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ADVANCING EPILEPSY CARE IN EMERGENCY MEDICINE

Report on Joint Public Meeting

Tuesday, 21 February 2023

**Speaker**

**Professor Ley Sander, MD PhD FRCP FEAN**

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Consultant Neurologist and Head of Department of Clinical and Experimental Epilepsy, UCL, Queen Square, London,

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**Hosts**

Healthwatch Hackney

&

Patients’ Forum for the LAS

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PROFESSOR LEY SANDER

Professor Sander is an international leader in the treatment of Patients with Epilepsy, and research to unravel the challenges facing people living with Epilepsy. A major focus of his work concerns enhancing seizure preparedness in emergency medicine.

Professor Sander has more than 750 publications to his name, including research articles, books and reviews. He is a member of the Editorial Board of Lancet Neurology and Neurological Advisor to the British National Formulary (BNF).

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HEALTHWATCH HACKNEY

Healthwatch Hackney is the local health and care watchdog, with statutory powers to monitor the NHS and social care. Its vision is for a borough where health and social care provision is equal and accessible to all; where residents are at the heart of the design, delivery and improvement of health and social care.

The ambition of Healthwatch is to improve health and social care provision and outcomes for people in Hackney by working to ensure that treatment and care is of the highest quality, and are provided with respect and dignity, valuing diversity, encouraging participation and working together. It does this by being the independent champion for residents and people who use services, ensuring the voices of people across the Borough are heard, in order to influence decision makers.

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PATIENTS’ FORUM FOR THE LONDON AMBULANCE SERVICE

The Patients’ Forum has monitored the LAS and other urgent and emergency care services across London for 20 years.

Its members are local people who examine services both as users and active lay people. It obtains the information it needs to monitor health services from many sources including the LAS, the Commissioners and NHS service providers across London.

The Forum raises awareness of the needs and views of patients and the public, and attempts to place them at the centre of health service decision-making.

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PROFESSOR LEY SANDER

Professor Ley introduced himself and mentioned that, during his training as a Medical Student in Brazil, he joined the ambulance service as a Paramedic, and that was when he first came across a person suffering from Epileptic seizures. He said that this had an impact on his career and that he is now an Epilepsy Specialist.

His Presentation covers:

* What is Epilepsy and what are seizures?
* Types of Seizures
* Differential diagnosis and the mimics of Epilepsy
* Providing the right treatment, first time
* Emergency treatment of seizures
* A&E attendance for seizures

Epilepsy is not a condition or a disease – it is basically a tendency to suffer from unprovoked seizures. This is very important to understand, because there are so many causes for Epilepsy, particularly what is known as a ‘symptom complex’, which may be caused by anaemia.

Unfortunately, there is a tendency for many people, including Neurologists, to see Epilepsy as a disease, and this can often be unbeneficial to the patient.

Professor Ley Sander is:

* Medical Director of the Epilepsy Society
* Consultant Neurologist and Head of the Department of Clinical and Experimental Epilepsy at the Institute of Neurology, UCL, Queen’s Square, London
* Development Director of Stichting Epilepsie Instellingen Nederland (SEIN).

The Professor’s research interests include the epidemiology, outcomes and genetics of Epilepsy, the medical and surgical management of Chronic Epilepsy and the delivery of Epilepsy care in resource-poor settings.

EPILEPSY and EPILEPTIC SEIZURES

A clinical condition characterised by repeated and unprovoked seizures.

UNPROVOKED SEIZURES

These seizures occur with no known precipitants or warnings. However, there might be a history of a traumatic injury of the Central Nervous System (CNS), a Traumatic Brain Injury (TBI) or Spinal Cord Injury (SCI). For instance, if one has seizures and has had a severe head injury, the risk of seizures may persist for about 10 years.

PROVOKED SEIZURES / ACUTE SYMPTOMATIC SEIZURES

These are seizures occur in a close temporal relationship with an acutely damaged CNS, for example when someone has a massive stroke, an infection, trauma, metabolic derangement, or changes in the blood chemistry.

