

# PATIENTS' FORUM FOR THE LONDON AMBULANCE SERVICES

AUGUST 2020

THE LAS NEEDS TO LISTEN AND LEARN FROM PATIENTS  
AND STAFF IN ORDER TO IMPROVE THE QUALITY OF CARE  
THAT THEY PROVIDE

**PATIENTS' FORUM NEWSLETTER FOUR**



## FROM SEAN AND VIC HAMILTON: PATIENTS' FORUM LEADS ON EPILEPSY

**IDENTIFYING SERVICE IMPROVEMENTS FOR THE LAS TO ENHANCE  
THEIR CLINICAL CARE OF PATIENTS WHO HAVE EPILEPTIC  
SEIZURES**

### **PRIORITY No.1**

**LAS-wide and stakeholder education, not just about epilepsy and seizures, but the factors and components that often come with it, such as Auras in the period leading up to a seizure – the Ictal Stage.**

Front-line staff need to learn from the experiences of patients who suffer epileptic seizures. As Patients' Forum leads on Epilepsy, we are willing to present to the LAS Board, Quality Oversight Group (QOG) and staff training at LAS Education Centres.

Key issues could include understanding and responding to the post-ictal state; the period that typically follows seizures and is part of the recovery/brain resetting process.

At this stage, some patients appear unintentionally aggressive or hostile, sometimes even violent. It is important to understand that this behaviour is not who that person normally is ... it is part of their condition - and can at times be made worse when clinical staff fail to listen or do not respect the patient's requests and guidance.

The post-ictal state can last for hours in some cases, or even for days. For others, their post-ictal state may mean they need to sleep. On some occasions the patient may present, or even give the impression that they are fully recovered when, in fact, they are not.

More experienced Paramedics fully understand these states and try to support the patient in any way that they can - sometimes up to and including taking them home by request or consulting the next of kin for clarification. When this type of sensitive information is placed on Co-ordinate my Care (CmC), clinical outcomes are much improved.

## **AURAS**

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, an FAS develops into another type of seizure. The FAS is, therefore, sometimes a warning that another seizure will happen.

## **CO-ORDINATE MY CARE - CmC**

CmC is an interactive system that provides critical information about a patient's urgent and emergency care needs. It must be accurate and up-to-date, particularly if the patient has more than one major condition, e.g. epilepsy or a cardiac condition. It is essential to widely publicise CmCs, and for GPs to be receptive to patients who request a CmC be set up with the LAS and other health and care bodies.

<https://www.coordinatemycare.co.uk>

## **PRIORITY NO. 2**

**Developing 'whose shoes'<sup>1</sup> learning modules, focussed on treatment of epileptic seizures for all front-line staff.**

In addition to the regular CSR programmes, the 'Whose Shoes' methodology could be adopted for Paramedics, EACs and their Managers to experience seizures through the eyes of patients (EAC are emergency ambulance crew).

<sup>1</sup> **Whose shoes?** is an approach designed to help healthcare staff and patients see care through each-other's eyes, using a series of thought-provoking exercises and scenarios. The aim is to share good practice and challenge attitudes and assumptions in a non-threatening way.

This could also provide insight for patients, especially regular service users, in order to understand what it is like for Paramedics. By participating in training of staff, patients can also give something back to the amazing crews who have cared for them.

### **PRIORITY NO.3**

#### **LAS should develop an understanding of Tap2Tag methodology**

Tap2Tag is a system to ensure that when a clinician sees a patient in an emergency, that accurate, up-to-date information is immediately available about the patient's medical history, medication, allergies and any other critical information. This Tap2Tag approach, with NFC secure<sup>2</sup> and encrypted patient/summary record access, can be co-ordinated between **MedicAlert**<sup>3</sup> and the LAS Emergency Operations Centre (EOC). This would enable enhanced and immediate knowledge and understanding of patients' medical condition. <https://www.tap2tag.me/what-is-tap2tag-medical-alert>

Paramedics should always check the patient's wrist and around the patient's neck for medical ID jewellery supplied by Medic Alert. The jewellery has an ID number and a phone number, and by ringing the number, ambulance staff can get details of medication and clinical history.

