



**MEETING BETWEEN THE LAS, EPILEPSY SOCIETY AND PATIENTS' FORUM
DEVELOPMENT OF SERVICES FOR PEOPLE EXPERIENCING EPILEPTIC FITS
August 27th 2019**

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1) JRCALC guides all clinical practice for EOC, edics, Paramedics and EACs in the LAS and has recently been updated, but there are no significant changes to the guidance on the care of patients suffering epileptic fits. 111 service uses NHS Pathways.

2) Epilepsy Society Campaign – information taken to the Quality Oversight Group by MA.

3) Safe to Leave at Home or Take Home?

- a) See: Lisa Burrell, MSc in Neurosciences, Advanced Paramedic Practitioner
<https://www.laebritish.org.uk/epilepsy-emergency-care>
- b) Judgement is based on how safe and well-supported the person would be if they had 'fitted' at home and were not taken to hospital.
- c) Patients in a public place who have had an epileptic fit are usually regarded as being safer if taken to hospital, but there is a risk if they live far from the hospital A&E. There is a reluctance to take patients home after a fit if they live far from the location of the fit, because the ambulance may then not be available for other patients.
- d) There is a risk if someone has fallen at the fit of a fit of a cerebral bleed.
- e) Can patients object to going to A&E? Yes if they have capacity, they can refuse.

4) Co-ordinate my Care (CmC)

- a) CmC is the priority for ensuring that front-line staff have the Care Plans of patient's needs and specific care. Patients can update through: 'My CmC Record', but their GP or other clinician must update the record.
- b) Julia Riley, Consultant in Palliative Medicine, leads this work and is based at the Royal Marsden Hospital.
- c) Paramedics discovering the need to update a CmC record cannot make amendments, but they can refer patient to their GP, or phone the GP.
- d) About 30% of front-line staff are not using iPads, so their rapid access to CmC records is reduced.

5) Clinical Audit Research Group – CARU

- a) We asked if a patient voice component could be added to the next review by CARU, and it was agreed to discuss with Margaret Luce and CARU.
- b) Tim requested data from business intelligence on the number of patients seen by the LAS for whom a diagnosis of epileptic fit and seizures (non-epileptic), and how many were conveyed to hospital and how many were left at home.

6) POTS – “All that fits is not epilepsies”.

- a) NICE Guidelines - Transient loss of consciousness
- b) Hypoxic states – need to do ECG

7) Status of Paramedics

Fenella described the responsibilities and role performed by Paramedics and EACs as being ‘well in advance of that of staff on similar grades in the rest of the health sector’. A patient in A&E who has experienced an epileptic seizure would only be discharged having been reviewed by a Consultant.

8) Continuity of Care

- a) Patients’ receiving care several times within a short period would need to hand their PRFs to paramedics because the EOC system does not enable sharing of clinical information – this will change when ePRFs are introduced in 2 or 3 years.
- b) 24 hour recontact audits do not suggest that patients have suffered harm as a result of poor connectivity between clinical staff.

9) SUDEP – Sudden Unexpected Death in Epilepsy

- a) Tim shared an epilepsy referral proposal to the LAS from Sarah Fawzi, and an adult checklist produced by SUDEP Action for ambulance staff, which is designed to prevent SUDEP deaths.
- b) Obtain details of incidence of deaths following an epileptic fit.

10) Drug Administration

- a) The two main drugs are Midazolam and Diazepam in emergency care. Midazolam can only be given via PGD (Patient Group Directive) following prescription by a Doctor. Paramedics cannot prescribe this drug but can administer it. Midazolam is getting used more.
- b) Security around Midazolam is very high, they are secured in a Safe and must be physically signed out.
- c) Patients may carry Midazolam, but Paramedics can only use the drug if prescribed by a Doctor.

- d) Side effects of Midazolam and Diazepam can be very significant and may restrict a person's activities.
- e) Paramedics can go on one-year course to become independent prescribers.

11) Training and Education

- a) Epilepsy Society can provide staff training in the care of patients with epileptic seizures.
- b) We agreed to investigate the development of an LAS video on a range of issues e.g. empathy, safe places, safe non-conveyance, different types of seizures, safe to leave at scene, interaction with family/friends, right place/right time,
- c) CSR provides 24 hours/year statutory/mandatory training for all front line staff.
- d) LAS provides about 3 times more CSR than other LAS trusts.