These seizures are not considered to be Epilepsy, although many of these patients may be at risk of developing Epilepsy later on.

CNS – Cerebral Nervous System

STATUS EPILEPTICUS

This is when a seizure becomes a medical emergency.

This is prolonged or repeated seizures, one after another that will not stop unless there is a clinical intervention.

ACUTE SYMPTOMATIC SEIZURES

These are seizures closely associated with a brain injury. The causes can be a stroke, a metabolic imbalance, autoimmunity, infection, some toxic medications, drugs or alcohol, or a traumatic brain injury.

|  |  |
| --- | --- |
| CAUSES OF ACUTE SYMPTOMATIC SEIZURES | |
| Cerebrovascular Disease | 16% |
| Head Trauma | 16% |
| CNS Infection | 15% |
| Intoxication and withdrawal | 14% |
| Metabolic, e.g. demylination | 9% |
| Toxic substances | 6% |
| Other | 24% |

UNPROVOKED SEIZURE TYPES

There are THREE major types, according to where they start in the brain …



|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| |  |  |  | | --- | --- | --- | | **60%** | **30%** | **10%** | | of people with Epilepsy have FOCAL SEIZURES | of people with Epilepsy have GENERALISED SEIZURES | of people with Epilepsy have an UNKNOWN GENESIS |   FOCAL SEIZURES also known as PARTIAL SEIZURES  This is when a seizure starts in a ‘localised’ area of the brain. It begins in one side of the brain and may remain there - or it may spread.  This happens to about 60% of people having seizures. |
| GENERALISED SEIZURES  If the epileptic activity occurs simultaneously over all of the brain - and at the same time - this is called a Generalised Seizure.  People in this category do not have an ‘aura’ or ‘warning’, they go straight into loss of awareness, loss of consciousness and body convulsions. These are known as Focal to Bilateral Convulsive seizures.  This happens to about 30% of people having seizures.  UNKNOWN ONSET SEIZURES |

This is when in it cannot be determined where in the brain the seizure started. This occurs in 1 in 10 people. These are called Unknown Onset Seizures and are usually found with people who have severe Epilepsy. They may have other problems, such as learning disabilities and other complex needs.

This happens to about 10% of people having seizures.

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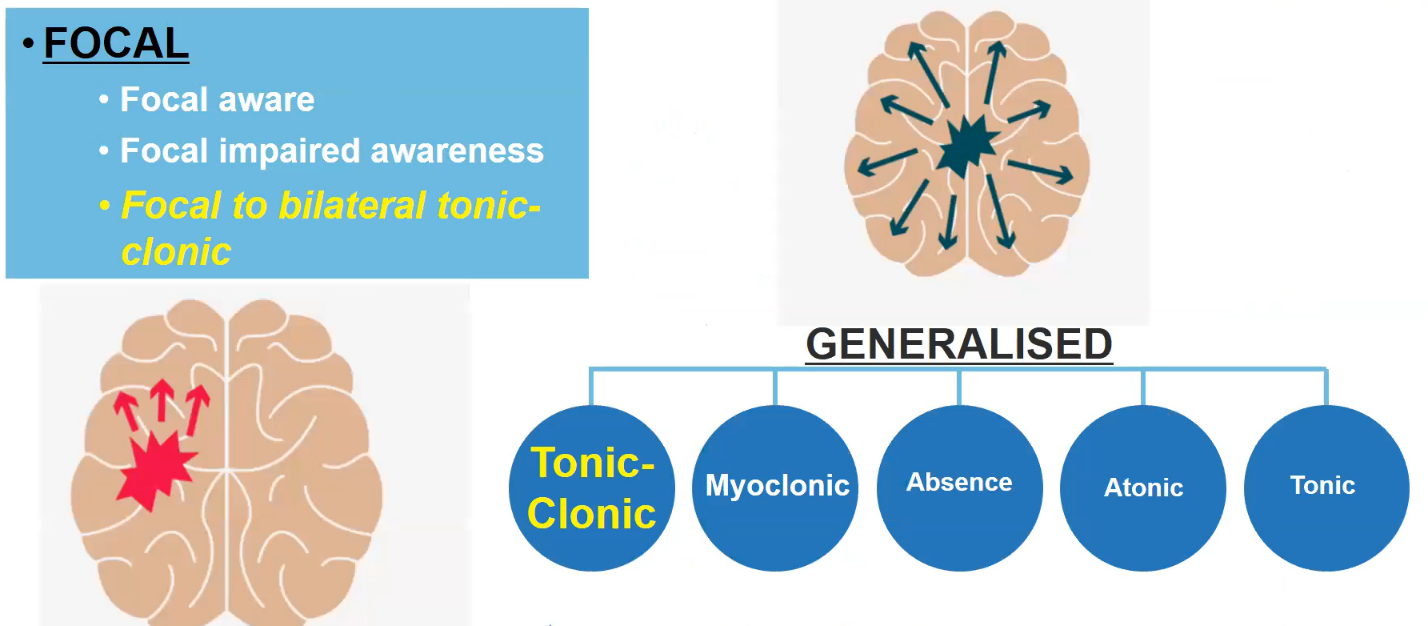
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EPILEPSY / SEIZURE TYPES

