

The Impact of Brexit on Epilepsy

23rd July 2019

Meeting Minutes

1. Attendees: Paula Sherriff MP, Daniel Jennings (Epilepsy Action), Sammy Ashby (AUDEP Action), Dr Arjune Sen (Oxford University Hospitals NHS Trust), Caiomhe Bennett (Epilepsy Research UK), Professor Matthew Walker (Epilepsy Research UK/ILAE), Dr Sallie Baxendale (ILAE), Susan Cole (Valproate Victims), Deborah Mann (OACS), Karen Buck (OACS), Torie Robinson (Epilepsy Sparks), Maxine Smeaton (Epilepsy Research UK), Mark Devlin (Young Epilepsy), Nicola Swanborough (Epilepsy Society)

Apologies: none

2. Plans for the Future of the APPGE

- 1) Paula Sherriff MP outlined the updates currently happening to the APPGE to ensure the group has impact and can demonstrate outcomes.
- 2) SUDEP Action have now joined Epilepsy Action as Secretariat for the meetings.
- 3) Standing agenda items for future meetings & the opportunity for attendees to contribute towards future meeting topics.
- 4) Aims and Values of the group shared (see slides for details of updates).
- 5) Paula reminded the group of her personal connection to Epilepsy and why this issue is of importance to her.

3. The Impact of Brexit on Epilepsy – Discussion

- 1) Paula Sherriff MP introduced the discussion topic – an issue on ongoing relevance and concern both inside and outside of Parliament.
 - a. Key focus points for discussions: Medicines Shortages, Research, Mortality, Access to Services, Social Care, NHS Staffing/Workforce, Voluntary Sector Impact & Education/Employment.
 - b. Paula Sherriff MP asked for an update on stated of medicines shortages - previous assurances were of a 6 weeks supply and people with epilepsy (PWE) were had been told not to stockpile.
 - c. Noted increasing worry among PWE in the event of a no-deal Brexit and a continued lack of transparency to help relieve this concern. Knowledge that many PWE are therefore stockpiling medication 'just in case'. Concerns echoed by other personal experiences by PWE in attendance and from both clinical/voluntary organisations contact with PWE.
 - d. Professor Matthew Walker noted that many PWE require specific brands/types of epilepsy medications in order to control seizures. Increasing numbers of patients experiencing medicine shortages/changes and expressing concern over this issue. Noted that currently pricing of medications is currently quite low but could spiral depending on Brexit outcomes.
- 2) Paula Sherriff MP asked for clarity on the impact on PWE if a Serious Shortage Protocol (SSP) or switch of medication (ie: if in shortage generally) happens?
 - a. Prof. Matthew Walker explained the potential impact on some PWE & why a switch could cause this (increasing seizures, loss of seizure control due to different absorption of medicine). Noted the particular impact this could have on those currently seizure free.
 - b. Dr Arjune Sen elaborated how gaining seizure control is complex but vital – disruption for this due to shortage or switching of medication could be life-changing & life-threatening. Changing seizures increases impact on PWE (eg: mortality, injury, accidents, lifestyle changes such as loss of driving licence/impact on independence, changes to mental health and overall wellbeing).
 - Clinicians are seeing increasing patient concern – this issue is having a cyclical impact on PWE (increasing worry → increasing impact on epilepsy / wellbeing → increasing impact on life → further increasing worry). Impact on wellbeing & mental health reiterated by PWE attendees

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both from own experience & via recent communications with other PWE: Torie Robinson, Susan Cole, Karen Buck & Deborah Mann.

