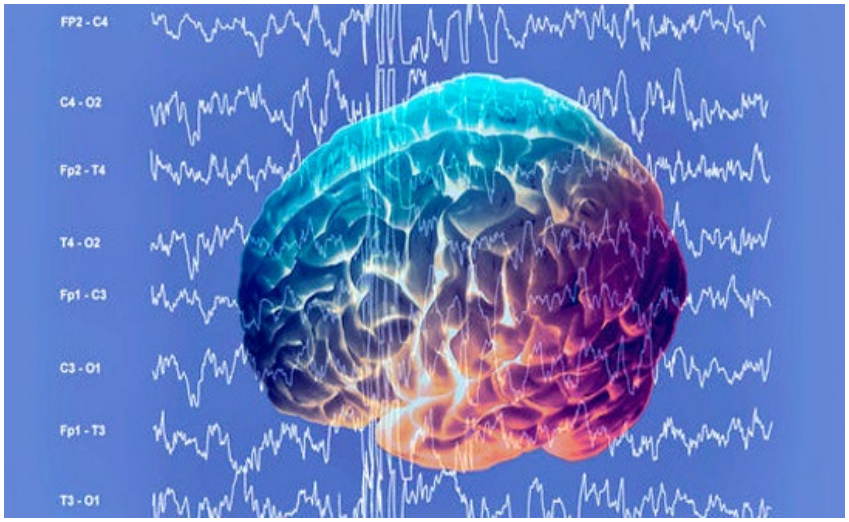
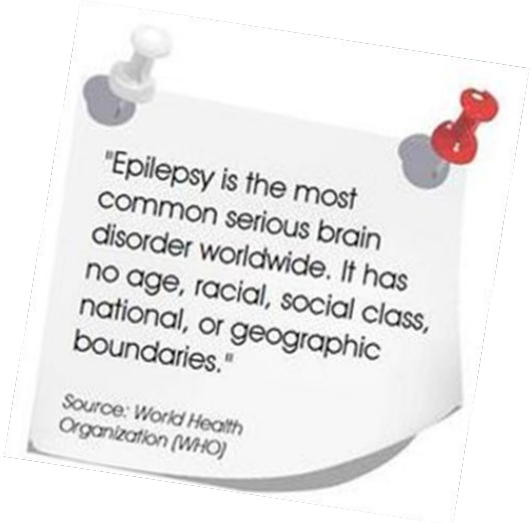
EPILEPSY AND FRAILTY

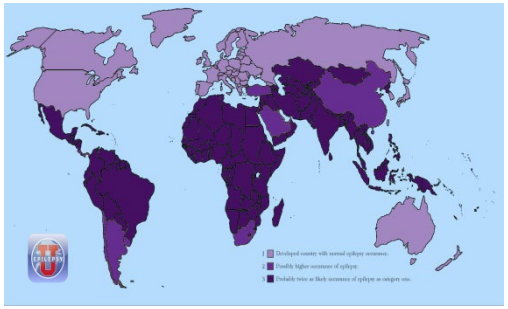




Presented by

Michelle Knight

Lead Epilepsy Specialist Nurse - Dorset Epilepsy Service



Epilepsy statistics

- One in 20 people will have a one-off epileptic seizure at some point in their life (although this does not necessarily mean that they have epilepsy).
- One in 50 people will have epilepsy at some time in their life (not everyone with epilepsy will have it for life).
- Around 87 people are diagnosed with epilepsy every day.
- Over 500,000 people in the UK have epilepsy. That's about one in every 100 people.
- There are around 60 million people with epilepsy in the world.
- Source: Epilepsy Society 2019

The epilepsies

- Epilepsy is usually only diagnosed after a person has had more than one seizure (occurring more than 24 hours apart). Not all seizures are due to epilepsy. Other conditions that can look like epilepsy include fainting, or very low blood sugar in some people being treated for diabetes.
- Anyone can develop epilepsy, at any time of life. It happens in people of all ages, races and social classes. Epilepsy is most commonly diagnosed in children and in people over 65.
- There are over 40 different types of epilepsy and at least 40 different seizure types (perhaps as many as 50)

Epilepsy Co-morbidities

(this page shows anyone in Dorset on a anti-epileptic, with filters for epilepsy)

