**Neurological Alliance: Submission to Department of Health and Social Care Inquiry into Delivering core NHS and care services during the pandemic and beyond**

7 May 2020

**Introduction**

The Neurological Alliance is a coalition of more than 80 organisations working together to transform outcomes for the millions of people in England with neurological conditions – disorders of the brain, spinal cord or nerves. One in six people in England now have one or more neurological conditions. According to the latest estimates, the total number of people with a neurological condition in England has now reached 16.5 million[[1]](#endnote-1).

Neurological conditions can have a wide range of causes including genetic and environmental factors - or can be caused by traumatic injury or infection. The Neurological Alliance (hereafter called the Alliance) campaigns for high quality care and support to meet the individual needs of every person with a neurological condition, at every stage of their life. We represent a wide variety of charities and groups, some who support people with relatively common neurological conditions such as multiple sclerosis and motor neurone disease, and others who support people with rare neurological conditions, such as Guillain-Barré syndrome. You can find a full list of our Members [here.](https://www.neural.org.uk/our-members/) Our work is shaped by the experiences of all people with a neurological condition and aims to address the underlying causes of poor care. People with neurological conditions often feel like a forgotten group.

Notwithstanding the COVID-19 pandemic**,** people with neurological conditions can have difficulty accessing the specialist care they need.For example, our 2018/2019 National Neurological Patient Experience Survey[[2]](#endnote-2) (England only) found that almost 40% of respondents said they had visited their GP five or more times before being referred to a neurologist. Variations in care also exist: the same Patient Survey found that people living in the most deprived areas experienced the longest waits for specialist neurology services, compared to those living in more affluent areas.

Finally, neurological conditions can also have a significant impact on quality of life.In our 2018/2019 Patient Survey, 46% of respondents said that their neurological condition affected their quality of life to a great extent.

* **Even without the changes to health and care services caused by the COVID-19 pandemic, people with neurological conditions and their carers face significant challenges, often unseen by the rest of society. Too often, access to the right treatment, care or support is dictated by where people live or their financial circumstances: this has to change. Redressing unwarranted variation in treatment,**

**care and support should be at the heart of restarting health and care services for people.**

1. **To achieve an appropriate balance between coronavirus and ‘ordinary’ health and care demand.**

Achieving an appropriate balance between COVID-19 and non-COVID-19 care has not always been possible since NHS services have been reconfigured in the wake of the pandemic. Whilst this is understandable, as significant NHS resources had to be diverted towards meeting the urgent needs of the rising number of COVID-19 patients - and the scale of the need was not known at the outset - there is no doubt that **people with neurological conditions have experienced a significant reduction in their levels of routine care and rehabilitation.**

In fact, only skeleton neurological services now remain in many secondary care settings: we have heard of situations where some nurses are single-handedly running outpatient clinics which otherwise would have been staffed by much larger multidisciplinary teams, often without adequate PPE. More commonly, outpatient services are now being provided via telemedicine (video or telephone).

This is clearly going to have an impact on the health and wellbeing of people with neurological conditions who may not be able to access their routine treatment and care, particularly the aspects of their care that ideally require routine ‘hands-on’ treatment, for example physiotherapy. It is important that a rigorous evidence-based impact assessment is made of how these skeleton services and telemedicine appointments are affecting the outcomes of people with neurological conditions, and what measures are being put in place to ensure that **scaled back services remain in** **operation for the minimum length of time possible.** The Association of British Neurologists has produced welcome guidance with partners such as the Royal College of Physicians (RCP), to provide support to their members and patients on how best to safely reconfigure services during the pandemic[[3]](#endnote-3).

* **Reduced or ‘thinned out’ services for people with neurological conditions must not become the new norm as this will only result in worse patient outcomes and higher costs to the NHS as patients run the risk of their condition deteriorating in the longer term.**

More specifically, the Alliance has heard from its members of:

* Pressure to cancel neurosurgery and thrombectomy appointments.
* People with **multiple sclerosis** experiencing significant delays to the initiation of disease modifying therapies (DMTs) and/or the administration of routine infusions, in some

parts of England. This could have a significant impact on the progression of their condition and potentially lead them to have a relapse, also causing additional stress and anxiety to patients. The MS Society has told us that some delays are clinically justified,