### **PRIORITY NO.4**

#### **Care Plans and Protocols**

Patients who do not have a Co-ordinate my Care Plan set up with the NHS, or a Medic Alert device, should have a personal Care Plan which they have agreed with their medical and nursing clinicians.

Ambulance staff should always ask to see the patient's Care Plan if this is possible. If the patient is not in a condition to provide the Care Plan, a relative or carer may be able to do so. Emergency medication protocols (sometimes part of the Care Plan) are vitally important as emergency medication might be indicated in certain situations - for example during a cluster of seizures. This is especially important for a patient with a learning disability.

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<sup>2</sup> **NFC**, based on contactless smartcard technology, allows **secure** data exchange by using encryption and a special processor. The wireless technology limits communication to within a short distance, reducing the opportunities for an attacker to eavesdrop on communications and adding **security** and privacy.

<sup>3</sup> MedicAlert helps save lives by retaining members' vital personal and medical information and makes this information available during emergencies. Items or jewellery, watches, bracelets can be used to hold essential information. <https://www.medicalert.org.uk/about-us>

## **PRIORITY NO.5**

### **Enhance the expertise of staff in the EOC Clinical Hub to respond more effectively to patients who have epileptic seizures**

We recommend the development of a Handbook and an App on the complexities of epilepsy and seizures, specifically for the EOC Clinical Hub (CHUB).

The Handbook and App should be developed through co-production between the LAS Medical Director, service users, epilepsy charities, CHUB staff and the LAS Pharmacist. It should include a section on the role and needs of carers and how the LAS can relieve the pressure on carers and families.

See: Patients' Forum-LAS Co-Production Charter on page 7:

[www.patientsforumlas.net/co-production-in-the-las.html](http://www.patientsforumlas.net/co-production-in-the-las.html)

## **PRIORITY NO. 6**

### **Focus on POTS (Postural Orthostatic Tachycardia Syndrome)**

It is essential that front-line staff learn about less common, but equally serious, seizure presentations. POTS can sometimes be confused with epileptic seizures.

Some patients with epilepsy also suffer with POTS, or other similar conditions. Cardiac conditions can trigger a seizure. The reverse can also happen.

[www.potsuk.org/types-of-pots](http://www.potsuk.org/types-of-pots)

[www.hearhythmalliance.org/stars/uk/conditions](http://www.hearhythmalliance.org/stars/uk/conditions)

## **PRIORITY NO. 7**

### **Prioritise Empathy – This is essential for effective care for patients who have had a seizure.**

A useful training approach could be role reversal, in which people who have Epilepsy join training sessions with students studying in the LAS to become EACs, Paramedics, EOC staff ... and those at university Paramedic Science courses. This role reversal will enable each other to encounter the other's real-life experiences and learn about their perceptions.

This approach could provide first-hand insight into what it is like to live with a complex and often hidden condition.

## **PRIORITY NO.8**

### **Developing a training video on Epileptic Seizures for CSR – Co-production in Action**

The Forum successfully worked with the LAS on the production of a stroke training video for all front-line LAS staff. We should like to use a similar model to produce an epilepsy video that actively involves people who regularly experience seizures, and their carers. 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 learned about it during their training. Diversity in the presentation of seizures is a key and fundamental issue. The use of rescue medications - such as Midazolam - and how it is administered should be included, using the experience of both Clinicians, service users and carers

We have obtained footage from TfL on a recent seizure at North Greenwich Station, which includes site of the escalator, where LAS crew attended to the patient. This unique and complex situation can be incorporated into a LAS training video.

