

PATIENTS' FORUM FOR THE LONDON AMBULANCE SERVICES

DECEMBER 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 FIVE



CO-PRODUCTION CHARTER FOR URGENT AND EMERGENCY AMBULANCE SERVICES IN LONDON

**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.

All paramedics and other emergency ambulance staff receive education in epilepsy and seizures including the post ictal state. It is also important to note that seizures of any type may indicate serious underlying illness or injury not necessarily related to epilepsy and therefore thorough clinical and risk assessments are required as part of joint decision making. Current JRCALC guidelines relating to management of patients where seizure activity has ceased include non-conveyance guidance incorporating referral to an epilepsy nurse specialist and/or GP where appropriate and advice regarding driving and DVLA regulations.

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>

LAS update: CMC no longer exists and has been replaced by the the urgent care plan. The Urgent Care Plan is updated by the patients treating clinician or GP. They are available to be used by clinicians who are assessing patients both remotely on the telephone and face to face.

PRIORITY NO. 2

Developing ‘whose shoes’¹ 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).

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.

LAS update – training material, which is regularly updated, includes videos are used in training from both the Epilepsydiagnosis.org and SUDEP.org

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 secure² and encrypted patient/summary record access, can be co-ordinated between **MedicAlert**³ 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>

¹ **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.

² **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.

³ 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>

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.

LAS update: Routine training is provided for all paramedics and other emergency ambulance staff in relation to MedicAlert bracelets and other similar insignia. Searching for such items is a routine part of the secondary survey once any potentially life threatening conditions have been identified and managed.

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.

LAS update: Training in the use of buccal midazolam where this is prescribed to the patient is provided for paramedics who would give this medication in accordance with a care plan. This is analogous to the use of medications prescribed to patients but not routinely carried by LAS staff in the End of Life Care scenario.

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

LAS update: It is important that universal guidance is utilised by all LAS staff to ensure a common standard and approach to care. CHUB staff are able to access guidance relating to epilepsy and seizures via the Manchester Triage system and by using the British National Formulary (BNF) for medicines information. Additional clinical advice is also available via the IUC/111 service.

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

www.heartrhythmalliance.org/stars/uk/conditions

LAS update: A range of conditions resulting in collapse may be associated with apparent seizure activity including POTS. These are dealt with in JRCALC guidance relating to Transient Loss of Consciousness (T-LOC) which mirrors NICE guidance on this subject <https://www.nice.org.uk/guidance/cg109>. This incorporates advice on how to differentiate other causes of seizure activity from epilepsy including risk stratification, ECG interpretation and onward referral.

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.

LAS update: As per comments above, training in the use of Midazolam is routinely provided and guidance is available via JRCLAC.

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 Nurses⁴

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/>

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

LAS update: JRCALC provides guidance that referral to an epilepsy nurse specialist may be considered as part of a range of responses to a patient who has suffered an epileptic seizure. Management in the community as opposed to hospital admission is also encompassed in this guidance.

There is current work ongoing in the form of the Supporting the ambulance service to safely convey fewer patients to hospital by developing a risk prediction tool: Risk of Adverse Outcomes after a Suspected Seizure (RADOSS) study. This work will provide additional insight into this important area of practice and may lead to the validation of a risk stratification tool to support ambulance service decision making.

PRIORITY NO.10

Conveyance to a Domestic Place of Safety

DRAFT

A. THE LONDON AMBULANCE SERVICE AND THE PATIENTS' FORUM AGREES THAT:

- **Services are organised so that they meet people's needs**
- **Patients will have a stronger voice in the LAS than ever before**
- **The patient is at the centre of everything that the LAS does**
- **The LAS will listen to staff and patients to determine priorities**
- **Patients & carers will be involved in all LAS improvement work**
- **Integral to all LAS programmes must be the aim of robust patient and staff involvement**
- **The LAS will listen to patients, their families and carers, and respond to their feedback**
- **The goal of the LAS is to have patient involvement in all service redesign programmes and a patient involvement framework developed to apply this goal consistently**
- **LAS will widen and increase public involvement in the development of Pioneer services and monitoring of success**
- **A co-designed and co-developed patient and staff engagement model will be used to drive quality improvement across the maternity care model**

(Key Statements from the 2018/19 London Ambulance Service
Quality Account)

B.THE LONDON AMBULANCE SERVICE (LAS) AND PATIENTS' FORUM FOR
THE LAS (PFLAS) AGREE THAT THE CO-PRODUCTION CHARTER:

- 1) 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.
- 2) Enables delivery of our shared objectives for the creation of better services and outcomes for patients.
- 3) 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.
- 4) Sets out the responsibilities of people taking part in the co-production of services.
- 5) Establishes principles which are intended to achieve a vision of service users as equal partners in the production of effective urgent and emergency care.
- 6) Signals the direction of travel for integrated service development between the LAS, patients and the public.

