

Rt Hon Dr Thérèse Coffey MP, Secretary of State for Health and Social Care  
Department of Health and Social Care  
39 Victoria Street  
London  
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7 September 2022

Dear Secretary of State

### **Working together to back the one in six people in the UK with a neurological condition**

Many congratulations on your appointment as Secretary of State for Health and Social Care and Deputy Prime Minister. This is a challenging time for many, including the one in six people in the UK who live with a neurological condition. As an Alliance, we stand ready to work with Government to deliver much needed improvements to services and support for our community.

The Neurological Alliance is a coalition of almost 90 organisations with a shared vision of ensuring every person affected by a neurological condition can access the right treatment, care and support at the right time. Our members cover the whole neuroscience speciality, from household names such as Parkinson's UK and MS Society to small volunteer-led organisations and those representing rare neurological conditions as well as leading professional bodies and regional Alliances.

One in six of us live with a neurological condition. This number is rising and will continue to increase, due in large part to our ageing population as well as advances in healthcare and treatment. There are over 600 identified neurological conditions. These include sudden onset conditions like Acquired Brain Injury (ABI) or Guillain-Barre syndrome, Intermittent conditions such as epilepsy or cavernoma, progressive conditions including Parkinson's disease or ataxia and stable conditions with changing needs like transverse myelitis or cerebral palsy.

My Neuro Survey, our biennial national neurological patient experience survey of over 8,500 people with neurological conditions, highlighted many common challenges facing the one in six with a clear thread throughout – there simply isn't the workforce or services in place to provide the support they need.

On mental health and wellbeing, four in ten respondents reported their needs are not being met at all. Most people reported delays to treatment and care with over half of adults and six in ten children and young people experiencing delays to appointments with specialists in the last year. This must change.

We welcome ongoing initiatives such as the ABI Strategy and NHS England and NHS Improvement Neuroscience Transformation Programme, both of which the Alliance continues to support and engage as a critical friend.

However there remains insufficient coordination of such initiatives, little leadership or prioritisation at the highest levels of government to support their implementation and very limited opportunities to share learning across systems.

**The Neurological Alliance is a charity registered by the Charity Commission for England and Wales (registration number 1039034) and a company limited by guarantee registered in England (registration number 2939840).**

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 The Neurological Alliance

Together with over 100 organisations, more than 13,000 people and Neurological Alliances across the UK, we're calling for a Neuro Taskforce to address common challenges and deliver real change.

The Taskforce would provide a framework to support greater collaboration and sharing of best practice. It would build on similar policy approaches in health and care, such as the recent Rare Disease Framework and associated implementation plans. Fundamentally, and most importantly, it would help to show that governments across the UK are listening to people affected by neurological conditions.

Action to address these common challenges is long overdue and now more urgent than ever. Over 255,000 people in England were waiting for either a neurology or neurosurgery appointment on the NHS in June 2022, an 85% increase since June 2020. These delays to treatment and care can be lifechanging.

Alongside challenges in accessing services and growing waiting lists is a worsening cost-of-living crisis that is disproportionately impacting those with disabilities and long-term conditions, including people with neurological conditions, as we head towards winter.

We would be delighted to meet to discuss how we can work together to improve services and support for the one in six people with a neurological condition including through establishing a Neuro Taskforce.

As an Alliance and as a community we are committed to working with your department and wider government, together with people with neurological conditions and those closest to them, to deliver real change.

Yours faithfully



Georgina Carr  
Chief Executive  
The Neurological Alliance (England)