Dorset Intelligence & Insight Service

Report refresh date: 15/10/2025

Primary Care Network & GP Surgery: All

Filter by Age Groups: All

Filter by Ethnic Groups: All

Anti-Epileptic Drug: All

Filter by Learning Disability: Learning Disability

Epilepsy and Learning Disability

1,081

Population Count

Total Patients on Epilepsy Register

10,475

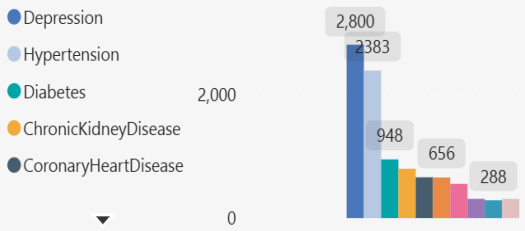
Population Count

Epilepsy and Depressi

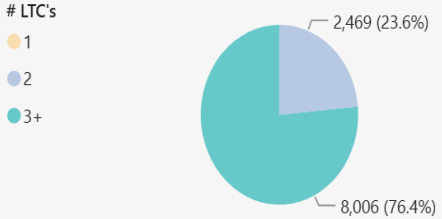
2,800

Population Count

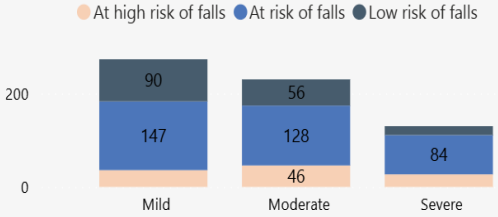
Long-Term Conditions



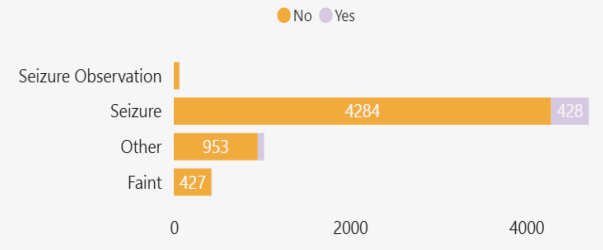
Number of LTC's



eFrailty Index Grouping and Fall Risk



Seizures Recorded in < 12 Months



For Practice Use Only: Drill Down to Patient Detail

Person Key	Surgery Name	Age Band	eFrailty Scores	Seizures (groups)	ConditionDescription	Asthma
[redacted]	Shore Medical	80+	0.89	Other	R0020 - [D]Blackout	0
	Shore Medical	80+	0.89	Other	XM010 - Syncope	0
	Stour Surgery	50-59	0.69	Other	R0023 - [D]Collapse	0
	Stour Surgery	50-59	0.69	Seizure	R003. - [D]Convulsions	0
	Stour Surgery	50-59	0.69	Seizure	R003z - [D]Convulsion NOS	0
	Stour Surgery	50-59	0.69	Seizure	X75YR - Fit - had one, symptom	0

DORSET

- 10,475 PwE in Dorset (total population 820,000)
- 5,710 PwE 50 or older (889 0-17; 3,876 18-49)

eFrailty groups:

- 273 considered "mild" (183 at risk of falls, with 36 thought to be at high risk).
- 230 considered "moderate" frailty (174 at risk of falls, 46 thought to be at high risk).
- 130 considered "severe" frailty (111 at risk of falls, 27 thought to be at high risk).

In the 50 & over category:

- Mild: 173, with 141 at risk of falls (33 at high risk).
- Moderate: 206, with 164 at risk of falls (45 high risk).
- Severe: 129, with 111 at risk of falls (27 high risk).

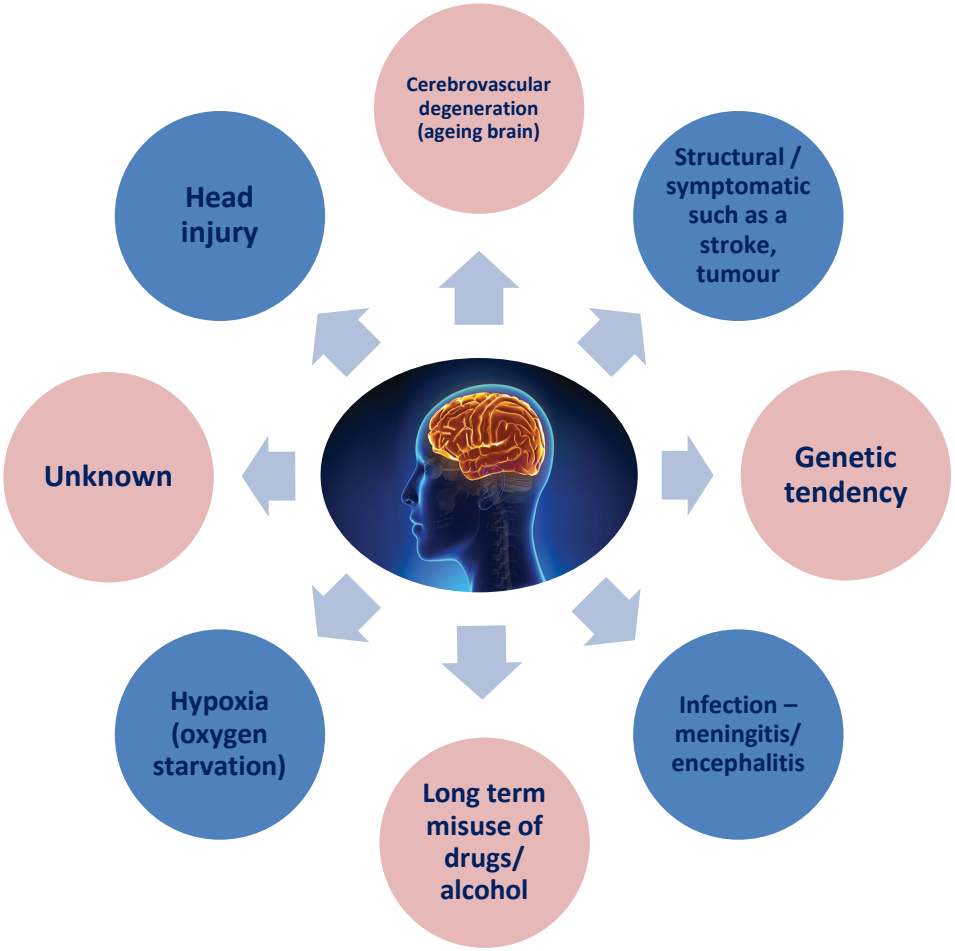
Comorbidities:

- 2,800 with epilepsy and depression
- 1,081 with LD and epilepsy
- 2,383 with hypertension and epilepsy
- 948 with diabetes and epilepsy
- 797 with chronic kidney disease and epilepsy
- 659 with coronary heart disease and epilepsy
- 656 with stroke and epilepsy
- 553 with osteoporosis and epilepsy
- 311 with TIA and epilepsy
- 288 with dementia and epilepsy
- 310 with heart failure and epilepsy

EPILEPSY IN LATER LIFE

- Epilepsy is the 3rd most common neurological disorder after dementia and stroke
- One in every four people who are newly diagnosed with epilepsy are over the age of 65

Causes of Epilepsy



How is epilepsy diagnosed?