12) Data on Diagnosis and Transfer to Hospital

Tim Edwards agreed to collect information from LAS Business Intelligence on the following issues:

Number of patients over the last 12 months coded as:

- Epileptic fit (code 23)
- Seizures – non-epileptic (code 57)
- How many in each case were conveyed to hospital versus referred to an alternative care pathway or refused aid?

Note prepared by Malcolm Alexander

APPENDIX ONE - EPILEPSY AND EMERGENCY CARE

EMERGENCY HEALTH SERVICES FOR EPILEPSY – THE PROCEEDINGS OF AN EXPERT WORKSHOP

Scope

The Council of the UK Chapter identified emergency care for people after a seizure as a priority topic.

An expert workshop was convened, and key stakeholders were invited. A one-day event was held on Tuesday 5 July at the University of Liverpool London Campus and these are the proceedings of that meeting. The meeting was intended as the beginning of a process, rather than an end in itself, and important topics for further work including defining the scope of the project were identified.

The day started with a series of brief Presentations from invited speakers. It was followed by discussions within three breakout groups who were asked to identify priorities for education, research and service provision. Each group had a chair who kept notes and took the lead with writing a narrative summary of the discussion. The top priorities for each Breakout Group are listed in Table 1.

Presentations

Pre-hospital Care After a Suspected Seizure: Guidelines, Patient Characteristics and Care Pathways (JMD).

National guidance for Paramedics and other ambulance clinicians is provided in the UK Ambulance Service Clinical Practice Guidelines [add citation]. The chapter on convulsions is focussed on the management of suspected seizures and there are separate chapters for adults and children. The majority of suspected seizures are self-limiting and do not require emergency treatment.

One of the major challenges for Paramedics is the diagnosis of paroxysmal events, involving and risk assessment of the patients to decide on appropriateness of community management versus transfer to hospital. But very little guidance is provided and the guideline focusses, almost exclusively, on the treatment of status epilepticus. Perhaps this is appropriate given the scope of the book, but it leaves Paramedics without good quality advice and guidance for most patients after seizure. The guidance would also benefit from updating in terms of ILAE terminology.

The EPIC study [add citation] was conducted in a regional ambulance service in the UK. It showed that suspected seizures are the 7th most common cause of emergency calls to the ambulance service, accounting for 3.3% of all emergency incidents.

The estimated cost in England is £45 million per year. 93.2% of these seizures had terminated on arrival of the vehicle, 36.4% were 'alert on arrival' and 46.2% were 'post-ictal'. 0% had suffered cardiac arrest. 8.3% required emergency drugs to terminate the seizures. Although most patients in the study were not acutely unwell, many had more problems in addition to the suspected seizure, creating complex clinical scenarios. Most suspected seizures are epileptic but a significant minority are cardiogenic or psychogenic.

Pre-hospital care may be a good environment to identify patients with epilepsy in need of specialist review. The YAS has begun a small Pilot Study of an alternative care pathway, the evaluation of this is ongoing, but preliminary results show it is able to identify patients at need of specialised epilepsy services.

What are the views and experiences of ambulance staff who manage patients with epilepsy? Lisa Burrell (Advanced Practitioner, London Ambulance Service).

Ambulance clinicians frequently encounter patients with epilepsy in their Practice. The majority of these cases are for seizures where the seizure has resolved prior to arrival of the ambulance clinician on scene.

A recent audit in London found 19% of patients presenting with epileptic seizures were not transported to hospital by ambulance. In almost half of these cases the decision not to transport was against the advice of the attending ambulance clinician. Of all patients with epilepsy attended, 11% were identified as requiring emergency intervention and transported under blue light conditions with a priority pre-alert to the receiving hospital. The remaining 70% of patients were transported to Accident and Emergency departments but the reasons underpinning the clinicians' decisions for conveyance were unclear.

A qualitative study was undertaken to explore this question. Ambulance clinicians, across all skill grades, were interviewed regarding their decision making for patients with epilepsy. These interviews were semi-structured to invite the clinicians to explain their views and experience and allow the emergence of themes.

One third of the ambulance clinicians interviewed reported low levels of confidence when managing patients with epileptic seizures, and nearly half did not feel they had sufficient training or supporting guidance to make decisions to

leave these patients in the community. Conveyance in some cases was therefore treated as a safe option. In addition, lack of feedback on patient outcome has limited the opportunity for learning leading to habitual decision making.