- 7) Is a living document and will be subject to annual review and improvements, where these will enhance patient and public involvement in LAS service development and/or improve the outcomes of patient care
- 8) Does not replace or substitute for any other democratic processes, NHS Constitution, Acts of Parliament or statutory instruments, including the statutory duty to consult on all significant service change.

C. PATIENTS AND THE PUBLIC WILL BE ENCOURAGED TO:

- 1) Participate at the earliest stages in the design or redesign of LAS services, where such changes may affect their care, treatment or interaction with front-line staff.
- 2) Operate and function as equally-valued voices, assets and partners.

D. EFFECTIVE COLLABORATION IS ESSENTIAL FOR EFFECTIVE CO-PRODUCTION:

- 1) LAS and the PFLAS agree to work collaboratively in the best interests of service users and the enhancement of their care.
- 2) The LAS and PFLAS agree to ensure that proposals for service changes and improvements, will be the subject of joint work from initiation of the process to completion, including feeding back to service users on the results and outcomes of co-production.

E. PROMOTING EQUAL OPPORTUNITIES TO INFLUENCE CHANGE - THE LAS AGREES TO:

- 1) **Acknowledge differences in the capacity to effect change and in access to resources between all those who participating in the Co-Production of London Ambulance services.**
- 2) Ensure the differential in influence and resources will not hinder the design of enhanced care for users of urgent and emergency services.
- 3) Provide access to all information/ documentation relevant to achieving shared goals of Co-Production in service design and creation.
- 4) Value equally all those who participate in and contribute to the joint process of Co-Production and decision making.

**F. SUPPORT FOR PARTICIPANTS OF CO-PRODUCTION -
THE LAS AGREED TO SUPPORT PARTICIPANTS BY PROVIDING:**

- 1) **Any necessary training required to enhance the process of co-production by the acquisition of new skills.**
- 2) **Equal opportunities for those who wish to participate and for those participating.**
- 3) Accessible venues and locations.
- 4) Sensitivity to the time when meetings take place, in order to avoid rush hours and excess expenditure.
- 5) Translation into different languages; British Sign Language (BSL) interpreters; Accessible Information Standards) and other formats (including Easy Read).

- 6) Feedback on all aspects of co-production projects.

G. THE PEOPLE

- 1) **The LAS and the PFLAS will encourage the participation of London based service users, patients, carers, experts by experience, residents, citizens, workers, children and young people in co-production projects.**
- 2) **Healthwatch in every London Borough shall be invited to sign the Co-Production Charter and participate in all co-production projects.**
- 3) **Health and social care related voluntary sector bodies will be invited to participate in relevant co-production projects, e.g. the Sickle Cell Society, Mind, Age UK, Diabetes UK, Epilepsy UK, the Stroke Association and St Mungoes.**
- 4) **Those engaged in co-production will encourage partnership and collaboration based on mutual trust and respect.**
- 5) **We shall encourage co-production participants to:**
 - **Listen to each other and answer questions respectfully**
 - **Share information with wider communities, groups and stakeholders and feedback their concerns/comments**
 - Commit to ongoing involvement to maintain momentum
 - Commit to working together towards shared goals.
 - Share outcomes of co-production in their newsletters, social media and reports.

H. PARTNERSHIP BODIES, TRAINING AND RESOURCES

- 1) **Co-production should be championed by all relevant partnership**

bodies including: LAS commissioners, the Clinical Quality Review Group (CQRG), strategic, commissioning and policy groups and boards.

- 2)** Training and capacity building shall be provided for staff engaged in co-production, where possible jointly with the members of the PFLAS, Healthwatch, service users and the voluntary sector.
- 3)** Dedicated resources and funding for co-production shall be provided by the LAS and their commissioners.

FOR THE LONDON AMBULANCE SERVICE

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FOR THE PATIENTS' FORUM FOR THE LONDON AMBULANCE SERVICE

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FOR 32 LONDON HEALTHWATCHES

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CONTACT THE PATIENTS' FORUM FOR THE LAS

Web: www.patientsforumlas.net

Mobile:07817 505193

Email: patientsforumlas@aol.com

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

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