affecting approximately one in 115 people. Five per cent of the general population will experience one seizure in their lifetime.

A seizure is a disturbance of the brain cell function in which a brief period of altered awareness or consciousness occurs. The seizure itself is usually short in nature and maybe followed by a period of tiredness or confusion.

TYPES OF SEIZURES

The International League Against Epilepsy designed a classification system in 1981. They defined seizures as:

Partial seizures
- Simple partial – sometimes also referred to as focal seizures or auras – consciousness is not impaired.
- Complex partial – consciousness is impaired.
- Secondary generalisation.

Generalised seizures
- Absence (formally known as petit mal)
- Tonic clonic (formally known as grand mal)
- Myoclonic (serial jerking movement of limbs, sometimes trunk can be affected)
- Atonic (sudden loss of muscle tone)

Generalised tonic clonic seizures are what were formerly referred to as grand mal seizures. These are the type of events that the general public associates with epilepsy.

CAUSES

For some people there is no known cause and this is called ‘idiopathic’ epilepsy. Sometimes however the reason is found; it could be because of a structural abnormality, brain damage caused by a difficult birth; a head injury; a stroke; or an infection of the brain such as meningitis/encephalitis. Very occasionally the cause is a brain tumour. Epilepsy with a known cause is called ‘symptomatic’ epilepsy.

DIAGNOSIS

The most important part in the diagnosis is the clinical history. This should be accompanied by an eyewitness event such as;
• What was the person doing prior to the event?
• Could they communicate during the event?
• What happened during the event?
• How long did it last?

Where possible the person should be encouraged to bring in a recording of a seizure into their consultant neurologist or epilepsy nurse. After the clinical history is completed some other investigations may be ordered including an electroencephalography (EEG) which is the recording of electrical activity along the scalp produced by the firing of neurons within the brain and magnetic resonance imaging (MRI), or nuclear magnetic resonance imaging (NMRI), which is primarily a noninvasive medical imaging technique used in radiology to visualise detailed internal structures and limited function of the body.

TREATMENTS
Once a definite diagnosis has been made, the individual is usually commenced on an anti-epileptic drug (AED). The exact drug and the dose prescribed depend on the nature of the particular person’s epilepsy, taking into consideration the person’s age, sex, medical history and lifestyle. This medication may need to be changed or altered until a satisfactory one or combination of medication is found. Some patient’s epilepsy may become refractory to medication after a period of time and require further investigations and interventions as a result.

Other treatments to be considered include surgery; this can include the removal of the focal point (only suitable in partial epilepsy). For individuals not suitable for surgery a vagus nerve stimulator may be an option.

The vagus nerve stimulator (VNS) is a device used for the treatment of intractable partial or generalised epilepsy i.e. those people not suitable for epilepsy surgery and for those who fail to respond to two or more AEDs. Mechanistically, the VNS is unlike any other previous treatment for epilepsy. After appropriate evaluation, a patient may undergo surgical implantation of a VNS, usually performed at a specialised epilepsy centre.

EMERGENCY TREATMENT OF SEIZURES
It is well documented that the longer a seizure persists the more difficult it is to bring under control. A new product by the name of Epistatus (buccal midazolam) has been introduced to the Irish market. The aim of this medication is to terminate any seizure lasting longer than 5 minutes, cluster seizures or different than usual seizures, thus endangering the person’s life. Some previous remedies include rectal – diazepam and oral – Ativan. However, as buccal midazolam is administered via the buccal cavity of the mouth or the nose, it is a lot easier to administer and does not impact on a person’s privacy and dignity.

LIFESTYLE IMPLICATIONS
There are many issues that need to be addressed with the individual and their family. Some of the most important issues that should be addressed include, driving, fertility issues, triggers, mood changes, memory problems, education, employment, social issues, disclosure, stigma, and personal safety to include SUDEP (Sudden Unexplained Death in Epilepsy). Informing the individual about adopting these changes into their lifestyle can help them take control of their epilepsy and thus educate them to highlight the particular concerns they are having to their nurse and or doctor.

SUDDEN UNEXPLAINED DEATH IN EPILEPSY
If a person with epilepsy dies suddenly and no obvious cause can be found after a post mortem examination has been carried out, it is called SUDEP.

It is difficult to know exactly how many people with epilepsy die each year, but it is estimated that there is between 60-80 epilepsy deaths in Ireland each year.

The causes of SUDEP are not well understood. Some studies have suggested that the part of the brain that controls breathing may be affected. This could cause the person to stop breathing during a tonic-clonic seizure. For most people, the breathing would start again once the seizure ends, but some are not so lucky. We don’t know yet whether these things happen because the person with epilepsy already has a weakness to their heart or lungs, or whether it is related to the epilepsy itself.
The proof is in the pudding:

- The supplement in 7 easy spoonfuls
- High energy and protein
- Easy to swallow and digest
- Convenient and patient-friendly
- 4 great tasting flavours
- Great alternative to nutritional drinks
- Perfect anytime of the day
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There is some suggestion that some people may be more at risk than others. These may be people who:
- Have poorly controlled seizures
- Have generalised seizures during their sleep
- Have a learning disability
- Are young adult males
- Are not taking their prescribed antiepileptic medication
- Are having frequent or sudden changes to their antiepileptic medication.

**REDUCING THE RISK OF SUDEP**
The following will help reduce the risk of SUDEP
- If seizures are not well controlled, the patient should be referred to an epilepsy specialist for their epilepsy and medication to be re-assessed.
- Advise your patient to continually take their prescription medication.
- Advise your patient to never make changes to, or stop, medication without talking to a doctor/nurse first.

**BRAINWAVE – THE IRISH EPILEPSY ASSOCIATION**
Throughout their existence Brainwave – the Irish Epilepsy Association has worked tirelessly to educate the wider general public and allied healthcare professionals through a variety of settings. Specific information leaflets and publications have been produced for general practitioners, employers and teachers. In 2008 a steering group was established to put together a Nurse’s Information Pack. This group was made up of Brainwave staff and some of the specialist adult and paediatric epilepsy nurses working in Ireland.

This very comprehensive pack includes a variety of information for nurses from all disciplines caring for people with epilepsy to include posters on how the brain works, medication posters for adults and children and the International Classification of Epilepsies and Epileptic Syndromes. It addresses the specific needs of individuals with epilepsy to include those working with special needs, children and women with epilepsy.

**HELPING THE PATIENT**
In particular the group put together a ‘helping your patient’ section. This is the kind of information gathering that is particularly important to the doctor in the hospital setting. It gives an insight to the type of information that is most beneficial: documenting of seizures in a seizure diary, particularly recording the persons activity prior to, during and post the seizure. It also highlights the importance of an eyewitness account and value of having that person accompany the individual to their hospital appointment. The pack has included a suggested patient checklist for the consultant appointment and what to bring to that appointment. It also informs nurses about the Long Term Illness Scheme and how all persons with a diagnosis of epilepsy are entitled to their epilepsy medication free of charge.

Finally the helping your patient section gives an insight into the particular lifestyle implications to discuss with your patient such as e driving and safety issues that may affect patients with epilepsy in general.

It is hoped that this pack will be an invaluable reference tool to all the nurses caring for individuals with epilepsy and that patients with epilepsy will benefit greatly from this sharing of information.

If you would like a copy of the Nurse’s Information Pack to download please send an email to info@epilepsy.ie or contact Brainwave’s head office on 01 4557500.

**References:**