



Dear Boris

The APPG on Epilepsy would like to congratulate you on being elected as the leader of the Conservative Party and Prime Minister. Following your inaugural speech on the steps of Number 10 yesterday where you stated your intention to improve healthcare and ensure funding reaches the frontline of NHS services, I would also like to take this opportunity to highlight the urgent need for prioritisation of epilepsy services and the catastrophic impact lack of prioritisation is having on thousands of people living with this life-altering and life-threatening condition.

Epilepsy, a serious neurological condition, affects around **one in every 103 people in the UK; 1 in 10 people will have a seizure at some point in their livesⁱ**. Every day, 87 people are diagnosed with one of the **40 different types of seizure, with many experiencing different types of seizuresⁱⁱ**.

The consequences of an epilepsy diagnosis are severe and wide-reaching. Diagnosis can result in the loss of a driving licence, loss of employment and a significant impact on education; particularly in those who cannot gain control of their seizures, through treatment such as medication or surgery. For example, currently, only 29.7% of people with epilepsy are in employment, compared to 42.4% in 2008ⁱⁱⁱ and a high proportion of children with epilepsy face academic underachievement^{iv}.

21 people with epilepsy die weekly in the UK (over 1000 a year) – many are young and otherwise healthy people^v. As many as 400 of these annual deaths could be prevented with improved access to information and services^{vi}. 50% of epilepsy deaths are due to Sudden Unexpected Death in Epilepsy (SUDEP); when someone with epilepsy dies and no obvious cause is identified.

People with epilepsy are also more likely to have mental health problems. Around 1 in every 6 people in the UK will have depression^{vii} but if you have epilepsy, this raises to 1 in 3^{viii}. However, only 12.8% of Health Boards and Trusts facilitate mental health provision within epilepsy clinics^{ix}. And among children with epilepsy, research has shown only 13% have access to mental health provision^x, despite being 4 times more likely to develop mental health problems compared to their peers^{xi}.

Neurology is known as the ‘Cinderella service’ of the NHS, facing geographical and socio-economic inequalities highlighted in the 2016 Public Accounts Committee inquiry^{xii}, the 2018 Public Health England report on Neurology Mortality^{xiii} and the recent Neurological Alliance Patient Experience Survey^{xiv}. **The Public Health England report flagged increasing neurology deaths, (increasing by 39% between 2001-2014), despite general deaths rates falling by 6% during the same period;** and that people with epilepsy facing deprivation are at least 3x more likely to die prematurely^{xv}.

Transformation health planning is happening nationally and locally, yet **most areas are not considering epilepsy (or neurology) as a priority.** Despite epilepsy featuring in some national NHS England projects^{xvi}, and despite significant potential to improve patient outcomes^{xvii}. Epilepsy has been the focus of high-profile news recently due to current issues such as medicines shortages^{xviii}, Sodium Valproate^{xix} & medical cannabis^{xx}, **however epilepsy remains highly stigmatised** publicly, and is treated as an invisible illness within the NHS and Government (despite reassurances at ministerial level that work is being done to address the issues being raised here) – this is costing lives and impacting on wider society.

The current burden of epilepsy on health services is significant – 67% of people with epilepsy are not regularly engaged with health services for their epilepsy, yet there are a staggering **100,000 emergency admissions due to epilepsy each year** (many of which could be avoided by empowering condition self-management and access to specialist epilepsy services)^{xxi}. **The cost of epilepsy on the NHS is estimated to be at least £1.5 billion annually**^{xxii}. A national focus on improving outcomes, lives and health and social care services for people with epilepsy could reduce this figure through improving efficiencies, while also benefiting those living with the condition.

The Quality Outcome Framework (QoF) for a yearly epilepsy review in General Practice was dropped without consultation in 2014, and while there are national epilepsy guidelines in place^{xxiii}, and wider national regulations meant to support people with long term health conditions^{xxiv} – there is significant variation in their implementation & in services for people with epilepsy across the UK; having devastating impact on those with epilepsy and their families.

As Chair of the APPG on epilepsy, who has a close relative living with epilepsy, and who is receiving increasing contact from constituents facing challenges and extreme worry due to these issues – this of huge concern. Add to this continuing unclarity regarding Brexit; which is already impacting on people with epilepsy, their families & the clinical and research communities due to: medication shortages and continuity of supply issues; reduced research funding & ability to collaborate with European colleagues; and decreasing epilepsy specialist workforce as headline examples (all of which putting patient safety further at risk) – this matter which cannot remain unchecked.

The APPG on Epilepsy therefore ask that you meet with us in order to discuss these issues and how we can work together to urgently improve the lives of the 600,000 people living with epilepsy in the UK. This is a fantastic opportunity to improve services and outcomes for people with epilepsy, who for too long have not received the healthcare and support they need and the public respect, fairness and understanding they deserve.

Yours sincerely

Paula Sherriff
Chair - APPG on Epilepsy

ⁱ <https://www.aan.com/PressRoom/Home/PressRelease/1371>

ⁱⁱ https://www.epilepsyscotland.org.uk/wpcontent/uploads/2019/05/Joint_Epilepsy_Council_Prevalence_and_Incidence_September_11_3.pdf

ⁱⁱⁱ <https://www.resolutionfoundation.org/app/uploads/2019/01/Setting-the-record-straight-full-employment-report.pdf>

^{iv} Young Epilepsy (2014) *The identification of educational problems in childhood epilepsy*: The Children with Epilepsy in Sussex Schools (CHESS) study.

^v https://sudep.org/sites/default/files/sudep_action_prevent21_summit_report_-_outcomes_recommendations_1.pdf

^{vi} Hanna N J, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, Fish DR (2002) *The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy-death in the shadows*. The Stationery Office

^{vii} <https://www.nice.org.uk/guidance/CG91/ifp/chapter/Depression-and-long-term-physical-health-problems>

^{viii} <http://www.ncbi.nlm.nih.gov/pubmed/22632406>

^{ix} https://www.rcpch.ac.uk/sites/default/files/2019-01/rcpch_epilepsy12_2018_organisational_audit_report_final_web_version.pdf

^x <https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-report-2018>

^{xi} Davies et al (2003)

^{xii} <https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/inquiries/parliament-2015/services-to-people-with-neurological-conditions-progress-review-15-16/>

^{xiii} Public Health England, report into *Deaths Associated with Neurological Conditions*, March 2018

^{xiv} <https://www.neural.org.uk/wp-content/uploads/2019/07/neuro-patience-2019-1.pdf>

^{xv} Thornton J. *Data show big rise in deaths of people with neurological disorders*. British Medical Journal. 2018; 360.

^{xvi} <https://www.neural.org.uk/assets/pdfs/nnag-epilepsy-event-write-up.pdf>

^{xvii} Marson, T (2019) Improving epilepsy care and patient outcomes: <https://www.youtube.com/watch?v=wmfxKncGP8w>

^{xviii} <https://sudep.org/article/mps-express-significant-concerns-over-government%E2%80%99s-medication-serious-shortage-protocols>

^{xix} <https://www.gov.uk/government/news/valproate-banned-without-the-pregnancy-prevention-programme>

^{xx} https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/1821/182105.htm#_idTextAnchor007

^{xxi} Dixon PA, Kirkham JJ, Marson AG, et al, *National Audit of Seizure management in Hospitals (NASH)*: results of the national audit of adult epilepsy in the UK, BMJ Open 2015;5:e007325.

^{xxii} Ibid

^{xxiii} <https://www.nice.org.uk/guidance/cg137>

^{xxiv} [section 100, Children and Families Act 2014]