## **PRIORITY NO.9**

### **Developing a Cadre of Epilepsy First Responders**

There are currently very few Epilepsy First Responders or Advanced Practitioners who specialise in epilepsy across the UK. Where these practitioners and lay First Responders have operated, it has been down to individual ambulance trusts to recruit, train and upskill these staff and volunteers - usually alongside a specialist NHS Trust. Some have been recruited from amongst specialist epilepsy nurses - known as Sapphire Nurses<sup>4</sup>

There is a pressing need for First Responders from across the epilepsy community, e.g. people who are carers of those with epilepsy, to ensure that patients having seizures get the right-care first-time. They can also support patients to safely remain at home in the community, rather than being conveyed to hospital if this is not necessary – providing experienced clinicians agree that this is a safe option.

We should also like to see ambulance services supporting the creation of dedicated neuroscience/ mental health and co-morbidity condition responders. Thereby making the best use of these combined specialist medical skills and experience, to ensure patients with co-morbidities and complex presentations get the best possible care.

<https://www.facebook.com/epilepsyaction/posts/do-you-know-about-our-sapphire-nurse-scheme-to-appoint-epilepsy-specialist-nurse/121319934564756/>

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<sup>4</sup> Sapphire Nurse scheme aims to appoint epilepsy specialist nurses within NHS trusts throughout the UK

## **PRIORITY NO.10**

### **Conveyance to a Domestic Place of Safety**

Investigate further possibilities for conveyance of patients who have had a seizure to a domestic 'place of safety', e.g. to their own home, rather than to A&E. This will require co-ordination between Ambulance Services if the original incident occurs away from home.

Often referred to as 'Home by Request' (HbR), this is consistent with the LAS 'leave at scene' approach, i.e. not taking patients to A&E if it is not clinically appropriate to do so. The HbR approach is used at the discretion of an Ambulance service EOC Manager following a risk assessment.

Transfer to a Place of Safety can reduce the risk of further seizures because the patient is in a safe and less stressful environment. We can collaborate with the LAS to write the Policy and Procedures for this patient-centred development.

## **KAIDEN'S STORY TOLD BY HIS MUM, ALICIA**

Kaiden is only two years of age and has spent much of these two years in hospital. Since having Kaiden life has not been easy as he started having seizures when he was 4 months old. The worst day of my life was when they took Kaiden by ambulance to hospital and diagnosed a 'febrile convulsion'. It took a few weeks for me to start to relax, and then on the eve of his first Christmas, Kaiden had another seizure and then had a CT scan at Medway Hospital.

Kaiden's dad, Taylor, went on-line and found a condition called Dravet's Syndrome<sup>5</sup>, which matched Kaiden's symptoms and then we had an appointment at the Evelina Children's Hospital after a few weeks, when this diagnosis was confirmed.

It has been really hard for our family to come to terms with this diagnosis, because it affects us all, including our four-year-old daughter. She is sometimes cared for by our family when Kaiden needs a lot of support from us, e.g. when he is in hospital.

Kaiden is now cared for at the Medway Hospital, where he knows all Nurses and Doctors on Dolphin and Penguin wards.

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<sup>5</sup> **Dravet's syndrome** is a rare, drug-resistant epilepsy that begins in the first year of life in an otherwise healthy infant. It is lifelong. It usually presents with a prolonged seizure with fever that affects one side of the body. Most cases are due to severe SCN1A gene mutations.

Kaiden also suffers problems with sleeping – he sleeps for about 2-3 hours a night and then can be awake for about 4-6 hours, so we get very little rest. He has really bad seizures and we are struggling to find the right kind of support, because Dravet's Syndrome, is one of the most complex and life changing forms of Epilepsy.

We need better support, information and advice on how to care for Kaiden, as well as more effective treatment programmes, because the usual treatments for epilepsy do not work well for him. Ultimately, we need a new national treatment programme for patients with conditions like Dravet's Syndrome and their families.

I want to thank all the wonderful ambulance staff who work with the Medway Hospital, who have supported us so well since 2018, and the First Responder who was so calm, caring and helpful.

One point for learning, is that some ambulance staff have acted as if they knew Kaiden's medical and family history better than us and told us we had nothing to worry about. That can feel disconcerting at times. Alicia

## **DRAFT CO-PRODUCTION CHARTER BETWEEN THE LAS AND PATIENTS' FORUM FOR THE LAS**

The Charter was agreed with the Chief Quality Officer of the LAS, Trisha Bain, on 17 October 2019 in a Meeting attended by Joseph Healy, President and Malcolm Alexander, Chair, of the Patients' Forum for the LAS.