FOCAL TO BILATERAL SEIZURES



In terms of the Focal Seizures, there may be different types.

During a Focal Aware Seizure, the person is aware that they are experiencing a seizure. However, if the patient’s awareness becomes impaired, this becomes an ‘Focal Impaired Awareness’ seizure, or an ‘Unaware Focal Seizure’.

The seizure may cease at this early stage, or become a Focal to Bilateral Tonic-Clonic Seizure, and this is probably the most common type of seizure. These tend to commence just after waking up – or within the first hour of waking up. This type of seizure has a very good prognosis.

The rarer and harder to treat forms of seizure include:

* MYOCLONIC – sudden jerk of parts of the body, such as an arm or leg. The person may fall over and there is a brief interruption of awareness, so the person may be confused upon recovery.
* ABSENCE - blank stares, usually lasting less than 10-20 seconds. The seizure starts and ends abruptly. An Electroencephalogram (EEG) will record these as ‘3 per second spikes in waves’.
* ATONIC and TONIC – these are basically ‘drop attacks’.
* Atonic is when the person loses muscle tone and falls forward to the ground, drops objects and nods their head involuntarily.
* Tonic is when the person goes rigid and may then fall backwards, possibly hitting the back of the head.

EPILEPSY’S NATURAL HISTORY

Epilepsy is a fairly common condition, which may affect 50-60 million people worldwide. In the United Kingdom, in the region of 1%-5% of the population will experience seizures … and the risk of seizures rises according to age. Those living to the age of 80 years, are more likely to experience Epilepsy.

Epilepsy tends to have a very high rate of ‘somatic and psychiatric co-morbidity’. This highlights the prevalence of mental health issues in the cause of epileptic seizures, such as unemployment, deprivation and poverty. Seizures may also occur in people who are struggling to achieve employment, even in the areas in which they are trained.

In about 50% of people who have developed Epilepsy it is a short-lived condition and once a diagnosis is made and treatment is commenced, there is likely be a good outcome.

However, people with Epilepsy also have a high risk of premature mortality, and if the person has active Epilepsy of the Focal type and starting in childhood, this may take 20-30 years off their life expectancy. It is not, therefore, a benign condition.

IS IT REALLY EPILEPSY?

A serious problem with Epilepsy relates to misdiagnosis – people who have the condition but are not accurately diagnosed. In Primary Care, the most common misdiagnosis occurs when people faint and are wrongly believed to have had an epileptic seizure. It has been found that, when a person with Chronic Epilepsy is referred to a Tertiary Epilepsy Unit for assessment that one in five do not actually have epilepsy.