Limited access to necessary patient information 'on scene' was recognised as a significant challenge. In such cases the patient may be conveyed for recovery and observation until key information can be established. Participants also described limited access to appropriate referrals or alternative care pathways. This means patients may be conveyed to Accident and Emergency Departments, as a Place of Safety, for recovery with hopeful intention that this will also expedite onward referral to specialist teams, where review is deemed necessary.

How can we support ambulance crews through electronic information provision? Eman Altuwaijri (PhD student, Engineering and Computing Sciences, Durham University).

We are investigating ways of improving services for people with epilepsy, by providing better-informed responses by ambulances to callouts for people who have had an epileptic seizure - working in collaboration with the North East Ambulance Services (NEAS) and a hospital in the North East.

Electronic information provision can be provided by implementing the concept of the 'Information Broker' (IB), a software system that acts as a trusted agent with the ability to provide reliable up-to-date patient health information from different sources.

The IB provides a service by receiving a request, then searching and gathering relevant patient health information. The Data Access Service (DAS) acts as a transforming agent; it is an access medium for the data source as well as representing that data source to the IB. The DAS will translate the query, which has been received from the IB, to the local format of the data source, get any relevant data and send it back to the IB.

We are initially developing a limited implementation of the broker model. When an ambulance is called to a patient identified as having a 'blackout', an enquiry will be sent to the Epileptic Patient Database (EPD) that we are constructing in a North East Hospital, and where patient history is available. If the ambulance crew requires additional health information, then they too can make a patient specific enquiry and the relevant information will be summarised and relayed back to them.

Finally, on scene the crew will create an Electronic Patient Record Form (ePRF) which will be added up to the EPD at the hospital

Who is visiting emergency departments for seizures and how might improving ambulatory access to specialists help? Tony Marson (Professor of Neurology, University of Liverpool).

The National Audit of Seizure Management in Hospitals (NASH, www.nashstudy.org.uk) has collected data on over 8,000 Emergency Department attendances with a seizure. Data was collected from around 160 UK Emergency Departments (EDs), who were each asked to identify 30 prospective cases. 22% were patients with a suspected first seizure, 61% had an established diagnosis of epilepsy and 17% had a history of previous blackouts, but no definite epilepsy diagnosis.

Of patients with a known epilepsy diagnosis, half were taking only one antiepileptic drug, mainly valproate indicating significant potential for improving seizure control via medication changes medication. 45% had attended the ED in the previous 12 months, and 20% had a CT head scan, which was likely unnecessary for many. Only 63% had been seen by an epilepsy specialist (neurologist, specialist nurse etc) in the previous 12 months. Following ED attendance, correspondence with or a referral to a neurologist or epilepsy specialist occurred for only 44%.

Of patients with a first suspected seizure, 54% had a CT head scan and 87% had an ECG, which should be done in all suspected first seizures. Only 60% were referred to a neurologist or first seizures / epilepsy clinic.

These results indicate that the co-ordination of and access to care are currently inadequate; there is a serious disconnection between the Emergency Department and epilepsy/neurology services. One challenge is that, in many district General Hospitals, the neurology service is often a visiting one from staff based at a neuroscience centre. As a result, there is no 'epilepsy champion' on the staff to drive up standards. Improved access to ambulatory care should reduce ED attendance and also length of stay, particularly if DGH staff were confident that specialist assessment will occur soon after discharge.

Does seizure management confidence amongst patients and their family and friends have a role in emergency department use and what can be done? Adam Noble (Tenure-track Fellow, Psychological Sciences, University of Liverpool).

Most Emergency Department (ED) visits for seizures are clinically unnecessary. They are by those with diagnosed epilepsy who have experienced uncomplicated seizures. Those making frequent visits and their informal carers appear unsure about how to manage seizures and worry about seizures. Offering them a self-management intervention that improves confidence to

manage seizures may lead to fewer visits. As no such intervention exists, we were funded to develop one and pilot trial it.

To develop it, an existing 3-hour group-based seizure management course offered by the Epilepsy Society within the voluntary sector to a broader audience has been adapted. Feedback on changes needed was obtained from 20 people with epilepsy (PWE) who had visited ED and carers and 9 representatives from the different professions caring for epilepsy.

Feedback identified the intervention required significant revision to ensure it addressed the unique needs of ED attendees, and was suitable for use in the UK health service. The intervention now lasts 4 hours and is more patient focused.

New content helps patients and carers better understand when emergency medical attention is - and is not required - for different seizures and how to manage post-ictal states and risk. Interactive tasks have been introduced to elicit and challenge patients and carers fears.

