



The Rt Hon Wes Streeting MP
Secretary of State for Health and Social Care
Department of Health and Social Care,
39 Victoria Street,
London,
SW1H 0EU
By email: dhsc.sofs@dhsc.gov.uk

1 August 2024

Dear Mr Streeting,

RE: Request for urgent meeting to discuss critical medicine supply issues

Congratulations on your appointment as the new Secretary of State for Health and Social Care. We are a group of charities keen to meet with you to urgently address medication shortages and the impact on people living with epilepsy and Parkinson's, where a consistent supply of medicine is vital to maintaining well-being and safety.

As you may be aware, medication shortages are a serious ongoing issue for people with long-term health conditions.

A recent [report](#) by the Nuffield Trust showed that medication shortages had become the 'new normal' in post-Brexit Britain, with a 'shock rise' in shortages of life-saving drugs such as anti-seizure medications.

In the last three years, the number of drug shortages reported by drug companies has doubled. Price concessions have risen sharply, with products costing £220 million more within one year. And the UK's ability to respond to shortages has been severely weakened by its split from the EU.

Despite efforts to date by the Department of Health and Social Care and NHS England to improve and resolve the medicine supply issues for people with epilepsy and Parkinson's, patients continue to be significantly impacted by ongoing supply chain issues. This has been highlighted extensively in the media, including reports by the BBC, Sky, ITV, and Channel 5 News. Urgent action is required to provide a permanent solution.

Impact on people with epilepsy and Parkinson's

In recent months, helplines at Epilepsy Society, Epilepsy Action, SUDEP Action and Parkinson's UK have been inundated with calls from people who are desperate to find a pharmacy that can fulfil their prescriptions. People are being forced to travel miles and visit multiple pharmacies before they are able to access their medication.

All too often they are being asked to make do with a fraction of the medication required, or to switch brands – which can be problematic for people with both conditions. The stress and uncertainty are causing seizures in people with epilepsy which impact employment, education, and the ability to drive, halting many people's lives.

Seizures can be fatal, but many epilepsy deaths are preventable, with regular access to medication being the first line of defence. Sadly, many people are not getting a regular

epilepsy review and are therefore unaware of the potential risks posed by a lack of medication.

This spring, we conducted a survey of almost 1500 people with epilepsy and Parkinson's to understand the full extent of the problem and the results were very worrying:

- **70%** of respondents have had difficulties getting vital medication over the past year
- **22%** report problems in the previous month
- **55%** had to visit multiple pharmacies before getting hold of their medication
- **66%** were only given a fraction of the amount that was on their prescription until more supplies were available
- **40%** saw a worsening of symptoms that they attributed to the stress of trying to get their prescription filled
- Almost **40%** of respondents with epilepsy reported having seizures induced by having to switch or skip medication
- **36%** of respondents with Parkinson's said that facing this difficult choice led to their symptoms worsening

It makes for very grim reading and the problem is not new.

Preparation for Brexit meant that all drug manufacturers were required to have a minimum six-week stockpile of medications to ensure continuous supply for patients. It showed that the system could work more efficiently when challenged. Today, it would seem that the industry has reverted to a 'just-in-time' model. We appreciate that the problem is multifactorial and that the supply chain is complex. But so are epilepsy and Parkinson's.

The two conditions both pose huge challenges for people on a daily basis, but the one given is that they should be able to access – without question – their life-saving medication.

We believe that the whole of the medicines supply chain needs urgently reviewing. We need clarity and a guarantee that pharmacists will be able to dispense the medications people with long-term health conditions desperately need..

On behalf of the 800,000 people with epilepsy and Parkinson's in the UK, as the newly appointed Health Secretary, we would urge you to meet with us to discuss the worrying issue of medicine supply and develop long-term solutions to resolve this critical problem.

Yours sincerely,

Nicola Swanborough, Head of External Affairs, Epilepsy Society
Alison Fuller, Director of Health Improvement and Influencing, Epilepsy Action
Jane Hanna OBE, Director of Policy and Influencing, SUDEP Action
Juliet Tizzard, Parkinson's UK