It is important that a very careful diagnostic assessment is undertaken. A patient may have had seizures in the past, and recovered, and then lost their State Benefits. However, the loss of benefits may result in the person developing a mental health trauma.

MIMICS OF EPILEPSY

These are conditions that have been associated with, or diagnosed as Epilepsy - but upon review, they are not.

SYNCOPE and ANOXIC SEIZURES

These are the most common ‘mimics’ and encompass fainting, resulting from certain stressful triggers, which lead to a sudden drop in blood pressure and cardiac arrhythmias.

These are non-epileptic events.

BEHAVIOURAL, PSYCHIATRIC and PSYCHOLOGICAL EVENTS

These may include panic attacks, rage attacks and fabricated and/or elaborative beliefs.

SLEEP DISORDERS

During sleep, experiencing body jerking movements (hypnic jerks), parasomnias, REM-sleep disorders, periodic leg movements, or narcolepsy-cataplexy.

VASCULAR EVENTS

Transient Ischemic Attack (TIA) and Strokes – slurred speech, vision problems, weakness, numbness, loss of balance, sudden and severe headaches.

MIGRAINES

A throbbing headache, cyclical vomiting and Hemiplegic Migraine.

MOVEMENT DISORDERS

Tics, Dystonia, Paroxysmal Kinetogenic Dyskinesia.

THE EXTENT OF THE PROBLEM IN THE UNITED KINGDOM

Every year in the UK, about 30,000 people develop Epilepsy. Eighty percent will have a good outcome if the correct medication is taken for the correctly diagnosed type of seizure.

Many patients will have other health issues, such as cancer or a degenerative disease and about one in six may die in the first year – usually with the same things that caused the seizures in the first place.

About 20,000 people diagnosed with seizures, will have at least one seizure per month. One of the commonest reasons for having a seizure is ‘forgetting to take the medication’.

The most tragic outcome of Epilepsy is known as Sudden Unexpected Death in Epilepsy (SUDEP). This occurs without warning, during or right after a seizure. Approximately 1,200 people die of SUDEP annually, and this is usually within the younger population.

Status Epilepticus is diagnosed when people develop Epilepsy, attend A&E and are admitted to hospital, without any previous history of the condition. Infection, including brain infection and stroke trauma can lead to Status Epilepticus, and it has a very high mortality rate. The earlier the treatment for this condition, the better … people not treated within the first 30 minutes can have grim outcomes, including death and Cognitive Sequela following a traumatic brain injury. They can also develop Chronic Epilepsy, and this is not easy to treat.

DEMOGRAPHIC SHIFT IN THE LAST FOUR DECADES

There has been a major demographic shift within the last 30-40 years – not only in the UK, but in most western societies, including a dramatic increase in Epilepsy amongst the elderly. So, in the general population, the incidence is about 50 per 1,000. Within the age of 80+, it is about 330 per 100,000.

The probable reason for these statistics is that people are experiencing less severe strokes, and the incidence of strokes has decreased, although mini-strokes are prevalent and could result in Epilepsy.

In childhood, it is more difficult to understand why there has been a dramatic fall in the number of Epilepsy cases, but there are fewer malformations of cortical development within the first year of life, and fewer birth traumas owing to improved peri-natal care.

However, it is usually bad news for children to develop Epilepsy within the first year of life.

A CONDITION OF BOTH ENDS OF LIFE

Epilepsy is really a condition of ‘two ends of life’ – the beginning of life and towards the end of life. These are the groups with the highest incidence of Epilepsy.

People over the age of 65 are within the group with the highest incidence of Epilepsy and cerebrovascular disease.

Mini-strokes (TIA-Transient Ischaemic Attack) account for approximately 50% epileptic seizures, and a number of people in the over 65 age group will be found to have cancer … and there is also an increase in the numbers of people with Dementia who have epileptic seizures - and this could be related to the amyloid and tau proteins in the brain.