Eye witness accounts – Video recording

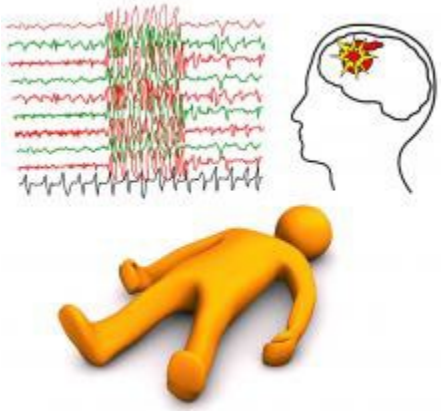
EEG – electroencephalogram

Video telemetry

CT – computerised tomography

MRI - Magnetic resonance imaging

Blood test



POSSIBLE TRIGGERS

Anything that puts the body under stress and reduces seizure threshold such as:

- Underlying physical cause such as constipation or an infection
- Forgetting or suddenly stopping medication
- Alcohol
- Sleep deprivation / tiredness
- Hormone changes (Menstruation / menopause/ pregnancy/ puberty)
- Emotional upset (fear, anger, stress, anxiety, overexcitement
- Boredom
- Sudden noise / flashing lights (rare)
- Overheating

SUDEP
SUDDEN UNEXPECTED DEATH IN EPILEPSY

- Sudden unexpected death in epilepsy (SUDEP)). 3 people with epilepsy die everyday from SUDEP. It can happen to both adults and children. Around half related epilepsy deaths are SUDEP.
- he cause of SUDEP is not yet known. Researchers are investigating a range of possibilities such as the effect of seizures on breathing and the heart.
  SUDEP occurs in approximately 1 per 1000 people with epilepsy (1 in 4,500 children)..
- **There are certain factors which can increase the risk of SUDEP**:
- Having generalised tonic-clonic seizures
- Having poorly controlled seizures
- Having seizures at night or in bed
- Having seizures when on your own
- Frequent and abrupt changes to medication
- Not taking medication as prescribed
- Drinking lots of alcohol
- **Reducing the risk of SUDEP**
- optimizing seizure control and preventing seizures as much as possible
- being aware of potential risks at night
- medication compliance sensible lifestyle

For more on information on SUDEP visit www.sudep.org.

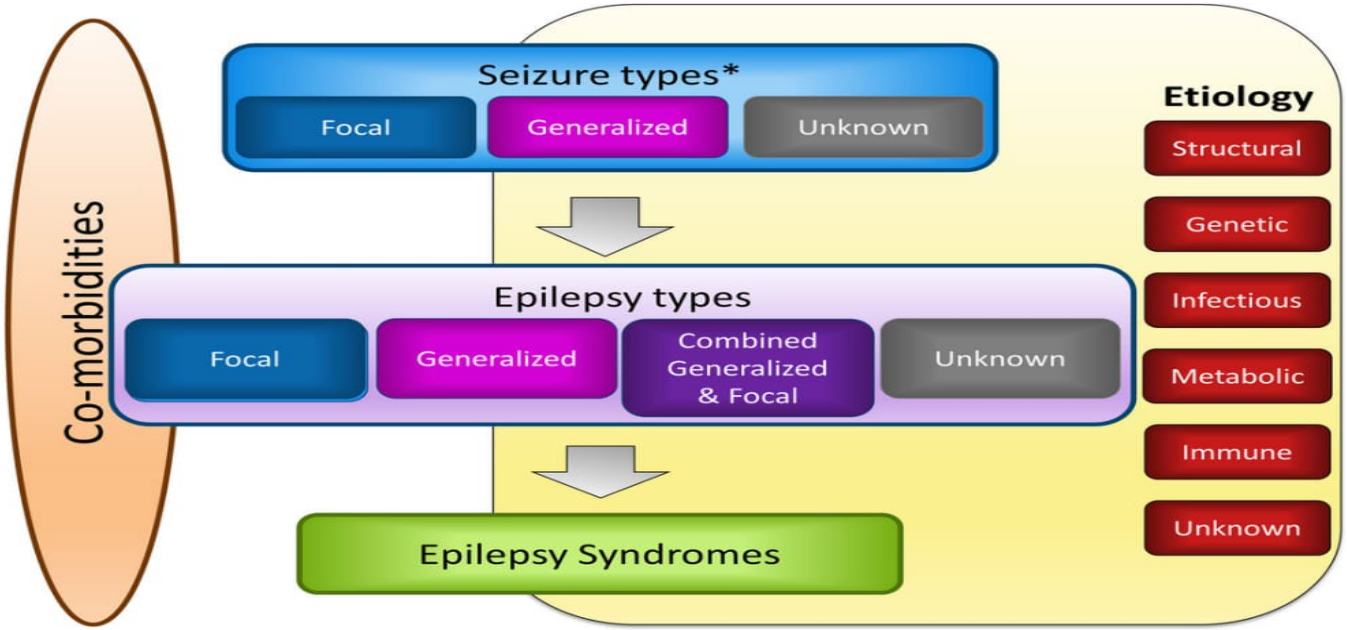
Seizure classification

In March 2017 the International League Against Epilepsy (ILAE), a group of the world's leading epilepsy professionals, introduced a new method to group seizures. This gives doctors a more accurate way to describe a person's seizures, and helps them to prescribe the most appropriate treatments.