* where treatment cannot, for example, be started because it risks compromising the immunity of the patient, thereby putting them at increased risk of catching COVID-19. The Alliance does not, however, believe that it is reasonable to cancel or postpone vital infusion services beyond what is clinically safe and where the long-term health and wellbeing of patients is at risk.
* People with **motor neurone disease** having routine proceedings postponed indefinitely e.g. gastric feeding and ventilation. There is no reason why non-invasive ventilation (NIV) services should not be kept running so long as suitable infection control measures are taken in outpatient departments. People with motor neurone disease are also very concerned that they will not receive ventilation support, in the event that they contract COVID-19 and need to go to hospital, which may prevent them seeking emergency assistance if needed.
* Outpatient services for people with **epilepsy** being reduced to a skeleton service. Epilepsy Action have also told us that:
* Some people with suspected first seizures are experiencing delays to receiving an accurate diagnosis and subsequent treatment plans (and medication) in the light of greatly reduced epilepsy services in some hospitals and Trusts. While teleclinics are suitable for many existing epilepsy patients, diagnosis and, in particular, more complex diagnosis, can be very challenging to deliver through teleclinics, an issue that is also of concern to some neurologists.
* There is reduced capacity for, and availability of diagnostic testing, including electroencephalograms (EEGs) which are sometimes needed to assist in accurate epilepsy diagnoses. This both represents a potentially increased risk to people with suspected first seizures in the short term, and means there will a backlog of patients requiring these services in the longer term, with further subsequent delays to accurate diagnoses when normal services start to resume. More generally, there are some interventions that cannot be delivered through teleclincs or during periods of reduced service provision, including Vagus Nerve Stimulation (VNS) adjustments and changes to medication, with an associated impact on patients.
* Large-scale redeployment of epilepsy specialist nurses to general medicine and COVID-19 wards, combined with staff sickness, is causing challenges for some people with epilepsy. Epilepsy specialist nurses (ESNs) are often the first point of contact for people with epilepsy who require advice or support related to their condition. Some hospitals and Trusts currently have no ESN contacts for people with epilepsy with answerphone messages stating that services are not available at present, leading to

potential increased risk and distress. While some regions are continuing to provide a reduced ESN telephone services or SOS services, these are suboptimal options and could present a potential increased risk to people with epilepsy. The crucial role of

epilepsy specialist nurses in caring for and supporting people with epilepsy was set out in a recent Epilepsy Action report[[4]](#endnote-4).

* A non-mobile person waiting eight months for an outpatient rheumatology appointment - for suspected auto-immune disease with neurological deficits - being told that their neurology appointments have now been cancelled due to the COVID-19 outbreak, leading to a decline in their condition. This person is totally dependent on a carer who is also on the extremely vulnerable list. To date we have been told that no help has been received concerning the delivery of their repeat medication, although if the carer cannot shield themselves, both will be at risk.
* To treat **dystonia** (a condition characterised by uncontrollable and sometimes painful muscle spasms) most clinics providing botulinum toxin injections - one of the main treatments for dystonia - are being cancelled; these injections are normally administered around every 12 weeks in clinics. While it is perhaps understandable that, because of patient safety and redeployment of staff in the NHS, most of these clinics have been cancelled, this does raise several concerns according to Dystonia UK:
* Not receiving their botulinum toxin injections can leave dystonia patients in pain and with more disabling symptoms. No alternative treatments have been offered while most of the clinics are closed. While many outpatient appointments are currently being delivered via phone or video consultations, because this treatment involves injections, this is not possible.
* People with dystonia already often experience long delays in accessing treatment in over-subscribed clinics, but now, during the pandemic, there is an even wider variation in care with very few clinics still operating in some locations, while none are operating in others, leading to significant variations in treatment.
* Communication of appointments being cancelled has often happened just a day or two beforehand, leaving patients worried and uncertain about future appointments and left to find ways to cope without their normal appointments and care.
* There is uncertainty about the resumption of clinics and how this will be managed. As mentioned, these services are normally over-subscribed and the expectation is that there will now be an increase of patients needing routine treatment as clinics seek to clear the backlog built up during the lockdown.
* All of the above can cause significant mental distress to people with dystonia.
* As mentioned above concerning epilepsy, the Alliance has heard, more generally, of instances where people have been given a new diagnosis of a progressive neurological

condition over the phone, which would normally be done face to face. Being given the diagnosis of a potentially life-limiting or degenerative condition on the phone, when complex, important and life-changing information is being shared with patients, is far

from ideal. In addition, healthcare professionals who are delivering such diagnoses may not have received training and support in now to deliver such a diagnosis over the phone or via videoconference. In principle, all people with new neurological symptoms should be able to access primary and secondary neurological services in a timely fashion, even during the COVID-19 pandemic.