[www.patientsforumlas.net/co-production-in-the-las.html](http://www.patientsforumlas.net/co-production-in-the-las.html)

### **CHARTER: SUMMARY**

- Provides an effective means of designing, shaping, and delivering services in a partnership between the LAS and people who have used the service or may use it in the future.
- Enables delivery of our shared objectives for the creation of better services and outcomes for patients.
- Sets out the potential outcomes that people can expect from the co-production of urgent and emergency care services and other care services provided by the London Ambulance Service.
- Sets out the responsibilities of people taking part in the co-production of services.
- Establishes principles which are intended to achieve a vision of service users as equal partners in the production of effective urgent and emergency care.
- Signals the direction of travel for integrated service development between the LAS, patients, and the public.
- Enables the LAS and the PFLAS to work collaboratively in the best interests of service users for the enhancement of their care.

**All Front-Line Ambulance Clinicians should see and share the following websites for detailed patient-centred information.**

**This will ensure that they have a focus on each stage of seizures – before, during and after the seizure. This will include 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)

[www.epilepsysociety.org.uk/what-epilepsy](http://www.epilepsysociety.org.uk/what-epilepsy)

[www.epilepsysociety.org.uk/epileptic-seizures#.XFMpZvZ2v0g](http://www.epilepsysociety.org.uk/epileptic-seizures#.XFMpZvZ2v0g)

[www.epilepsysociety.org.uk/living-epilepsy#XFMpa\\_Z2vOg](http://www.epilepsysociety.org.uk/living-epilepsy#XFMpa_Z2vOg)

## **SUDEP Action**

There are over 1000 epilepsy related deaths each year in the UK. SUDEP Action is dedicated to raising awareness of epilepsy risks and tackling epilepsy deaths, including Sudden Unexpected Death in Epilepsy. They are a UK charity which specialises in supporting and involving people bereaved by epilepsy. Better, improved & more appropriate case/ patient specific/ personalised care/ response could greatly reduce SUDEP deaths <https://sudep.org/epilepsy-related-deaths>

## **CONTACT THE PATIENTS' FORUM FOR THE LAS**

Web: [www.patientsforumlas.net](http://www.patientsforumlas.net)

Email: [patientsforumlas@aol.com](mailto:patientsforumlas@aol.com)

Mobile:07817 505193

Sean Hamilton:07591550059

### **Abbreviations used in Newsletter:**

CHUB ...	...	...	...	...	Clinical Hub
CMC ...	...	...	...	...	Co-ordinate My Care
EAC ...	...	...	...	...	Emergency Ambulance Crew
EOC ...	...	...	...	...	Emergency Operations Centre
HbR ...	...	...	...	...	Home by Request
NFC ...	...	...	...	...	Near Field Communication
PFLAS	...	...	...	...	Patients' Forum for the LAS
POTS ...	...	...	...	...	Postural Orthostatic Tachycardia Syndrome
TfL ...	...	...	...	...	Transport for London

## PREVIOUS FORUM NEWSLETTERS – 2020

These can be found on [www.patientsforumlas.net](http://www.patientsforumlas.net)

**MAY 2020 – LAS Review their Patient Involvement Performance**

**JUNE 2020 – “My Experience of Stroke Care in the LAS”**

**By Courtney Grant: Forum Lead on Stroke and Human Factors.**

**JULY 2020 – “My Experience of the LAS – Suicide and Self-Harm”**

**By Alexis Smith, Forum Lead on Acute Mental Illness**

**epilepsy society**

Remember the 3 'C's and make sure you're **#seizuresavvy**

**Calm**

**1.** Stay calm and take control of the situation

**Cushion**

**2.** Cushion their head with something soft

**Call**

**3.** Call an ambulance if it lasts longer than five minutes

[seizuresavvy.org.uk](http://seizuresavvy.org.uk)