

Dear Sir

Re: Plea from patients and clinicians for rethink on emergency plans for medicines

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. We predict unnecessary deaths resulting from the use of these emergency powers.

There are 21 epilepsy-related deaths each week, many in the young. Abrupt or unsupported medication changes, or stopping of medication, are flagged regularly in - fatal accident inquiries, surveillance and audits of epilepsy-related deaths (including over half of recent deaths in pregnant women) - as vital risk factors which need careful management. 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 lack of a published risk assessment and communication plan 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 across government and across political parties to address the likelihood of medicine shortages in the near future, and the risk this would present for patients. We call for 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, there should be 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.

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

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

Sarah Vibert, CEO, The Neurological Alliance

Phil Lee, Chief Executive, Epilepsy Action

Chair of Young Epilepsy

Paula Sherriff MP, Chair of the All Party Parliamentary Group for Epilepsy

Maxine Smeaton, CEO, Epilepsy Research UK

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

Mr Phil Tittensor, Chair of Epilepsy Specialist Nurses Association

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

Norman Lamb MP

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