

Meeting with Vic and Sean Hamilton - Improving Care for Patients who Suffer Epileptic Seizures

We agreed the following priorities:

**1)    To identify service improvements in the LAS that would improve the**

**care of patients who have epileptic seizures.**

**2)    Examine progress regarding Tap2Tag methodology.**

[**https://www.tap2tag.me/what-is-tap2tag-medical-alert/**](https://www.tap2tag.me/what-is-tap2tag-medical-alert/)

Tap2Tag style approach, with NFC secure & encrypted patient/

summary record access and bio, can also be co-ordinated with

MedicAlert whose emergency operations centre Is contracted to

LAS  (www.medicalert.org.uk/about-us/ )

**3)    To propose areas for improvement in the annual LAS Quality**

**Account**

Priority No1: Organisation wide & stakeholder education, not just epilepsy or seizures but the factors and components that often come with it such as part auras in the period leading up to a seizure which is the ictal stage.

An 'aura' is the term that some people use to describe the warning they feel before they have a tonic clonic seizure. An epilepsy 'aura' is in fact a focal aware seizure. Focal aware seizures (FAS) are sometimes called ‘warnings’ or ‘auras’ because, for some people, a FAS develops into another type of seizure. The FAS is therefore sometimes a warning that another seizure will happen.

In the postictal state, which Is the period that typically follows a seizures/part of the recovery/ brain resetting process, what can sometimes happen patients is that patients appear unintentionally aggressive or appear hostile, even sometimes violent. The most important thing to remember is that this behaviour is not who that person normally is- it’s part of their condition and can at times be made worse when clinical staff don’t listen or respect the patient’s requests or guidance. The postictal state can last for hours in some cases even days. For others their postictal state may mean they need to sleep. On some occasions the patient may present or even give the impression they fully recovered when in fact they are not.

More experienced paramedics fully understand these states and try to support the patient in any way they can, sometimes up to and including taking them home by request, or even consulting the next of kin for clarification.

Patient Specific Protocols need to be accurate and up to date, particularly if the patient has more than one major condition, e.g. epilepsy and a cardiac condition. It is essential to widely publicise PSPs and for GPs to be receptive to requests from patients who have major conditions and to facilitate their production. Education of GPs, STPs, CCGs and NHS Trust is essential.

**4) To propose learning modules focussed on treatment of epileptic**

**seizures to be included in the CSR for front line staff.**

In addition to the regular CSR programme, a ‘whose shoes’ methodology could be adopted for paramedics, EACs and their managers to experience seizures through the eyes of a patient. This also provides insights for patients, especially regular service users, to understand what its like for paramedics and they can also give something back to the amazing crews who have cared for them.

**5)    Ensure focus is on each stage of epileptic seizures – before – during and after the seizure, including pre and post-ictal care and associated behaviours.**

[www.epilepsy.com/learn/about-epilepsy-basics/what-happens-during-seizure](http://www.epilepsy.com/learn/about-epilepsy-basics/what-happens-during-seizure)

<https://www.epilepsysociety.org.uk/what-epilepsy>

<https://www.epilepsysociety.org.uk/epileptic-seizures#.XFMpZvZ2vOg>

<https://www.epilepsysociety.org.uk/living-epilepsy#.XFMpa_Z2vOg>

**6)    To make recommendation regarding enhancing the expertise of staff in the**

**EOC clinical hub.**

This might include the development of a handbook on the complexities of epilepsy and seizures (and an app) specifically for staff in the Clinical Hub. The handbook would be developed through co-production between service users, epilepsy charities, Clinical Hub staff and the LAS pharmacist. It will include a section on carers and how LAS can assist & relieve some of their pressure.

**7) A focus on POTS – Postural Orthostatic Tachycardia Syndrome**

POTS can sometimes be confused with epileptic seizures. Some patients with epilepsy also suffer with POTS or other similar conditions & their cardiac condition can trigger a seizure. The reverse can also happen:

<http://www.potsuk.org/types_of_pots>

<http://www.heartrhythmalliance.org/stars/uk/conditions>

**8)   To promote a focus on empathy, which is essential for effective care of patients who have had a seizure.**

Role reversals perhaps with people who have epilepsy and students studying in the LAS or university to become paramedics to provide first-hand insight into what its like to live with a complex, hidden condition.

9)   Developing a training video on epileptic seizures for the CSR

A Forum member is obtaining footage from TFL of his latest seizure at North Greenwich station, which included the escalator, where LAS crew attended to him, which can be incorporate into an LAS training videos.

A key message is that no two seizures are the same even if they are epileptic in nature/ origin. A seizure may not appear to be as a paramedic has experienced it during their training, but diversity in the presentation of seizures is a real issue.

The use of rescue medications such as Midazolam and how its administered could also be included using the experience of both clinicians, service users and Epilepsy Society First Responders.

**10) To look at the possibilities for conveyance of a person who has had a seizure to a place of safety, e.g. their home rather than A&E. This could include coordination between ambulance services.**

Often referred to as ‘Home by Request’. This is consistent with the LAS ‘leave at scene’ approach, i.e. not taking patients to A&E if it is not required. This approach is used at the discretion of an EOC manager following a risk assessment and transfer to a place of safety can reduced the risk of further seizures because the patient is in a safe, less stressful environment.

**11)  Ask Chair if Sean and Vic could present to the Board of the LAS in the ‘patient story slot’.**

**12)  Ask Academy re possibility of Sean talking to students at the Academy.**

Key Questions

1)    What is the plan for replacement of the LAS airwave radio system?

2)    How reliable is the current airwave radio system?

3)    What progress has been made with implementation of the

Emergency Service Network (ESN)?

[www.gov.uk/government/publications/the-emergency-services-mobile-communications-programme/emergency-services-network](http://www.gov.uk/government/publications/the-emergency-services-mobile-communications-programme/emergency-services-network)

4)    What is the final date for implementation of ESN?

5)    What progress has been made with implementation of the

Samsung-tag system?

6)    Will the Motorola radio system be adopted to streamline front end emergency

care?

7)    Ask Mark Docherty from West Midlands about ESN rollout and use of Samsung

devices for front line staff.

End