Seizures are divided into groups depending on:

- where they start in the brain (onset)
- whether or not a person's awareness is affected
- whether or not seizures involve other symptoms, such as movement

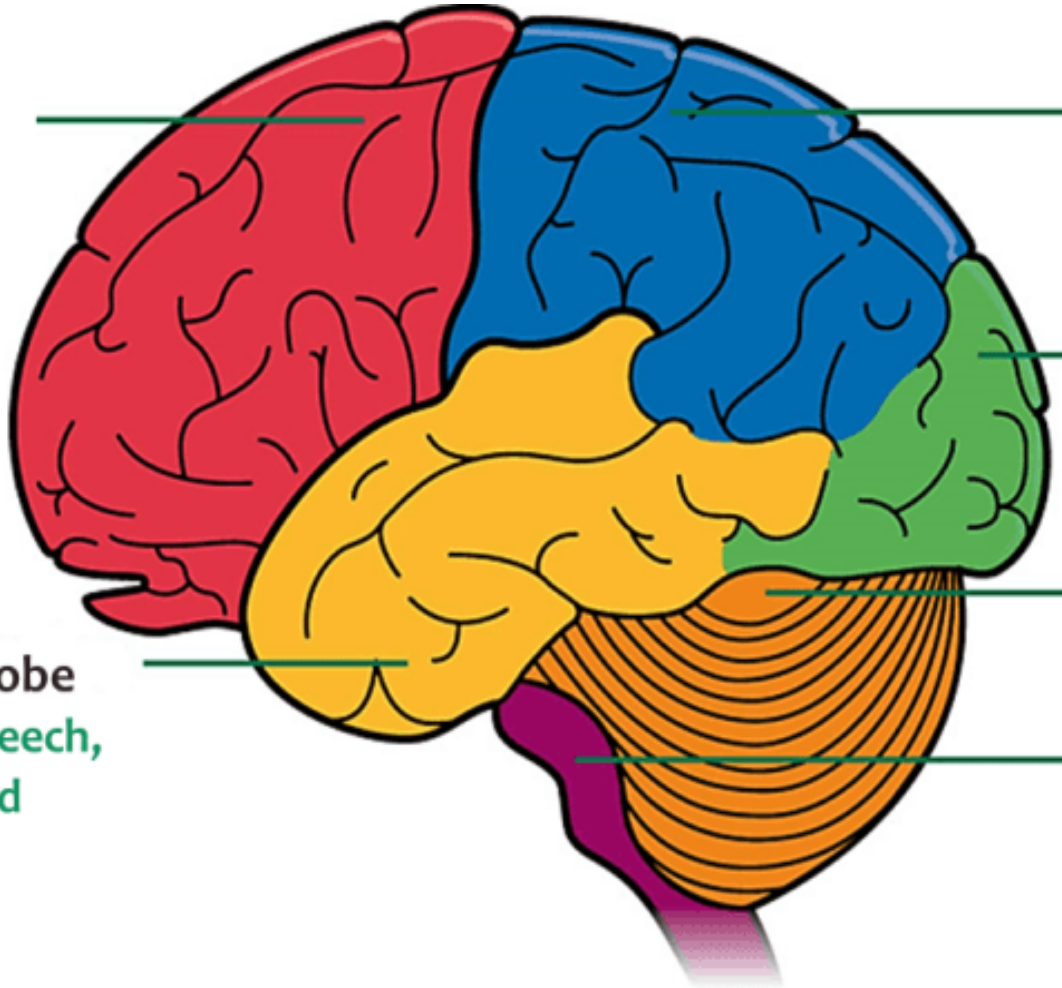
Depending on where they start, seizures are described as being focal onset, generalised onset or unknown onset.



FOCAL Seizures

- Involve only part of the brain and have an epileptic focus
- **Simple focal** – consciousness is not impaired. Some patients may describe this as an aura or warning
- **Complex focal** - Consciousness may or may not be impaired
- Symptoms will vary, depending on where in the brain the epileptic focus starts

Focal seizures - symptoms vary



Frontal lobe
Movement, emotions, memory, language, social, sexual behaviour, and personality

