

PATIENTS' FORUM

FOR THE LONDON AMBULANCE SERVICE

December 9th 2019

Improving Care for Patients who Suffer Epileptic Seizures

Most of the priorities show below were agreed by the Patients' Forum, following our public meeting on epilepsy led by Ian Wilmer, LAS Advanced Paramedic Practitioner. Our objective is to promote service improvements in the LAS that would enhance the clinical care of patients who have epileptic seizures. We will continue our discussions with the LAS to achieve implementation of our priorities.

The Forum's Priorities

Priority 1) Promoting the Use of Tap2Tag Medical

When a patient is having a seizure, access to CmC data may be difficult for paramedics. Tap2Tag Medical enables a paramedic to know about a patient's medication, medical conditions and name, which can be vital in life-threatening situations. For those who have a complex medical condition or are on a regime of medication that changes frequently, the importance of being able to communicate accurate clinical information quickly and precisely is paramount.

Tap2Tag Medical uses medical wristbands /bracelets, identification cards and key fobs, and each device has a special chip inside it. A paramedic or first responder simply taps their NFC enabled phone against the device and the patient's medical information appears. There are no apps to download, the information simply appears on their phone's browser. The Tap2Tag, with NFC secure and encrypted patient/summary record access and bio, can be co-ordinated with MedicAlert whose emergency operations centre could develop liaison with the LAS Clinical Hub.

www.medicalert.org.uk/about-us/ www.tap2tag.me/what-is-tap2tag-medical-alert/

Near-field communication (NFC) is a set of communication protocols that enable two electronic devices, one of which is usually a portable device such as a smartphone, to establish communication by bringing it within 4 cm of each other. This is sometimes referred to as NFC/CTLS (contactless) or CTLS NFC.

MONITORING LONDON'S AMBULANCE SERVICES FOR THE PEOPLE OF LONDON

Priority No2: LAS wide and 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 epileptic 'aura' is 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 during this stage. 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 fail to 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.

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.

Coordinate my Care (CmC) needs 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 CmCs, and for GPs to be receptive to requests from patients, who have chronic and serious conditions in order to facilitate CmC production. Education of the LAS front-line, GPs, STPs, CCGs and NHS Trusts is essential for the successful implementation of CmCs to the wider population who are in need to this level of clinical information and expertise.

Priority No 3) Learning modules focussed on treatment of epileptic seizures to be included in the CSR and other learning modules for all front-line staff.

In addition to the regular CSR programme, the 'Whose Shoes' methodology should be adopted for paramedics, EACs and their managers, to experience seizures through the eyes of patients. This could also provide insight for patients, especially regular service users, to understand what it's like for paramedics, and they can also give something back to the crews who have cared for them.

MONITORING LONDON'S AMBULANCE SERVICES FOR THE PEOPLE OF LONDON

Priority No 4) 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 working with students studying paramedic science in the LAS or university, in order to provide first-hand insight into what it's like to live with a complex, hidden condition. Sean Hamilton could also be invited to talk to students at the Academy about his vast experience of seizures.

Priority No 5) Ensure there is close clinical focus is on each stage of epileptic seizures.

This should focus on the patient's condition: before, during and after the seizures, including pre and post-ictal care and associated behaviours, by sharing the following web sites with patients and clinicians for detailed, patient centred information.

www.epilepsy.com/learn/about-epilepsy-basics/what-happens-during-seizure

www.epilepsysociety.org.uk/what-epilepsy

www.epilepsysociety.org.uk/epileptic-seizures#.XFMpZvZ2vOg

www.epilepsysociety.org.uk/living-epilepsy#.XFMpa_Z2vOg

<https://sudep.org/checklist>

Priority No 6) Develop a training video on epileptic seizures for CSR including:

- A) A Forum member has obtained footage from TFL of his latest seizure at North Greenwich station, which included the escalator where LAS crew attended to him, this can be incorporated into a LAS training video.
- B) 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.
- C) The use of rescue medications such as Midazolam and its administration could also be included in the video using the experience of both clinicians, service users and Epilepsy Society First Responders.
- D) SUDEP (sudden unexpected death in epilepsy). SUDEP accounts for 50% of epilepsy deaths and is potentially avoidable. Patients may or may not experience a seizure and SUDEP is not well recognised amongst clinical staff. A SUDEP & Seizure Safety Checklist has been produced by the charity SUDEP Action, which should be make available to all staff and included in the proposed training video.
<https://sudep.org/checklist>

MONITORING LONDON'S AMBULANCE SERVICES FOR THE PEOPLE OF LONDON

Priority No 7) Enhancing the expertise of staff in the EOC clinical hub.

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 should include a section on carers and how LAS can assist & relieve some of their pressures. See attached Co-Production Charter.

Priority No 8) Focus on POTS – Postural Orthostatic Tachycardia Syndrome

Training staff about the importance and significance of POTS.

POTS can sometimes be confused with epileptic seizures. Some patients with epilepsy also suffer with POTS or other similar conditions and their cardiac condition can trigger a seizure. The reverse can also happen: www.potsuk.org/types_of_pots
www.heartrhythmalliance.org/stars/uk/conditions

Priority No 9) 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 not required. This approach is used at the discretion of an EOC manager following a risk assessment and transfer to a place of safety. Taking a person to their own home can reduce the risk of further seizures, because the patient is in a safe, less stressful environment.

Priority No 10) Speaking to the LAS Board

We asked for our lead on epilepsy Sean Hamilton and his father/carer Vic, be given the opportunity of addressing a LAS Board meeting regarding the priorities listed above. Vic Hamilton has enormous and unique experience of responding to both his son and wife who regularly experience epileptic seizures.

We will continue our discussions with the LAS clinical team regarding implementation of these priorities.

Malcolm Alexander, Chair, Patients' Forum for the LAS
WWW.PATIENTSFORUMLAS.NET

Copy to Sean and Vic Hamilton