

## All Party Parliamentary Group for Epilepsy Statement: The Impact of Brexit on Epilepsy



The APPG on Epilepsy recently met to discuss the impact that Brexit will have on people with epilepsy. Patients, charities and clinicians raised a number of concerns about the impact of Brexit, particularly a no-deal Brexit. An issue which due to a lack of transparency and ever-changing deadlines is causing significant concern, putting patient safety at risk and impacting on already overstretched epilepsy services.

Key issues outlining the impact Brexit will have on people with epilepsy:

### Medicine shortages

The epilepsy community remain concerned about the impact of Brexit on the supply of anti-epileptic drugs (AEDs). Medicine shortages are already impacting on patients, with varied continuity of supply. The inability to obtain a prescription, as prescribed by an epilepsy specialist puts lives at significant risk and there is worry this will be worsened by Brexit uncertainty.

- Clinicians have informed us that they have increasing numbers of patients experiencing medicine shortages/changes and expressing concern over this issue; something echoed by people living with the condition and their families. This is having a cyclical impact on people with epilepsy, as increased stress can lead to more seizures, increasing the impact on the individual and further increasing their stress.
- Many people with epilepsy require specific brands/types of epilepsy medications in order to control seizures. Changing epilepsy medications (such as in instance of shortage or in the event of activation of a Serious Shortage Protocol) can lead to increased seizures, and can be life-changing and indeed, life-threatening. With 21 epilepsy-related deaths weekly – there is a danger this number could rise further.
  - It is well known not all people with epilepsy (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.
- The government have confirmed that pharmaceutical companies have been asked to maintain a rolling six-week supply. However, a standard prescription lasts for 4 weeks. An extra 2 weeks supply is not sufficient and will not reassure people with epilepsy. A lack of clarity on this, coupled with the knowledge that epilepsy can be fatal (particularly if medication is not taken regularly as prescribed) means many people with epilepsy, their families and clinicians are worried and stockpiling of medication is happened due to fear.
- Currently pricing of medications is quite low but could increase depending on Brexit outcomes, putting further pressure on NHS finances particularly if reliant on non-EU countries for medication supplies.

### Research

Research is an important part of the epilepsy community. It is evident that EU grant funding will change as a result of Brexit, and the impact is already being felt in the research community. Not only will this impact on our knowledge development about the condition, it impacts on our ability to remain at the forefront of epilepsy research. As a result of Brexit, particularly a no-deal Brexit UK:

- Researchers will find it increasingly difficult to be Principal Investigators (leads) on EU funded projects and may face exclusion from multi-site European grants (or the UK will be on unequal footing if eligible to participate)
- There will be a significant impact on the UK's ability to collaborate internationally. For example, the 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.

All Party Parliamentary Group for Epilepsy

Chair: Paula Sherriff MP

Secretariat:



SUDEP Action   
Making every epilepsy death count

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### Workforce

Concerns were also raised about the potential impact of Brexit on the workforce in the NHS. Epilepsy services are already over-stretched and reliant on expertise from EU nationals; Brexit is already impacting on these services and the care they are able to provide to people living with epilepsy. There is concern this will be impacted further if deadlines continue to move, uncertainty remains or in a no-deal Brexit scenario.

- UK Medicine & Research communities attract worldwide input; however, there has been a decrease in applications, and some European clinicians/researchers are leaving due to uncertainty and feeling of rejection linked to Brexit messaging
- There are also concerns 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

As a group we are urging Government to provide clarity on Brexit and to consider the impact continued uncertainty is having on those living with a serious neurological condition. Further action and assurances are needed to ensure that people with epilepsy can be confident that they will be able to continue living safely and independently after Brexit. The APPG will continue to call on the Government to provide these assurances and take action to ensure that people with epilepsy have access to the treatment, services and support they need.