From the seizure point of view, Epilepsy amongst the senior citizens is very easy to treat. The challenge is the diagnosis, but once the diagnosis is recognised, the treatment is highly successful.

Interactions with other drugs can cause problems, so it’s important to recognise this.

SEIZURE ENCOUNTERS

This is when we may see someone in the street suffering a seizure. It’s believed that about 70% of the people with Epilepsy should have had their condition controlled but did not take their medication.

Forgetting to take medication tends to happen during or following major life changing events – a wedding, a party, a holiday, a break in a relationship or a house move. As a result, there are approximately 40,000 hospital admissions and overnight stays per annum. This number is from approximately 60,000 annual attendances at A&E as a result of a seizure. Overnight bed occupancy can be quite detrimental to some people.

About one-third of people attending A&E with seizures account for two-third of the A&E attendances. These groups tend to be people most isolated, live alone or have mental health or mobility problems.

About 60% of people attending A&E with Epilepsy will have a recurrence. About 25% of people attending A&E will have Acute Symptomatic Seizures – these are seizure that do not have a known cause, or conditions that resemble seizures but are difficult to diagnose.

If you have a seizure encounter, it is crucial that the person has someone with them, although this is not always possible. However, a witness who saw the whole ‘episode’ and is able to provide timings, etc to paramedics is very helpful as an aid to diagnosis.

THE SEIZURE

The most common seizure presentation attended by an ambulance is a person with Epilepsy who will recover within half an hour. Experience, rather than training and guidelines, seem to guide a paramedic’s decision to take the person to A&E.

Most seizures, particularly convulsive seizures, are generally:

* Short – most will be over within 2-3 minutes and rarely more than 5 minutes.
* Self-limited – they will stop of their own accord.
* Rarely result in a serious injury.
* Do not usually require intervention – although the person must be kept safe.

People with suspected seizures account for 1.5% of all emergency admissions for neurological conditions, and 80% do not need to go to A&E.

Seizures, particularly convulsive seizures, appear very frightening and concerning and this will pressurise an ambulance crew to take the person to hospital.

HOW TO MANAGE A SEIZURE

When a member of the public witnesses a seizure, and if that person falls and recovers quickly with or without confusion, or falls, or wanders aimlessly, or behaves strangely, 95% of those witnessing the seizure s will not know what to do.

So, during a seizure, members of public should:

* Stay calm.
* Prevent others from crowding around.
* Put something soft under the person’s head.
* Minimise the person’s embarrassment.
* Make the person comfortable, preferably lying down (should be eased down if sitting).
* Loosen tight neckwear or clothing.

DO NOTS:

* Do Not Move the person – unless in direct danger from fire/water/traffic, etc.
* Do Not Restrain the person.
* Do Not put anything in the person’s mouth (the person is unlikely to swallow or bite his/her tongue) and one does not want to cause a problem to the person’s airway. False or broken teeth may also be dislodged whilst putting something in the mouth, which could cause secondary lung damage.

AFTER THE SEIZURE STOPS

**After the seizure stops (usually within 2-3 minutes):**

* Role the person into the recovery position.
* Check the person’s airways are clear.
* Stay with the person and give reassurance until they have fully recovered.
* No drinks or extra drugs should be given during or straight after the seizure.

NON-CONVULSIVE SEIZURE

These are much less dramatic. The person having the seizure may act confused and may even do something that is not socially acceptable - climb a wall, or push something.

It is very important not to restrain them, unless these lead to dangerous wanderings – into fire/water/traffic etc. Attempts to restrain the person may lead to confusion and/or provoke reactive aggression.

PROLONGED OR SERIAL SEIZURES

If a seizure lasts for more than 5 minutes or the person has more than one seizure without the regaining consciousness, then seek emergency treatment. This will avoid the person going into Status Epilepticus and possible cerebral damage.

TREATMENT IN THE COMMUNITY

Treatment:

* Buccal Midazolam … 5mg – 10mg – by mouth.
* Rectal Diazepam … 10mg – 20mg – not usually used in the UK.