* For people with **spinal muscular atrophy**, Spinal Muscular Atrophy UK tell us that some routine outpatient clinical appointments have also been cancelled or postponed; while people understand why, they have concerns that early detection of breathing problems, swallowing and feeding issues, contractures and development of scoliosis may be missed. Telephone or video appointments again go some way to addressing this where arranged, but waiting times are already long and people are concerned that any ‘backlog’ will have a knock-on effect for many months to come.
* It now appears that a significant percentage of people with COVID-19 in ITU (maybe up to 35% of cases[[5]](#endnote-5)) have some neurological symptoms, including being at an increased risk of stroke and functional neurological problems. This must be reflected in **additional service provision post-COVID-19,** in terms of commissioning adequate neurological health and care services, particularly rehabilitation services. There is now an Association of British Neurologists (ABN) reporting tool for suspected neurological complications in patient with COVID-19 (RADAR) [[6]](#endnote-6). The ABN requests that all members track suspected neurological complications of COVID-19 infection via RADAR, whether short-, medium-, or longer-term neurological symptoms or conditions.
* **Data needs to be collected on all NHS neurology service cancellations within Trusts and on the numbers of patients affected so optimal services can be reinstated with an adequate workforce.**
* **It is important that an ongoing impact assessment is made of how these skeleton services are affecting the health and outcomes of people with neurological conditions and what measures are being put in place to ensure that scaled back services remain in operation for the minimum length of time possible.**

1. **Meeting the wave of pent-up demand for health and care services that have been delayed due to the coronavirus outbreak**

Given the above there will be almost certainly be a significant backlog in delivering some medical treatments which could have a long-term impact on the physical and mental health of people with neurological conditions. The Association of British Neurologists and the Royal College of Physicians have considered how to manage the return to more normal service for people with neurological conditions[[7]](#endnote-7) and they should be involved in how best to address and prioritise the backlog of patients in order that:

* **The most urgent neurological cases are prioritised according to agreed and validated tools, procedures and pathways.**
* **Cancelled procedures such as infusions are reinstated as quickly as is safely possible, bearing in mind the long-term risks to health of not doing so.**
* **New diagnoses are prioritised, delivered in face-to-face consultations.**
* **Telemedicine is used appropriately but never seen as substitute for high-quality care where face to face appointments deliver better outcomes.**
* **People who do not have access to the appropriate technology (e.g. a computer) are not unfairly disadvantaged through the anticipated more widespread use of telemedicine for routine appointments.**

1. **Meeting extra demand for mental health services as a result of the societal and economic impacts of lockdown**

Neurological conditions relate to the brain and nervous system. So, the interaction between physical needs and broader emotional, cognitive and mental health needs is complex. Changes in the brain can directly affect a person’s emotions, cognitive abilities and executive functioning. Conversely, depression or anxiety can coexist alongside neurological symptoms. People’s mental health difficulties often have an impact on their neurological condition, triggering or exacerbating it. In other cases, apparent mental health issues may reflect an undiagnosed neurological condition. For people with functional or dissociative conditions ‘neurological’ symptoms are not caused by structural changes in the brain. Providing accurate diagnosis and effective treatment for emotional, cognitive or mental health needs is challenging, but essential for people with neurological conditions.

Some neurological conditions significantly affect the cognitive function of those affected, for example autism, making it harder for them to understand the need for social distancing. People with some neurodevelopmental conditions (NDC) are also at greater risk of developing mental health difficulties. Many people with NDCs, for example, struggle with anxiety, managing uncertainty and social isolation, and the current situation is exacerbating those significant challenges for them and their families/carers.

It is also known that many people with epilepsy face an increased risk of poor mental health, including anxiety and depression. This is likely to be exacerbated by prolonged periods of social distancing and self-isolation especially when combined with a lack of access to ESN support (mentioned above). Stress and anxiety can be a seizure trigger for some people with epilepsy, potentially contributing to worsening seizure control.

If people are living on their own with conditions such as multiple sclerosis and Parkinson’s, anxiety around securing their regular medication and food supplies, and not having as many, if any, regular visitors because of the need for social distancing, is almost certain to have had a significant psychological impact in terms of engendering a sense of isolation and loneliness.

* **Consideration should urgently be given to prioritising access to mental health services for all people with neurological conditions after the peak of the COVID-19 crisis, as they are likely be at increased risk of having mental health complications following the social distancing and other measures introduced.**
* **Mental health services should be provided holistically as part of a person’s overall care, delivered by multi-disciplinary teams.**

1. **Meeting the needs of rapidly discharged hospital patients with a higher level of complexity**

Rehabilitation is critical for the long-term recovery of people who have, for example, had a stroke or brain injury, as well as minimising the long-term impact of progressive neurological conditions. We are aware of instances where people who were receiving a programme of neurorehabilitation in hospital or via speciality neurological centres, were sent home early, potentially affecting the long-term progression of their condition and their best possible chance of recovery. Physiotherapists are, understandably, rarely able to visit people in their own homes because of the risk to people with progressive neurological conditions or traumatic brain injury of catching COVID-19, meaning many rehabilitation services are being put on hold. Some physiotherapy and speech and language therapy sessions are being successfully delivered via telemedicine. However, we are hearing that some rehabilitation services requiring close face to face contact are simply not happening and being put on hold because of the lack of PPE. This is clearly not acceptable.

