

15 April 2020

Dear Mr Fitzpatrick,

I hope this letter finds you well in these incredibly challenging times. The Neurological Alliance has been encouraged by the ongoing dialogue and information sharing between ourselves and the Scottish Government, and it is in the spirit of this openness that I write to you today.

On Thursday 2 April we held a virtual members' meeting, which was joined by 14 of our members. As you can imagine there were many concerns shared across the neurological community, and I wanted to take this opportunity to share a few of those with you.

One of the key issues shared across the membership and conditions was the current risk to neurological services, with many members reporting that their condition specific health professionals had already been redeployed. While there is a complete understanding that the NHS is working under an unimaginable pressure, we are already receiving a high volume of communication from our communities who are incredibly anxious about how their (often degenerative) conditions will progress and de-stabilise without the treatments and services they currently receive. We are also concerned for those who are awaiting diagnosis or initial referral to neuro services. Since that meeting, we have heard from the Interim Chief Medical Officer, Dr Gregor Smith, that the NHS "remains open" for people who have worrying symptoms other than Covid-19, and we know that our members will be interested to know how this fits with ongoing access to specialist neurological support when it is needed.

There was also a concern that, because people had less access to their neuro professionals, the risk of their health deteriorating was higher and therefore it was more likely that hospital admissions would be needed. It was felt by the membership that there was an immediate risk for those with neurological conditions, but also a longer term impact to loss of services. There were questions of how long it would be before redeployed posts would return to neuro services.

We also had concerns about the impact of the Covid-19 (Scotland) Act on discharge plans for those with neurological conditions. There was a concern that people with neurological conditions may be discharged too quickly, without adequate community support in place, which may put them – and any unpaid carers - at huge risk.

We wanted to raise with you the issues faced by those with neurological conditions who have been identified as vulnerable but who are not included within the shielding group. We welcome the launch of the national helpline which will offer much needed support to some people in this group. However, for those living with - and often

caring for - these people, this will not provide the evidence they need to be able to insist on working from home in the way the shielding letter does. While we understand why a 'blanket approach' hasn't been taken for those with neurological conditions, we are leaving a significant proportion of people in a situation that puts them at significant risk, both of contracting Covid-19 but also their carers becoming unwell and no longer being able to support them.

The final issue we wanted to raise was around the ability of those to comply with social distancing requirements -and by default the shielding programme- if they have cognitive impairments as a result of their neurological condition. We need to ensure that other agencies such as the police -who may respond to someone with cognitive impairment in this situation -have an understanding of the challenges faced by this group and respond proportionately and appropriately.

We would welcome a further conversation about how we can address these concerns of the neurological community, and look forward to working with you going forward.

Yours sincerely,

Rebecca Duff

Chair Neurological Alliance of Scotland