

The Rt Hon Steve Barclay MP
Secretary of State for Health and Social Care
Department of Health and Social Care,
39 Victoria Street,
London,
SW1H 0EU

15 June 2023

Dear Rt Hon Steve Barclay,

As a group of charities representing the 625,000 people living with epilepsy in the UK, we are writing to you to raise our concerns that epilepsy has not been included in the Major Conditions Strategy.

Neurology, and specifically epilepsy, has long been overlooked for consideration within the wider NHS framework and planning, which has had a negative impact on the provision of epilepsy services. We believe that the strategy should be amended to include neurology as a 7th priority, with a particular focus on epilepsy, given that the condition affects 1 in 100 people in the UK.

Epilepsy, like cancer is complex and includes many co-morbidities and associated conditions, which is why we are asking you to reconsider the inclusion of **epilepsy as a neurological priority**. This condition affects all age groups.

We are aware of a significant number of NHS initiatives, ones which cover health and social care to improve patient experience, quality of services, address workforce requirements and to introduce new surgical initiatives and enhanced use of technology. All of which have the ability to reduce the burden on valuable resources, reduce inequalities and Sudden Unexpected Death in Epilepsy (SUDEP), and pioneer new technologies for people with epilepsy. But these are not co-ordinated and actively monitored against as a priority. Again, if these work streams were pulled together into an **epilepsy priority** the impact would be so much more profound on a UK wide scale, with significant cost reduction and would address health inequalities.

Investment in epilepsy research has been endorsed by the Minister of State for Science, Research and Innovation, George Freeman MP, which again indicates that epilepsy as a condition is a significant health condition in need of recognition. In the 2018 UK Health Data Research Analysis and in [Epilepsy Research UK's #ALifeInterrupted Report](#), research into epilepsy received just 0.3% of the £4.8 billion invested in health-related research by the Government. This we now hope will provide meaningful investment in innovations to treat and prevent epilepsy.

This request to make **epilepsy a priority** is underpinned by a repository of evidence and national work.

People with epilepsy have a [higher mortality rate](#) than the general population and deaths in epilepsy continue to rise and many are known to be [preventable](#) – a fact that has been in the public domain since the National Sentinel Clinical Audit of Epilepsy Deaths in 2002. Certain factors associated with risk of death in people with epilepsy [could be addressed](#) with clinical intervention and more information on self-management. Inclusion of epilepsy in the major conditions strategy would cut avoidable deaths and tackle the systemic inequalities identified in a series of national surveillance reports including most recently the stark findings of [NCEPOD](#) of epilepsy as a 'disordered service' leading to a high level of avoidable emergency admissions.

[A new study](#) presents the most recent incidence of epilepsy (the number of new cases) and the prevalence (the number of people with epilepsy) in the UK. The study identified a connection between more deprived areas and a higher level of epilepsy. People in the most deprived areas of the UK are more than a third more likely to have epilepsy than those in the least deprived areas.

Many people with epilepsy live with other associated conditions. For example, approximately 32% of people who have a mild to moderate learning disability also have epilepsy. The more severe the learning disability, the more likely that the person will also have epilepsy. This link is more prevalent among children. [It is estimated that](#) 40% of children with epilepsy have a learning disability, 21% are autistic and 33% have ADHD. Children with epilepsy are also [four times more likely](#) to have a mental health problem than their peers.

People with epilepsy also have one of the lowest employment rates of all disabilities and health conditions, with only 42% of working age people with epilepsy in employment. [[Disability and employment - Office for National Statistics \(ons.gov.uk\)](#)]

Epilepsy is associated with high levels of [educational difficulties](#). However, despite [statutory guidance on supporting pupils with medical conditions](#), over a third of children with epilepsy (36%) [did not get the support they needed for full participation in school life](#) in the 21/22 academic year.

There are many epilepsy medications that pose a risk of causing harm to the unborn child if taken during pregnancy, as identified by the 2021 safety review carried out by the Medicines and Healthcare products Regulatory Agency (MHRA). However, the results of a [survey](#) carried out by Epilepsy Action, Epilepsy Society and Young Epilepsy, showed that 33% of women taking carbamazepine, topiramate, pregabalin, phenytoin, or phenobarbital didn't know they increase the risk of physical birth abnormalities (if taken during pregnancy).

In addition, concerns have been raised by all epilepsy charities ([correspondence as sent 23rd March 2023](#)) relating to the new measures proposed by MHRA for the prescribing of valproate and the impact this will have on patient safety and available resources. Who on behalf of the government or NHS will be monitoring these changes if it is not a priority condition?

There is focus on some areas of epilepsy care throughout the NHS, such as:

- Data on unplanned hospitalisations for epilepsy in under-19s is one of the [NHS Outcomes Framework](#) indicators.
- Epilepsy is an area of focus in the [CORE20PLUS5](#) health inequalities NHS framework for children and young people.
- NHS England's CYP Transformation Programme is progressing commitments made in the Long-Term Plan, including strengthening paediatric clinical networks for long-term conditions such as epilepsy. NHS England recommendations for paediatric epilepsy care are currently being developed, which seek to address many of the challenges identified above.
- Programmes of national audit and best practice all presenting outcome measures to improve service delivery and patient outcomes e.g. NCEPOD, Get it Right First Time (GIRFT), NICE clinical guidance

Focus on the NHS Children & Young People transition work has demonstrated that focussed, targeted work has the ability to significantly improve health outcomes, predominantly in health inequalities and resource allocation. This needs to be part of an adult service review.


The Major Conditions Strategy has the opportunity to capture all of this work through its strategic focus and provides a potential to level-up funding for epilepsy care. By adopting national performance and patient outcome measures the inequalities, health and social expenditure can be

evaluated and targeted to deliver work force planning, appropriate cost-effective care and treatments for people with epilepsy.

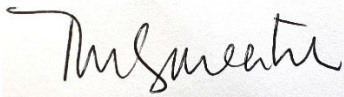
Given the unique and specific challenges facing epilepsy services, and people with epilepsy, it is an opportunity to revisit the Major Conditions Strategy and include **epilepsy as a focus within a neurological priority**.

We would welcome a commitment from the Department of Health and Social Care that this submission be acknowledged and more importantly given serious consideration.

Yours sincerely,



Alison Fuller
Director of Health Improvement & Influencing
Epilepsy Action



Maxine Smeaton
Chief Executive
Epilepsy Research UK



Rosemarie Pardington
Director of Health, Research & Compliance/Deputy CEO
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