People with diagnosed Epilepsy should carry:

* A MediAlert / Health ID Card.
* A Care Plan.
* A Person Specific Protocol.

MANAGEMENT OF PROLONGED SEIZURES

If a seizure is prolonged and cannot be controlled, it is important to ensure that the cardiovascular function is OK. This is best achieved through A&E.

If they do not respond to the first part of the treatment, then they should go to A&E.

TREATMENT AT A HEALTH CARE SETTING

There are very effective treatments available within hospitals. Two forms of treatment will probably take care of around 90% of seizure patients - Intravenous Diazepam or Lorazepam.

REDUCING ATTENDANCE

There should be educational interventions. Persons at risk of seizures should:

* Be educated to enable self-care.
* Make sure that they always carry their MediCard.
* Ensure that their ‘person specific protocol’ is held by their local Ambulance Service.
* Treatment should be reviewed/updated regularly to ensure that nothing is missing.
* Ambulance staff should be educated in Epilepsy-specific emergency treatment.

THE NATURAL HISTORY OF THE EPILEPSIES

Overall, there is a good prognosis. Over 80% of patients will stop having seizures in a short time and the great majority of seizures do not require treatment.

However, Status Epilepticus has a lot of complications, and a rapid out-of-Hospital response is important.

QUESTIONS TO PROFESSOR SANDER AND RESPONSES

SISTER JOSEPHINE UDIE

About the age gap.

* In the older age groups, people tend to be given so many drugs/medications, so could this be part of what causes Epilepsy?

There used to be more young people with Epilepsy rather than the older people.

PROFESSOR SANDERS

I agree, it used to be more prevalent in the younger generation. This is still the case in the more resource poor parts of the world.

People are now living longer and blood vessels are clogging, so the commonest cause for people over 65, is what is called ‘small vessel disease’. This is similar to strokes, but with a smaller percentage of blockages. Instead of having a Stroke, where there could be paralysis, people may have seizures. Senior citizens often take many medications, so the big challenge is to find medications to treat Epilepsy that will not interact with these other medications and cause problems. There are some medications that will increase the risk of having seizures … and there are some drugs that are used that can even trigger seizures. This is a multi-factorial problem, but I think that Cerebral Vascular Disease is a big culprit here.

STEPHEN SARTAIN

My interaction with Epilepsy is in my work for more than 30 years as a Welfare Benefits Advisor. I have had people applying for benefits and they have been suffering from different forms of Epilepsy and have had difficulty in obtaining benefits.

We always had the debate about whether or not Epilepsy was a ‘disability’ and often this was why they could not get benefits, because it is not classed as a ‘disability’. This is a very specialised area.

* Do you feel there are enough staff in the Hospitals and GP surgeries who are able to deal with Epilepsy effectively?
* Do you think that there should be allocated funding for Epilepsy training?
* How can we get the message across that people must take their medication - as many are going to Hospital unnecessarily?

PROFESSOR SANDER

I think that adherence to taking medications is a big issue. Sometimes medication is missed because people have cognitive problems, and they forget to take their medication.

It would be a great help if we could provide advice and put these people into contact with Pharmacies to provide ‘medication boxes. We could set up alarms on people’s mobile phones, so there are ways in which we could help much more. The problem tends to occur when people have a major break in their routine – a bereavement, for instance.

If a person is taking a medication for Epilepsy once-a-day, the risk of failing to adhere is about 10%. However, if you go to those taking medication 3 times a day, then the rate of failing to adhere goes much higher. Ideally, we should like patients to have a drug to take once-a-day, so if a person skips the one tablet, the window of safety up to the next tablet one is much longer.

It is always a bit of a trade-off, but what I am looking for are improvements in and understanding of the genetics of Epilepsy. That will enable clinicians to target treatment at an earlier stage, not so much to control the seizures but to stop the Epileptic genesis. In terms of benefits, that is one big challenge. The Epilepsy Society receives many calls on this topic. I have seen many letters to people refusing them benefits because it is felt that the person can walk and do many things, so that they do not qualify.

