

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

December 21st 2018

Dear Rt Honourable Matt Hancock MP

Emergency Planning: Epilepsy medications

The Government's planned use of "serious shortage protocols" as emergency powers to authorise pharmacists to overrule medical prescriptions (**'Ministers will order pharmacists to ration drugs if UK crashes out'** - The Times, 7th December 2018), is frightening, with a no deal Brexit being a scenario that risks national shortage in the very near future. Epilepsy affects 600,000 people in the UK, and people with epilepsy risk developing new seizures if their usual medication is altered.

There are at least 21 epilepsy-related deaths each week, many in the young. Abrupt or unsupported medication changes, or stopping of medication, are flagged regularly as un-managed risks in surveillance and audits of epilepsy-related deaths (including over half of recent deaths in pregnant women) as well as fatal accident inquiries. Many of these untimely deaths can be avoided and, in this regard, treatment of this life-threatening condition is essential.

It is of huge concern to learn about a planned contingency measure that has the potential to make matters worse.

The decision about the best drug treatment for epilepsy should be worked out in partnership between doctor and patient over time. No change to a prescription should be made without checking with the prescribing clinician and the patient. Notwithstanding, the accepted norms of the doctor patient relationship, legislation should not be side-stepped by ministers. The categories of risk are clearly stated on the <https://www.gov.uk/drug-safety-update/antiepileptic-drugs-updated-advice-on-switching-between-different-manufacturers-products>

The lack of a published risk assessment and communication plan for the proposed emergency powers is an unacceptable risk to anyone with a long-term condition and should be recognised as such by anyone considering contingency powers.

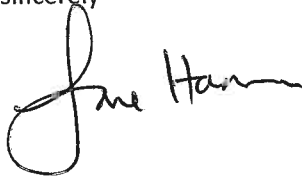
In light of the upcoming Brexit-debates, we call for consideration and action to address the likelihood of medicines shortages in the near future, and the risk this would present for patients. We urgently need reassurance that there will be openness and transparency on planned emergency powers;

formal consultation with organisations that have signed this letter and open to all affected organisations and meaningful parliamentary scrutiny.

In the meantime, the sector needs clear communication of the recognised risk and acceptable measures set in place that take account of the treatment needs of patients with serious long-term conditions like epilepsy.

We look forward to your response.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Jane Hanna', with a large, stylized initial 'J'.

Jane Hanna OBE, CEO of SUDEP Action (linked charity Epilepsy Bereaved)

On behalf of

John Hirst CBE, Chair of SUDEP Action (linked charity Epilepsy Bereaved)

Phil Lee, CEO of Epilepsy Action

Carol Long, CEO of Young Epilepsy

Maxine Smeaton, CEO of Epilepsy Research UK

Sarah Vibert, CEO Neurological Alliance

Professor Matthew Walker, President of the British Branch of the International League Against Epilepsy

Professor John Paul Leach, Immediate Past President of the British Branch of the International League Against Epilepsy

Professor Phil Smith, Immediate Past President of Association of British Neurologists

Phil Tittensor, Chair of Epilepsy Specialist Nurses Association

cc. Sarah Wollastan MP, Chair of the Health Select Committee

cc. Paula Sheriff MP, Chair of the All Party Parliamentary Group on Epilepsy