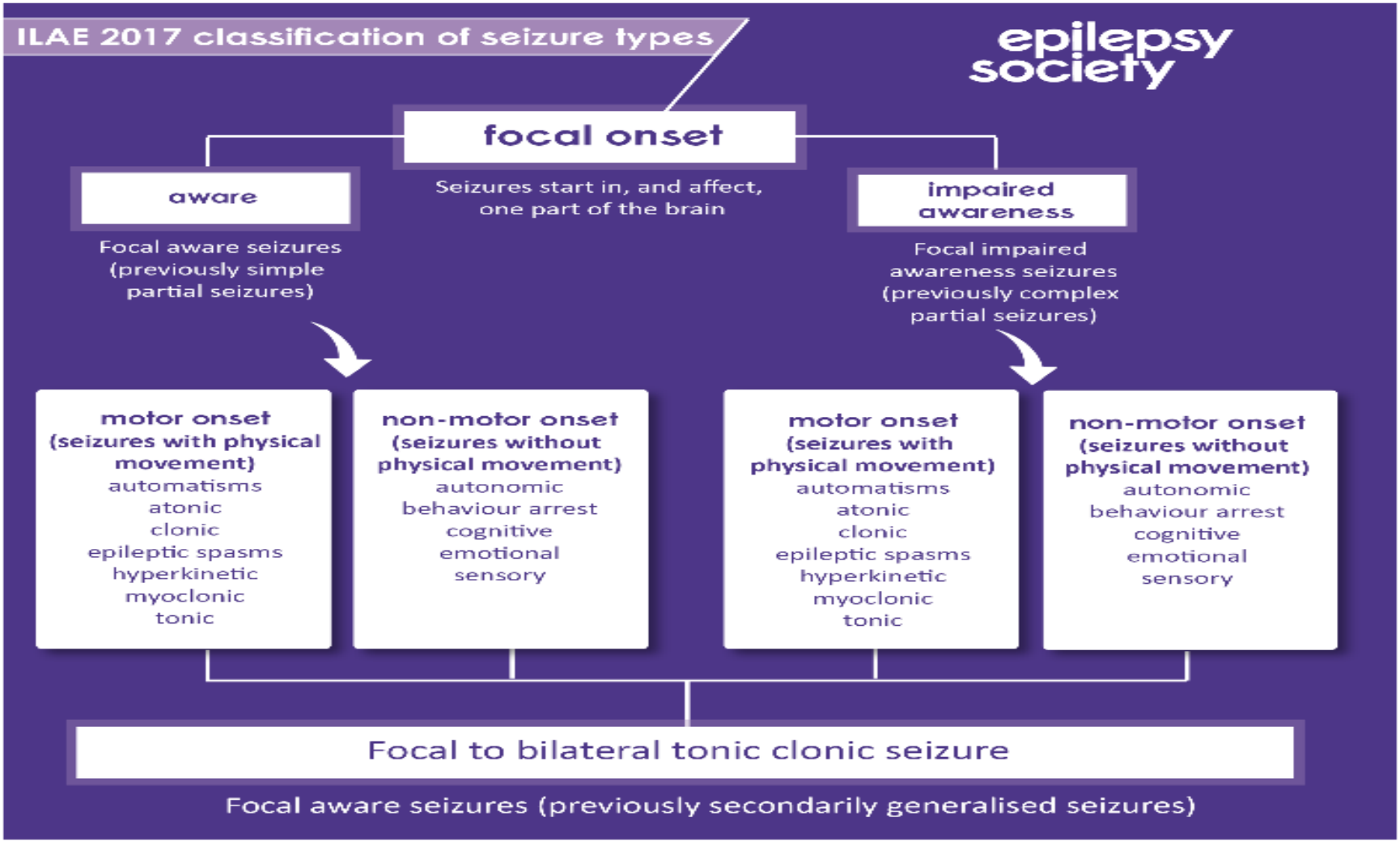
Parietal lobe
Bodily sensations

Occipital lobe
Processing vision

Temporal lobe
Hearing, speech, memory and emotions

Balance and coordination

Breathing, heart rate and temperature



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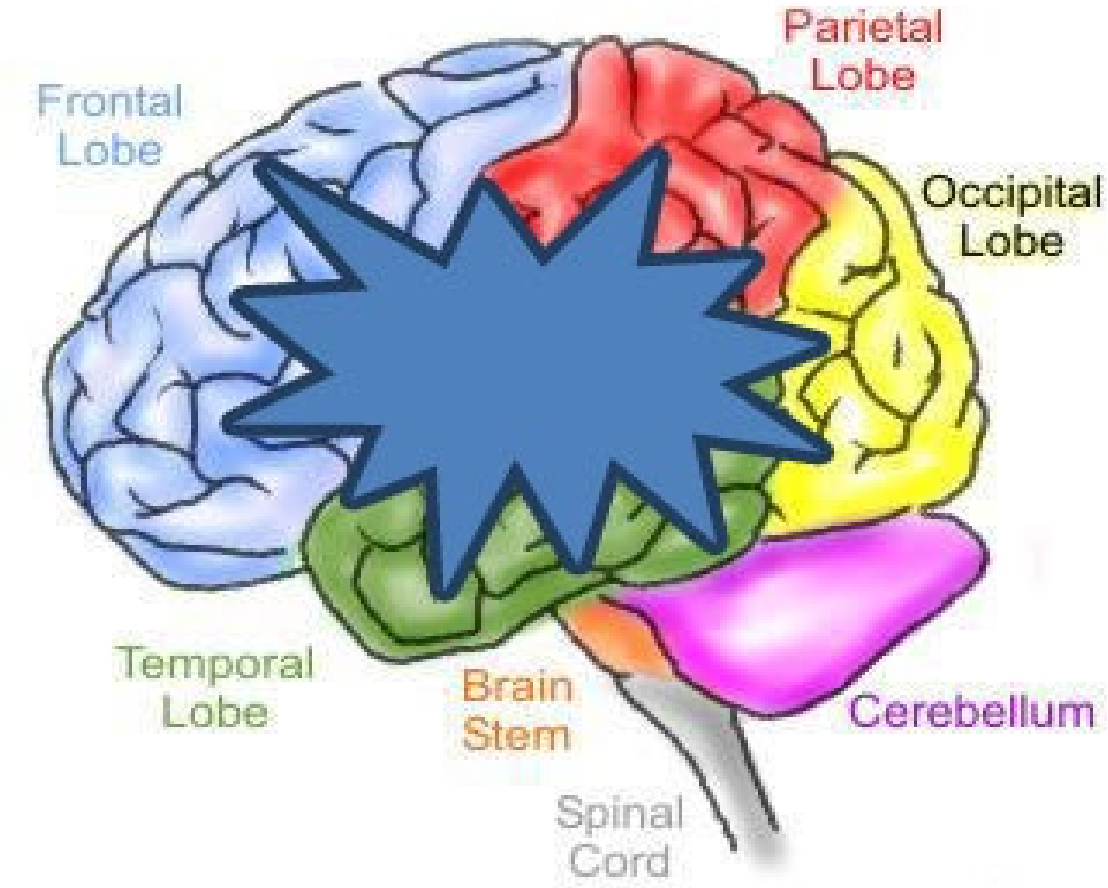
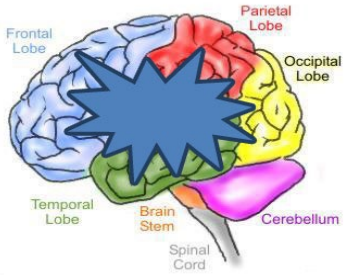
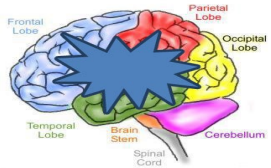
Generalised Seizures (Affecting the whole brain)