However, if you have three seizures in one month – that might be for 6 minutes a month … and these 6 minutes can seriously impact on your life. If a person has an unpredictable seizure then, perhaps, they cannot walk or undertake normal affairs, and this is a disability.

Things are improving and Epilepsy is now covered by the Equality Act 2010. But this is an area which needs improvement.

**Someone has a disability if they have:**

A physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

***Equality Act 2010***

‘Substantial’ means it is difficult and time-consuming to do activities compared to someone without a disability, and ‘long-term’ means at least 12 months. ‘Day-to-day activities’ include being able to get around, hear, see, remember and concentrate.

Epilepsy is a physical, long-term condition and **people with epilepsy are protected under the Equality Act,** even if their seizures are controlled or if they don’t consider themselves to be ‘disabled’.

ALAN ALEXANDER

* I wonder whether Generalised Seizures start with a Mini Focal Seizure, or whether they are quite different?
* Is there a gender difference with regard to the frequency of seizures?
* You mentioned that 50% of people with Epilepsy are only affected for a short time. Can you clarify? Does the condition just disappear because of medication, or does it just disappear?

PROFESSOR SANDER

We know that many seizures is self-limited and benign. If a person has started treatment and, regardless of the drug used, 50% will get better with the first drug.

This is telling us that a symptomatic medication is having a big impact. These people are still in the statistic, but most of the time they are not really a big problem for the medical system. They only have the label of ‘Epilepsy’ because they were diagnosed with it, and they will be taking the medication.

A great majority of seizures are self-limited and are very short and just fizzle out.

Gender differences. There are some syndromes, particularly some genetic syndromes, that are more likely to affect males/boys – others affect females/girls.

We know that in some places, not so much here, but if a person is in area of violence, war, post-war, and head injuries are suffered, there may be a disproportionate number of males having seizures. In general terms, if we look at the population, it is about 50%-50%.

In answer to the first question, I am unable to give an answer, as there is some debate about that.

For instance, when an Electroencephalogram (EEG) is undertaken, the features come out ‘all over’ and we assume that they are Generalised. However, there is some experimental evidence that shows that some of seizures start as Mini Seizures.

Maybe, in a few years, we might have a different approach to this.

MARIA GOMEZ

My daughter is now six years old and has been diagnosed with autism. In December she had her first seizure, and an EEG was performed.

The result of the EEG came back as ‘normal’ and it is not Epilepsy. Sadly, she has had another ‘episode/seizure’.

* Is it likely that her seizure was associated with her autism?
* What further steps could be taken to make a correct diagnosis?

PROFESSOR SANDER

Autism is a very common ‘comorbidity’. Autism and Epilepsy ‘go together’ and there are some discussions about these conditions sharing common parts of a spectrum.

The problem with the EEG is the EEG itself. It helps if it shows something - it does not help or rule out something unless it is recorded during a seizure. This is not an easy task.

It would be a good idea to discuss having a more prolonged EEG with her GP. Recordings can be more prolonged, e.g. overnight, sometimes over 48 hours and the results will be more analytical than the routine half-an-hour EEG in A&E.

AMBER DOBINSON

I have a question about SUDEP education for patients and their families, and the attitude of Clinicians explaining SUDEP risks, and then the referral to Primary and Community Care.

We experienced a great reluctance to share and explain SUDEP risks when our 1-year-old was being diagnosed. He died of SUDEP while waiting for genetic testing and was diagnosed with Dravet’s Syndrome (SUDEP - Sudden Unexpected Death in Epilepsy).

PROFESSOR SANDER

SUDEP impacts so strongly on many families and, hopefully, one day we shall be able to say that this has ended.

