Epilepsy—an introduction

Epilepsy is a common neurological condition that affects 1 in 103 people in the UK. 54,000 people in Scotland have epilepsy. It can affect anyone, of any age or race, either sex, from any walk of life. Seizures happen when there is an interruption to the electrical activity of the brain. The majority of people with epilepsy have their seizures controlled with medication and lead a full and active life.

Seizures

The experience of epilepsy and seizures is different for each person. Most seizures are over in a few minutes or less and the person recovers quickly.

Some seizures:

- only occur during sleep
- may be caused by flashing/flickering lights, geometric shapes and patterns that appear to be moving (Photosensitive epilepsy – only affects 5% of people with epilepsy)
- can be mistaken for other conditions, e.g. fainting, or for alcohol/drug related behaviour
- can be triggered by lack of sleep, missed meals, response to stress/anxiety, fever, excess alcohol.

Types of seizures

There are 2 broad categories:

Partial (focal) Seizures

Only part of the brain is affected and consciousness may be altered but not lost. Seizures in this category include:

- **Simple partial/aura (focal)**– the person may experience unusual sensations and/or movement in one part of the body, e.g. tingling or twitching, but awareness is not lost.
- **Complex partial** – awareness is disturbed or lost. The person may experience strange feelings and their behaviour may appear unusual.
- **Secondary generalised** – starts in one part of the brain as a simple partial (focal) or complex partial seizure, then spreads to the whole brain.
Generalised Seizures

The whole brain is affected and sometimes consciousness is lost. Seizures in this category include:

- **Absences** – the person looks blank for a few seconds, is unresponsive and doesn’t realise they have had a seizure. This can happen repeatedly and can be mistaken for daydreaming.

- **Myoclonic** – rhythmic muscle jerks that can affect part and/or the whole body.

- **Tonic-clonic** – the person stiffens, jerks, or convulses, loses consciousness and may fall. The person may lose control of their bladder/bowel and bite their tongue or the inside of their mouth.

- **Tonic** - the person may stiffen and fall and briefly lose consciousness.

- **Atonic** - the person loses muscle tone and crumples to the ground.

Status Epilepticus (Serial Seizures, Prolonged Seizures)

Status Epilepticus is when a person has a seizure that lasts 30 minutes or longer or a cluster of shorter seizures lasting 30 minutes or more with little or no recovery in between. It is a medical emergency because the longer a seizure lasts, the less likely it is to stop on its own. It’s also less likely to stop with emergency medication.

Any type of seizure can develop into status epilepticus, but convulsive tonic-clonic seizures are the most dangerous.

Most authorities would recommend the administration of emergency antiepileptic drug treatment when the seizure has lasted more than 5 – 10 minutes.

**For all types of seizures, call for an ambulance if the seizure continues for more than 5 minutes. Never wait for 30 minutes to pass before calling for an ambulance.**

Status epilepticus can lead to brain damage or death.

Diagnosis

It is important to ask your GP to refer you to an epilepsy specialist as epilepsy can be difficult to diagnose and can be mistaken for other conditions. There are many factors which a specialist will take into account, the most important being an eye witness description of the seizures so, if possible, take an eye witness to your appointments.

The tests

Tests are usually done to find out the cause of epilepsy rather than the diagnosis. Most people will have tests as an outpatient and not everyone will need any or all of the following:

- **EEG** (Electroencephalograph) – this is a painless test which records the electrical activity in your brain to identify any disruption to brainwave activity.

- **MRI Scan** (Magnetic Resonance Imaging) – magnetic fields scan the brain to identify very small lesions and scars.
The tests (cont)

CT Scan (Computer Assisted Tomography) – gives cross-section images of the brain and sometimes a dye is injected into a vein for greater detail.

ECG (Electrocardiograph) – a heart tracing can sometimes pick up heart conditions which can lead to seizures.

Blood tests may be done to check general health and identify other conditions, e.g. diabetes.

Causes

In around half of all people it may not be possible to identify what has caused the epilepsy. Sometimes there can be a clear cause, e.g.:

- brain damage, e.g. due to birth injuries, accidents, assaults, excessive use of alcohol/drugs
- neurological conditions, e.g. Stroke, Alzheimers
- infections and fevers, e.g. meningitis, rubella, encephalitis
- benign and malignant tumours
- genetic factors
- low convulsive threshold – some brains are more sensitive to seizures than others.

Recording Seizures

Recording as much information as possible about your seizures is very important and can help in making a correct diagnosis. It also helps your epilepsy specialist to monitor progress and identify possible seizure triggers. Special diaries designed to help you record your seizures are available from Epilepsy Connections.

Treatment

Once a diagnosis of epilepsy has been confirmed, a treatment plan will be put in place.

Antiepileptic Drugs (AEDs)

AEDs are usually the first choice of treatment for epilepsy. The majority of people with epilepsy will have their seizures controlled by AEDs, but seizure control can take time to achieve. AEDs don’t cure epilepsy, but aim to stop seizures from occurring. (See our leaflet on AEDs).

Other treatments

Surgery

Surgery is only suitable for some types of seizures and has a good success rate for a small proportion of people with epilepsy. People who are potentially suitable for surgery will undergo a range of tests during pre-surgical assessment, which can take up to a year or longer.

Surgery involves removing or separating areas of the brain where epileptic activity starts, providing this would not cause unacceptable damage or disability and there are no other medical issues.
Other treatments (cont)

**Vagus Nerve Stimulator (VNS)**

A VNS is a small device surgically implanted near the left collar bone.

The VNS is attached to the vagus nerve and is programmed to send electrical messages to the brain to reduce the frequency and duration of seizures.

Most people will continue to need AEDs in addition to the VNS implant.

**Ketogenic Diet**

The Ketogenic Diet is a medical treatment based on high fat, low carbohydrate intakes. It is prescribed by an epilepsy specialist and monitored by a dietician.

It is most often recommended for children whose seizures do not respond well to AEDs. However, recent studies have reported some success with adults.

Further information is available at:

[www.epilepsyresearch.org.uk](http://www.epilepsyresearch.org.uk)  [www.matthewsfriends.org](http://www.matthewsfriends.org)

**Sudden unexpected death in epilepsy (SUDEP)**

It is important to know that there is a small risk of dying because of epilepsy, e.g. as a result of a seizure or as a result of an accident caused by a seizure. In some cases there is no clear reason why a person with epilepsy has died and this is called sudden unexpected death in epilepsy (SUDEP).

Risk factors for SUDEP may be increased by the following factors:

- Having tonic-clonic seizures or having seizures that are not reduced or stopped by AEDs.
- Having seizures which occur during sleep or when you are alone.
- Status Epilepticus - having seizures which last 30 minutes or longer, or a cluster of shorter seizures lasting 30 minutes or more with little or no recovery in between.
- Not taking AEDs as prescribed by your GP or having sudden and frequent changes to AEDs.

The most effective way to reduce the risk of SUDEP is to have as few seizures as possible so, always take your medication as prescribed and never stop taking or changing it without speaking to your GP or epilepsy specialist first and avoid situations which you know may trigger your seizures.
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