- Noted a standard patient prescription is often for 4 weeks supply – Government’s plan for a 6 weeks post-Brexit supply therefore only enables 1, possibly 2 prescriptions to be filled for some PWE.
- c. Sammy Ashby reiterated the potential for this issue to be life-threatening. It is well known not all PWE (or clinicians) are aware of epilepsy risks/SUDEP as part of their condition management. Switches/shortages could therefore increasingly happen in the context of ignorance of risk, meaning informed choices cannot be made by PWE, their families or clinicians to reduce risks.
- d. Nicola Swanborough explained Government had provided direct assurances as part of their ongoing work with their organisation that an SSP wouldn’t affect epilepsy & any shortage issues would revert to the original prescribing clinician.
- Paula Sherriff MP questioned how public Government plans are as the epilepsy community need reassurance of safety measures in case of SSP activation. Concern expressed around the room on: continued ambiguity from Government on the impact of medication changes; what would happen if a protocol required activation; how PWE would be kept safe in instances of shortages; and what is being done to mitigate medication shortages more generally.
- 3) Issues of workforce for Neurology and Epilepsy specialisms raised as a concern that could be worsened by Brexit outcome (Prof. Matthew Walker & Dr Arjune Sen). UK Medicine & Research communities attract worldwide input; however, there is a decrease in applications, with some European clinicians/researchers leaving due to uncertainty and feeling of rejection linked to Brexit messaging.
- a. EU grant funding will change as a result of Brexit – impact already occurring in research community:
- UK researchers can no longer be Principal Investigators (leads) on EU funded projects
 - Facing exclusion from multi-site European grants (or the UK is on unequal footing if able to apply/be involved)
 - Significant impact on the UK’s ability to collaborate internationally for example: Epicare project currently has many UK members; this membership ceases if a no-deal Brexit occurs meaning UK experts are downgraded to participants rather than active stakeholders in the project/meetings.
- b. Paula Sherriff MP raised the concern that due to known variation in access to and quality of services for PWE (highlighted in the recently launched Neurological Alliance’s ‘Neuro Patience’ Report), workforce issues could become worse post-Brexit and widen this gap, further impacting on those living with epilepsy and their families/carers.
- Susan Cole questioned if it is possible to quantify the cost of these issues on the epilepsy community to demonstrate impact. Prof. Matthew Walker noted there are some UK specific & European studies on the general cost of epilepsy (likely not Brexit related). Dr Arjune Sen also highlighted the recent WHO report on Epilepsy as a health imperative.
 - Paula Sherriff MP noted this information would be useful, though likely difficult to draw together. The importance of using both evidence and personal experiences to raise awareness among MPs about epilepsy also discussed – stating how like among the general public, MP understanding is likely similar & further education from the APPGE is needed so more MPs can advocate on the group’s behalf.

4. Letter to the new Prime Minister and Secretary of State for Health and Social Care

ACTION – The APPGE will write an introductory letter to them, raising key Epilepsy facts and concerns, and requesting a meeting.

- 1) Those in attendance confirmed this was a positive step & it was agreed the letter would be sent ASAP. The letter would be drafted by the Secretariat and the letter plus any replies would be circulated to the wider group once sent/received.

All Party Parliamentary Group for Epilepsy

Chair: Paula Sherriff MP

Secretariat:



SUDEP Action 
Making every epilepsy death count

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- 2) Agreed the letter would be generic, concise & hard-hitting, given recipients are likely very unaware of key statistics, facts, issues, concerns or work being done on Epilepsy. Aim for this to be an initial introduction, which individual orgs can build on with separate contact on their specific niches in future if required.

ACTION – Any interested organisations to send 1 or 2 headline points pertinent (evidence based & referenced where possible) to their organisation’s focus for inclusion where possible.

Discussion points raised during this section:

- 1) Epilepsy is often stigmatized and ‘invisible’ to those not affected (Dr Arjune Sen)
- 2) Importance of raising the impact on families of PWE both generally & in relation to Brexit issues (Susan Cole, Karen Buck, Deborah Mann & Torie Robinson)
- 3) Paediatric issues flagged as another aspect to consider – particularly highlighting the potential use of Epilepsy12 Audit data which can help demonstrate service issues. EG: shows only 20% have access to an ESN and only 13% to mental health services. (Mark Devlin)
 - a. Issues surrounding Paediatric PWE – 1 in 3 not having a health plan in schools despite this being required.
 - b. Mortality is an important hard-hitting issue to include in initial contact – makes a strong case for action being required & significant data available to evidence this. (Sammy Ashby & Dr Arjune Sen)
 - Issues surrounding waiting lists also flagged (for diagnosis and also for surgery) – experiencing deaths in those waiting for surgery due to long waiting times; these patients have complex/uncontrolled epilepsy so likely at increased risk of death/SUDEP. (Prof. Matthew Walker)

5. Future Meetings

- 1) Potential ideas for future meetings raised for consideration:
 - a. IMNDS review; Medicine Errors; Sodium Valproate update; Mental Health/Wellbeing; Service Provision/Variation; Safety; Empowering PWE to push for improved services/care

ACTION – Minutes, slides and copies of letters to be circulated in due course. An update on progress regarding actions to happy at the next meeting (Autumn - date TBC)

Attendee photo taken – organisations encouraged to share this via social media using the hashtag #LetsTalkEpilepsy

6. Meeting Closed