One of my colleagues is running a big programme to try to understand the ‘ins and outs’ of the symptoms, and why Dravet’s Syndrome is linked to such a high risk of SUDEP. The colleague is also looking why patients with some specific types of Epilepsy may be at higher risk of SUDEP. The researchers are also looking for a genetic marker that will actually predispose the person to it.

This is really pioneering work and we are anxiously awaiting the outcomes so that we can make SUDEP a thing of the past. No family should have to suffer from the effects of this condition.

**Dravet syndrome (DS) is a severe form of epilepsy characterized by frequent, prolonged seizures often triggered by high body temperature (hyperthermia), developmental delay, speech impairment, ataxia, hypotonia, sleep disturbances, and other health problems.**

STEPHEN SARTAIN

* Do you think there is not enough investment in staff training, and are there enough experienced staff? Epilepsy is such a specialised field.
* You did mention that some ambulance crew ‘learn on the job’. Do you think the ambulance services and other NHS services should ring-fence funding for this training?

PROFESSOR SANDER

You are preaching to the converted!

I would always want ring-fenced funding to provide training and to improve the service, but when you talk to GPs, they say ‘Oh listen, I have 5,300 people on my list and only 10 have Epilepsy. I have many more priorities, so I won’t be able to go to the training that you are providing’.

I personally feel that Epilepsy is neglected – including the training aspect.

It is always surprising that young doctors do not seem to know much about Epilepsy. They seem to know a lot about ‘absence seizures’ (brief loss of consciousness) and this is such a rare form of Epilepsy – and the exception rather than the rule.

There are some key groups that should be ‘educated’ and I think that better trained Paramedics could make a significant difference very quickly. Perhaps, in a GP Practice, one GP could be able to provide a more tailored service for patients Epilepsy.

Although we have 35 Neuroscience Centres in the UK, not all of them have Epilepsy Clinics.

The Epilepsy Society, together with the NHS, provides the only Assessment Clinic for people with chronic Epilepsy in the UK.

That is 26 beds for the whole of the UK. There should be something like this in every region of the country – and we are far from that.

Absence Seizures cause a short period of “blanking out” or staring into space. Like other kinds of seizures, they are caused by brief abnormal electrical activity in a person’s brain.

SEAN

On genetics: we have a lot of family members with Epilepsy, and we want to know whether there is anything significant that occurs for this to happen with them.

PROFESSOR SANDER

I think that it is fair to say that this is an area in which a lot of effort is being placed.

The Epilepsy Society is sponsoring a big ‘genomic project’, trying to put together all the variations of Epilepsy, to see if we can then – eventually – explain why a specific person has Epilepsy, and what can be done to provide personalised treatment.

We have made progress, and we have realised how much bigger the topic is than we imagined. When the project started, there were about 20-30 genes involved with Epilepsy and now we have panels for genetic diagnosis, focussing on 400 genes.

As more data comes in the process will speed up and within the next 5-10 years, I believe we shall see major progress in this area.

DEVELOPING THE CHALFONT EPILEPSY CENTRE - PROFESSOR SANDER

The Epilepsy Society is trying to develop the Chalfont Centre to improve the facilities, and particularly to increase the research area. There is a Petition which the Epilepsy Society would really like people to sign – including passing on to any of their contacts too. The Epilepsy Society wants to revolutionise the treatment of epilepsy and give people hope of a life without seizures. They want to stop people dying from their epilepsy. By selling a part of their land in Buckinghamshire to create 975 homes they hope to raise £100 million which would be invested in cutting-edge research that would transform the diagnosis and treatment of epilepsy. **Please sign our petition today and give people with epilepsy hope.**

* [**https://tinyurl.com/26c2h5nh**](https://tinyurl.com/26c2h5nh)

GLOSSARY

|  |  |
| --- | --- |
| EEG | Electroencephalogram |
| CNS | Central Nervous System |
| SCI | Spinal Cord Injury |
| SUDEP | Sudden Unexpected Death in Epilepsy |
| TBI | Traumatic Brain Injury |
| TIA | Transient Ischemic Attack |