Generalised seizures

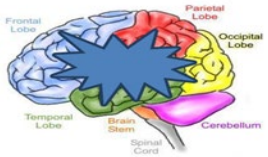


- Are bilaterally symmetrical, the whole of the brain is involved at onset
- **Consciousness is always lost**
- Often will occur without warning and the person will have no recollection of the seizure



Generalised Seizures

- Myoclonic jerks
- Absences
- Tonic
- Atonic
- Tonic-clonic
- Clonic



Bilateral Tonic clonic

Tonic phase:

- Consciousness is lost. Body goes stiff.
- Falls to the floor. May cry out.

Clonic (CONVULSING) phase:

- Body and Limbs jerk. May be incontinent.
- Eyes remain open with fixed gaze
- May bite tongue or the inside of cheek.
- Teeth may be clenched.
- May stop breathing, or have difficulty breathing. May go blue around mouth.

*May hyper salivate or vomit

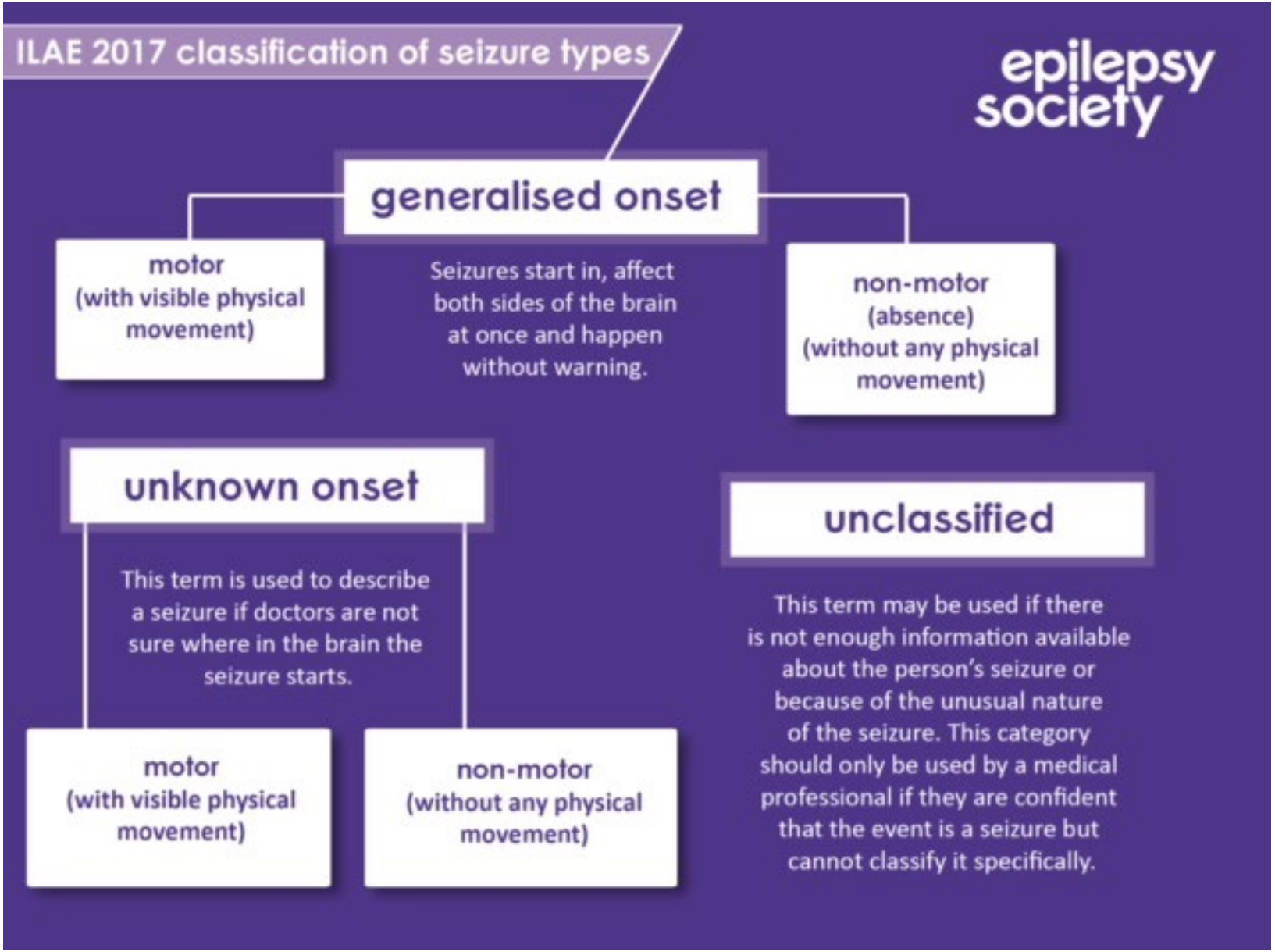
Recovery:

- Consciousness gradually starts to return when the convulsions stop
- The person will begin to recover
- Breathing will begin to normalise

Afterwards: Headache. Tired. Confused. Memory problems. Deep sleep

After waking: minutes or hours later, might still have headache, feel sore and have aching muscles, feel disorientated.