The recovery position is also practised, and personalised seizure Emergency Care Plans are developed to help Paramedics who may attend to the patients. To make the intervention appropriate for use in the NHS, it is now fully standardised, its behaviour change has been optimised, and a trainer's manual developed.

A pilot randomised controlled trial is now being completed (ISRCTN13871 327). For it, 80 people with established epilepsy aged ≥ 16 who have visited an ED in the prior 12 months on ≥ 2 occasions and who can provide informed consent, along with one of their family members or friends, are being recruited from three EDs. Dyads are randomised to receive the intervention or treatment as usual alone. The proposed primary outcome is ED use in the 12 months following randomisation. The intervention is being delivered by an epilepsy-nurse specialist to groups of 10 patient-carer dyads.

The collaborative approach we employed has allowed us to develop a patient-focused intervention which addresses the needs of PWE attending ED and their carers. Trial results will estimate the intervention's effect and, if appropriate, inform the optimal design of a future definitive trial.

Breakout Groups

Education

First Aid is an important part of acute care for seizures and education campaigns about simple First Aid measures - during and after a seizure - could improve quality of care and could potentially reduce the demand for unnecessary emergency care. Such a campaign could also contribute to the de-stigmatisation of epilepsy.

Educational measures, aimed at patients with a diagnosis of epilepsy and their families/carers, would be easier to target and likely to produce more rapidly measurable outcome than those aiming at the general population. The biggest improvements in care quality may be possible in frequent users of emergency services, however, these may prove to be complex.

Potential targets of such interventions are First Aid, Emergency Care Plans adherence. Educational and outreach programmes may benefit from other sources of potential patients than specialised neurological services (primary care, Paramedics, A&E), as many patients are not under the care of these services. GPs and neurologists may play especially important roles in the implementation of care plans.

Updating the national guidelines - for pre-hospital care after a seizure - for Paramedics (and other ambulance clinicians), is planned and many Ambulance Trusts have their own local guidance for these patients. Raising the profile of seizure care, especially the issue of non-conveyance, is important and this may be best achieved by targeting Senior Paramedics who mentor and supervise Trainees. The lack of feedback to Paramedics from hospital staff, was identified as a major barrier to on the job case-based learning.

A&E is a crucial part of the Care Pathway after a seizure and is likely to play an important role in identifying patients suitable for educational interventions. Medical and nursing staff in A&E, may lack awareness of problems with the current care provisions and their crucial role. But they are a difficult group to target with educational interventions, because of shift work and rapid turnover of Junior Doctors. Important topics for educational modules would include the differentiation of epilepsy and non-epileptic seizures and the recording of seizure manifestations.

Service Provision

Suspected seizures have diverse aetiologies, including non-epileptic events such as cardiogenic syncope and psychogenic non-epileptic seizures. When planning emergency services, intended for people with epilepsy, it is important

to be aware of the important role of diagnosis and signposting for patients with non-epileptic causes for their seizures.

The emergency care of people, during and after an epileptic seizure - including appropriate follow-up - encompasses many specialities, including ambulance services, A&E Departments, in-patient wards (neurology, general medicine, and others), Critical Care Departments and General Practice. It is often helpful to think of Care Pathways to conceptualise how patients move between discrete parts of the NHS. Emergency Care Pathways which aim to direct patients after a seizure to specialised services were thought to be an area of special importance. Information technology (IT) and effective communication are key elements in delivering best quality care and many aspects of this are suboptimal at present.

Most seizures are simple and self-limiting but a minority do not terminate spontaneously (status epilepticus) and/or are complicated by another factor such as an underlying injury or illness.

Much of the difficulty in organising emergency care for seizures stems from the lack of capacity in neurology and specialised epilepsy services which varies geographically. Innovations are required to increase capacity within these services and to make the most effective use of the resources available. Special areas of interest are Epilepsy Specialist Nurses and GPs with a special interest in epilepsy. It will be important to define the roles of ESNs and GPWSIs and to define competencies. Difficult to reach groups of patients may require outreach services, which could be delivered by ESNs rather than the traditional specialist in the hospital model.

The commissioning, co-ordination and leadership of care is important. Many CCGs do not seem to prioritise epilepsy, and in the absence of clear guidance on who should take the lead with care; who should take the lead; neurologists; GPs or another group? And should co-ordination be organised locally to allow 'a thousand flowers to bloom', or should it be mandated by a national framework? The importance of self-care was emphasised as was the role of patient and public involvement in design of services.

