

April 15th 2019

**Improving Care for Patients who Suffer Epileptic Seizures**

Dear Trisha, the Forum agreed the priorities below following the meeting on epilepsy led by Ian Wilmer. Could I suggest that our lead on epilepsy Sean Hamilton is given the opportunity of addressing the LAS Board meeting on the issues below? If you agreed he would be accompanied by his father Vic Hamilton who is his carer and has his own unique experiences of epileptic seizures.

Very best wishes

Malcolm Alexander

Chair

Patients’ Forum for the LAS

**Forum Priorities**

1. **To identify service improvements in the LAS that would enhance the**

 **clinical 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/)

The Tap2Tag approach, with NFC secure and encrypted patient/summary record access and bio, can be co-ordinated with MedicAlert whose emergency operations centre is we understand contracted with the LAS

 [(www.medicalert.org.uk/about-us/](http://  (www.medicalert.org.uk/about-us/) )

**3)    Areas for improvement -**

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

An 'aura' is the term 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 seizures and is part of the recovery/brain resetting process, some patients appear unintentionally aggressive or hostile, even sometimes violent. It is important to remember 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 or 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 consulting the next of kin for clarification.

Patient Specific Information (CmC) 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 PSIs and CmCs and for GPs to be receptive to these requests from patients, who have major conditions and to facilitate their production. Education of the LAS front line, 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, the ‘Whose Shoes’ methodology could be adopted for paramedics, EACs and their managers to experience seizures through the eyes of patients. This could also provides insight 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.**

See the following web sites for detailed, patient centred information.

[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 could 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. See also the Co-Production Charter.

**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.**

A useful approach could be role reversal, perhaps with people who have epilepsy and students studying in the LAS or university to become paramedics, in order 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**

1. 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 incorporated into an LAS training video.
2. A key message is that no two seizures are the same even if they are epileptic in nature/ origin. A seizure may not appear as a paramedic has previously experienced it or learnt about it during their training. Diversity in the presentation of seizures is a key issue.
3. 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 and can reduce the risk of further seizures, because the patient is in a safe, less stressful environment.

**12)  Suggest to the LAS Academy re possibility of Sean Hamilton talking to students at the Academy.**

Some 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) Are the clinical approaches of other ambulance services very different from those

 of the LAS in relation to the above developments?

End

**Copy to Ian Wilmer, Paramedic, epilepsy lead, Fenella Wrigley, Medical Director, Tina Ivanov, Deputy Director, Clinical Education and Standards.**