Usually last for 1-3 minutes



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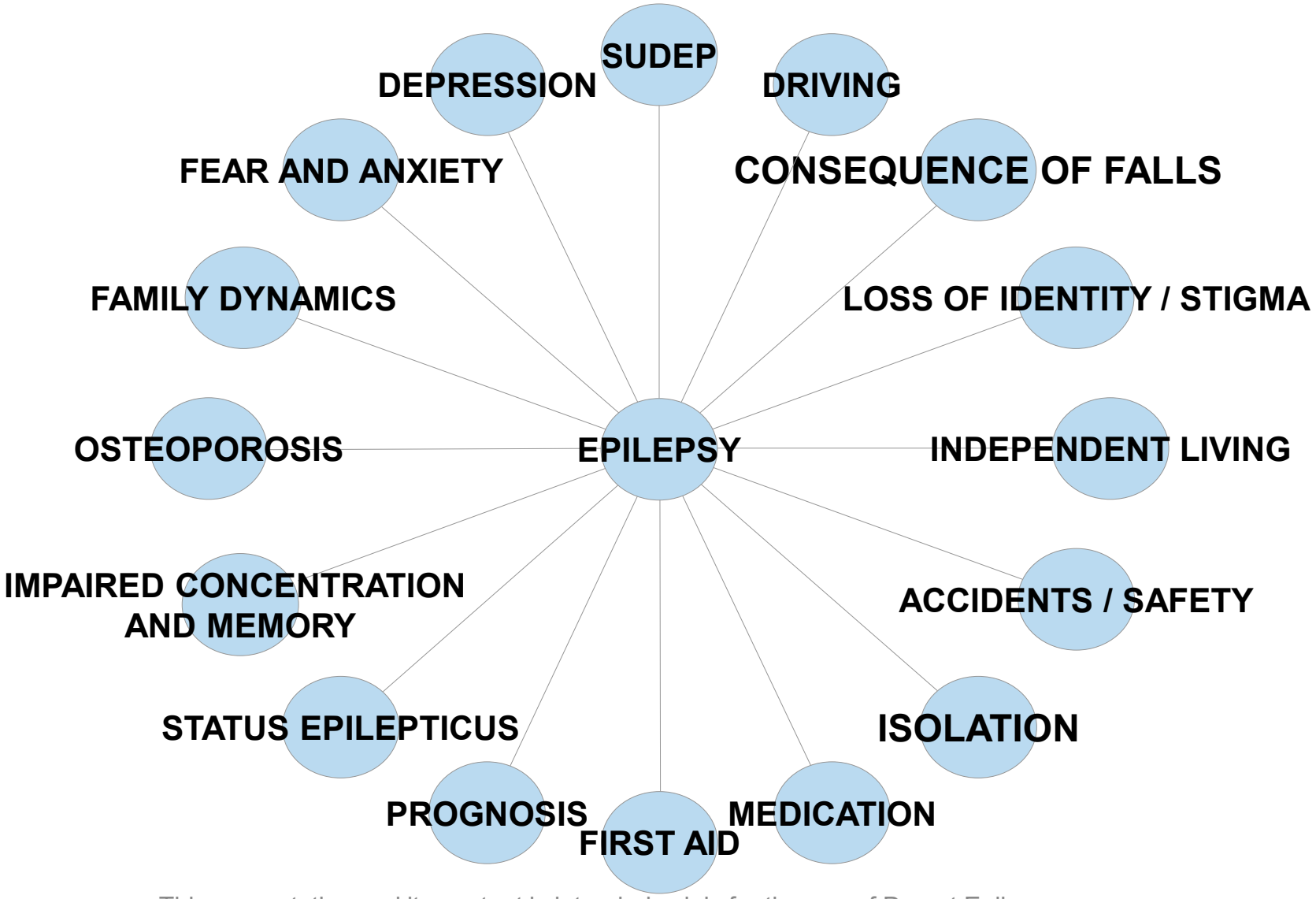
Inpatient Care

Having epilepsy can affect people in different ways. Knowing that a person 'has epilepsy' does not tell you very much about what happens for them or how epilepsy affects them.

Things to consider;

- Has the patient got an epilepsy care plan / rescue medication?
- Are they known to epilepsy services? If not, refer to neurology.
- Medication doses should be given on time. Medication should not be omitted, if patient is NBM or has an issue with their enteral feeding, consider IV or NG administration
- What type of seizures does the person have? How often? What usually happens during a seizure?
- Any identified triggers? (particularly infection, constipation, alcohol, missed medication)
- Consider safety – observation, bathing, fall alarm, cot sides, does the person need 1:1 support to minimalise risk?
- Co-morbidities

Associated Issues



Driving

Group 1 licence - ordinary driving licence - 1 year

Group 2 licence – vocational - 10 years

- **Asleep seizures - Permitted seizures**
- **Isolated seizures - Provoked seizures**
- **Functional seizures**
- **Stopping or changing medication.**

Functional seizures
(Non Epileptic seizures)

