



The Rt Hon Boris Johnson MP, Prime Minister  
10 Downing Street  
London  
SW1A 2AA

25<sup>th</sup> July 2019

Dear Prime Minister,

Please accept my congratulations on your appointment as Prime Minister. After our time together at City Hall (I briefed you on strategic projects/policy evaluation) I'm rather pleased to have experience working with the UK's new 'head honcho'.

I am now Chief Executive of The Neurological Alliance – a coalition of 80 organisations campaigning together to transform outcomes for people with neurological conditions. You may not have heard of us before but may know of some of our members (e.g. Sue Ryder, Parkinson's UK, MS Society) and will certainly know of conditions we represent such as dementia, epilepsy and stroke. According to our latest estimates, there are around 12 million people living with a neurological condition in England – more than diabetes, more than cancer. There are over 600 types of neurological disease (conditions of the brain, spinal cord and nerves). Many of these are very rare, and some are particularly distressing – such as Batten Disease which is a terminal form of childhood dementia that your colleague Jacob Rees-Mogg MP has most helpfully drawn attention to in The House of late.

We want to flag up to you, and your health team, the looming burden of neurological disease coming down the track, and the repercussions on the NHS and beyond. The number of people living with neurological conditions in England is rising and will continue to increase, due in large part to our ageing population – as well as advances in other areas of health care. There is an associated increasing trend in deaths associated with neurological conditions: 39% increase in neurological deaths compared to 6% decrease in all-cause deaths since 2001. Neurology accounts for significant – and increasing – NHS activity and spending in England – over £4.4 billion at last count. And people with neurological conditions report the lowest health-related quality of life of any long-term condition. Back in 2016 the Public Accounts Committee concluded that there had been insufficient progress in improving neurological services since it first investigated in 2012. Our 2019 survey of over 10,000 people with neurological conditions suggests that the experience on the ground is yet to improve.

In your first full speech as Prime Minister, you spoke of your responsibilities in relation to ensuring that people don't have to wait three weeks for a GP appointment. We commend this and wanted to additionally flag that once people have seen their GP, if they need to see a specialist they ought to be referred as quickly as possible. Our aforementioned patient experience survey found that 39% of people saw their GP five or more times before being told they needed to see a neurological specialist (with wide regional variation), and one in three waited more than 12 months for an appointment with a neurologist, after being referred. Early diagnosis by a specialist can result in appropriate treatment and symptom management being in place sooner, less irreversible neurological damage and associated disability, thus reducing wider repercussions on an individual's life, such as job loss. As well as freeing up GP appointments and reducing pressure on A&E.

In order to meet the growing challenges to the NHS and improve outcomes for people with neurological conditions, we're calling for national plan for neurology in England. We have been engaging with NHS England over this matter and are hopeful of a positive response. England must not be allowed to fall behind Scotland, which already has such a plan in place to address the challenge of neurological disease.

We were very pleased indeed to hear your commitment to resolve the social care crisis, and your intention to take personal responsibility for this. Our research found that 38% of people with neurological conditions reported their social care needs are not being met at all. After so many green papers, and countless people still having their needs underserved, at great distress to them and their families and friends, resolution cannot come too soon and must become a government priority. We would encourage the team you are putting together on this to engage with the Care and Support Alliance at the earliest opportunity. We also want to ensure the needs of working aged people with social care needs are not lost in policy discussions.

I hope that the new government you are putting together will take the burden of neurological disease seriously, and that your health team affords it the focus needed to prevent a growing burden. We look forward to working productively with them on this and would welcome the opportunity for a meeting with Matt Hancock's team.

Best regards,

Sarah Vibert  
Chief Executive  
The Neurological Alliance

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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