Research

One of the breakout groups focused on developing a priority list of inter-related research questions, the aim of which, was to help assess current service performance and future service developments and innovation.

1. What data are available and required to inform decisions made by Paramedics attending people with epilepsy and seizures?

At present, attending Paramedics rarely have access to vital information that can improve outcomes and inform immediate management and decisions about conveyance. We need to establish

- Which data sources are available, such as hospital records, epilepsy care plans, recent ED attendances, local services available?
- Which key data items will inform paramedic decisions?
- How can data be integrated from a range of sources?
- How can easy access to these key items be facilitated?
- How can we paramedics receive feedback about patient outcomes?

2. What outcomes should be measured in order to assess the performance of clinical services and the outcomes of new interventions?

A set of core outcomes should be developed, in consultation with a range of stakeholders, using a consensus technique such as Delphi. It is likely that outcomes will include patient reported outcomes, and experience measures, as well as measures of process of care and economic outcomes.

3. Can we improve risk stratification and risk management?

Paramedics often have insufficient data about individuals they attend with seizures, and there is currently no risk stratifying tool to help inform decisions - such as whether to convey a patient to the ED or not. The following questions were identified

- Can subsequent risk of seizure or injury be stratified?
- Can a risk stratifying tool be developed and implemented?
- What are the risk perceptions and tolerance of risk for patients, paramedics, ED staff
- What process can be put in place to mitigate risks?

4. Models of care

The following questions around the wider provision of care, were identified:

- Is there an alternative to ED as a place of safety for patients that do not require acute medical intervention?
- Can a public information campaign improve awareness about seizure management?
- What is the variation of provision of and use of ambulance services according to postcode and health inequalities?
- What is the impact of hospital 'did not attend' policies on patients losing touch with epilepsy services and their subsequent need for emergency services?

APPENDIX TWO – TONIC CLONIC SEIZURES

Tonic-clonic seizures are a type of epileptic seizure formerly known as grand-mal seizures.

Tonic-clonic seizures can have a generalised onset, meaning they affect both sides of the brain from the start. When this happens, the seizure is called a generalised tonic-clonic or bilateral convulsive seizure.

Some seizures start in one side of the brain and then spread to affect both sides. When this happens it's called a focal to bilateral tonic-clonic seizure.

What happens during a tonic-clonic seizure?

There are 2 phases in a tonic-clonic seizure: the 'tonic' phase, followed by the 'clonic' phase.

During the tonic phase:

- You lose consciousness, so you won't be aware of what's happening
- All your muscles go stiff, and if you're standing you fall to the floor
- Air might push past your voice box, which can make a sound like you're crying out
- You may bite down on your tongue or inside your mouth

During the clonic phase:

- Your limbs jerk quickly and rhythmically
- You may lose control of your bladder and/or bowels
- Your breathing may be affected, causing a blue tinge around your mouth

Focal to bilateral tonic-clonic seizures

If the seizure starts on one side of the brain and spreads to affect both sides, it's called a focal to bilateral tonic-clonic seizure. If you have this type of seizure, you might get the symptoms of a focal seizure immediately before you lose consciousness. Examples of these symptoms are feeling frightened, having a rising sensation in your stomach or smelling something that's not there. This can act as a warning that you're about to have a tonic-clonic seizure. Some people call this warning an aura.

How long do tonic-clonic seizures last?

Most tonic-clonic seizures last between one and 3 minutes. If a tonic-clonic seizure lasts longer than 5 minutes you may need emergency medical treatment.

What happens after a tonic-clonic seizure?

After a tonic-clonic seizure, you might have a headache and feel sore, tired and very unwell. You might feel confused, or have memory problems. You might go into a deep sleep. When you wake up, minutes or hours later, you might still have a headache, feel sore and have aching muscles.

The length of time it takes to recover after a tonic-clonic seizure is different from one person to the next. Some people feel better after an hour or two, but for some people it can take several days to feel 'back to normal'.

Some people find they have temporary weakness or can't move part of their body after they've had a seizure. This is called Todd's paresis or Todd's paralysis. It can last from a few minutes up to 36 hours, before going away.

How can someone help me during a tonic-clonic seizure?

There are simple first-aid steps people around you can take, to keep you safe during a tonic-clonic seizure. See our first aid information, or ask them to take our short online course which shows them what to do when someone has a seizure.

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