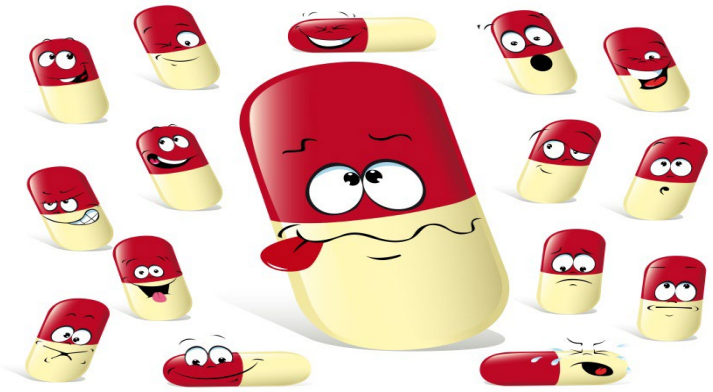
- Functional seizures are not caused by changes in the brain which can be picked up with a brain scan or EEG
- People can have a dual diagnosis of epilepsy and FND
- Underlying Psychological cause
- Unconscious mechanism, which the brain uses to protect itself against overwhelming distress – 'shuts down'
- Functional seizures can be triggered by a wide range of situations, emotions, physical sensation, thoughts or memories – Post Traumatic Stress Disorder (PTSD)

Anti-seizure (ASM) medication

- Formulation - not crushing prolonged release
- dosing regime
- Avoid abrupt changes / missing medication
- Adherence
- Little additional benefit for more than 2 agents
- generic vs branded
- Side effects – allow time to adjust/settle
- Polypharmacy

Anti-seizure medications

- Acetazolamide (1952) - diamox
- Benzodiazepines (1950's) – clobazam, lorazepam, midazolam, diazepam
- Brivaracetam (2015) - briviact
- Carbamazepine (1964) – tegretol
- Cenobamate (2022) - Ontozry
- Ethosuximide (1958) - zarontin
- Eslicarbazepine (2010) – zebinix
- Cannabidiol (2019) - **Epidiolex**
- Felbamate (USA – 1980's) - felbatol
- Gabapentin (1990's) - neurontin
- Lacosamide (2008) - vimpat
- Lamotrigine (1990's) – lamictal
- Levetiracetam (2000) - keppra
- Oxcarbazepine (1980's; UK 2000) - trileptal
- Perampanel (2012) - fycompa
- Phenobarbital (1912)
- Phenytoin (1952) - epanutin
- Piracetam (1967; myoclonus 1978) – nootropil
- Rufinamide (2008) - inovelon
- Stiripentol (2007) - diacomit
- Tiagabine (1990's) - gabitril
- Topiramate (1990's) - topamax
- Valproate (late 1960's) - epilim
- Vigabatrin (1990's) - sabril
- Zonisamide (Japan 1970's) - zonegran



SIDE EFFECTS

- Cognitive Impairment
- Impaired coordination
- Memory problems
- Slowed Speech
- Emotional Disturbance
- Confusion
- Nervousness
- Sedation/Fatigue/Drowsiness
- Tremor
- Unsteadiness/vertigo
- Dizziness/Headache
- Skin Rash
- Weight Gain- Anorexia
- Coarsening of facial features
- Blood disorders
- Sexual dysfunction

- Behaviour Disturbances
  Aggression, Irritability
- Psychosis , Depression, anxiety
- Visual Disturbances -Double vision
- Increased Seizures
- Brittle Bone Disease- osteopenia, osteoporosis
- Softening of the Bones osteomalacia
- Induced production of liver enzyme
- Diarrhoea/Constipation
- Nausea/vomiting
- Hair loss/excess hair growth
- Low sodium/low vitamin D
- Joint pain/back pain
- Pins and needles

Bone health

Anti-seizure medication (ASM) can be associated with an increased risk for osteoporosis and fractures. It is also thought that some ASM's alter the way vitamin D, which helps with the absorption of calcium, is broken down and used by the body. We encourage patients to:

- Eat a well-balanced calcium rich diet.
- Make sure you get adequate vitamin D through safe sunlight exposure.
- A calcium and vitamin D supplement may be prescribed if calcium and vitamin D intake needs to be boosted.
- A drug treatment to make weak bones stronger and less likely to break may be prescribed by your doctor.
- Pain relieving medications will help if fractures have already occurred.
- Take plenty of weight-bearing exercise - any exercise in which you are supporting your own body weight through your feet or legs.

- www.nos.org.uk

Case study - Doris

- Admitted to ED due to seizures
- Diagnosis of epilepsy made in childhood
- Reported to be photosensitive
- Not known to Neurology previously
- On Epilim and Phenytoin
- Rectal diazepam as rescue medication
- Found to have Hypernatremia
- Lives with husband. One daughter who is abroad and rarely in contact

Doris

- Referred to see Consultant Neurologist
- Noted to be quite slow and jerky
- Old notes requested
- EEG – Epilepsy and likely Functional seizures in addition
- Started on Levetiracetam with a plan to wean off phenytoin
- Referred to ESN for follow up

ESN

- Home visit carried out – discovered patient was unable to read or write
- Buccal midazolam / SWAST
- Involvement of GP
- Referral to LD team
- Ongoing support with medication changes including medicines technical officer
- Carer support
- Fracture clinic – bone health
- Now off phenytoin, sodium valproate reduced and remains on Levetiracetam
- Mild thrombocytopaenia – better since VPA reduced

Dorset Epilepsy Service

Telephone advice line

0300 019 2231

E-mail - **uhd.epilepsy.service@nhs.net**

Useful information

Epilepsy society
01494 601400
www.epilepsysociety.org.uk

Epilepsy Action
0808 800 5050
www.epilepsy.org.uk

Sudep Action
01235 772850
www.sudep.org

Useful Information

International League Against Epilepsy
ilaebritish.org.uk/

National Institute for Health and Clinical Excellence
www.nice.org.uk