Cancelled rehabilitation services are likely to lead to greater NHS and social care costs being incurred in the longer term: we know that high-quality rehabilitation saves the NHS money. People with traumatic brain injuries who receive intensive rehabilitation once they have left an acute hospital ward cost the NHS and social care less each year than those who do not receive such services. For example, the Final Audit Report on Specialist Rehabilitation

Following Major Injury (April 2019) found that the mean net life-time savings from specialist rehabilitation amounted to £504,106 per patient[[8]](#endnote-8).

Without providing catch up and intensive rehab, people who have for example suffered brain injury will not make as good a recovery, meaning they may not be able to work and they will require more support in the longer term. It will also lead them to experience a significantly poorer quality of life which can cause mental health problems.

* **Pandemic planning should include setting up contingency measures so people requiring urgent neurorehabilitation are still able to access that, for example at non-COVID-19 treating NHS sites.**
* **Data must be collected about the provision of rehabilitation over time, in particular, how provision may have changed or been reduced/cancelled as a result of COVID-19. This is essential as rehabilitation must not become an add-on extra, but be seen as an essential component of care, enabling people with progressive or sudden-onset neurological conditions to attain maximum recovery of function. Rehabilitation services are NHS money very well spent.**

1. **Providing healthcare to vulnerable groups who are shielding**

In fact, the Alliance is very concerned, as are many of our members, that people with some progressive and life-limiting neurological conditions, such as motor neurone disease and multiple system atrophy, which compromise people’s ability to live independently, and which have a significant impact on their health and wellbeing, were not included on the Government’s ‘extremely vulnerable’ list. We understand that some people with neurological conditions have been added to the list, but data on the conditions people have who *have* been added to the ‘extremely vulnerable’ list is not, as we understand it, available. The concern is that decisions about who qualifies to be added to this list may have been applied differently in different areas.

In addition, errors within the data have now emerged: it is estimated that 100,000 people received a shielding letter despite not needing to[[9]](#endnote-9). Our members have also reported considerable confusion amongst people with neurological conditions about whether or not they ought to be ‘shielding’, and indeed the additional support they ought to be able to access.

Our key concerns around healthcare for people with neurological conditions are set out in section 1 above. The Alliance understands that some people with neurological conditions have been extremely reluctant to seek emergency care, for example for seizures or a stroke, because of fears around catching COVID-19 in hospital and potentially being asked to sign Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) Orders. We have heard, anecdotally, of people with neurological conditions coming into A&E in a ‘worse condition’

that clinicians have ever seen because of a fear of catching the virus. The COVID-19 pandemic and the reconfiguration to health and care services this has involved, has made living with a progressive and/or rare neurological condition, or brain injury, much more difficult for many people - and their carers.

1. **Supporting mass testing and vaccination once they become available**

Testing must continue to be prioritised to protect vulnerable groups, including those with neurological conditions, especially those living in adult residential care or receiving domiciliary care at home, provided by carers who are travelling between sites to deliver care in the community. Unpaid carers should also have priority access to testing.

* **Without rapid access to regular testing, vulnerable groups, including those with progressive neurological conditions, cannot be adequately protected.**
* **Testing must also be accompanied by the use of high-quality PPE to the required standard in all health and residential care settings to protect vulnerable people with neurological conditions from infection with COVID-19.**

1. **How to ensure that positive changes that have taken place in health and social care as a result of the pandemic are not lost as services normalise.**

The ‘new norm’ for specialist neurology services is likely to include more telemedicine, greater reliance on digital tools, more flexibility about how clinics are conducted, which patients are seen in clinic and who should be followed up over time[[10]](#endnote-10). The Association of British Neurologists say they have gained skills in providing advice and guidance and become very focused on delivering the most essential services.

Of course, telemedicine delivery can be effective and save unnecessary transport of patients to hospital, where they risk infection. However, if telemedicine is to be rolled out more widely, evidence must be collated on the impact on patients and clinical outcomes.

The role of charities in supporting the NHS to deliver care to people with neurological conditions should also not be underestimated or overlooked. The preliminary results of an ongoing survey by The Neurological Alliance, National Voices and the Arthritis and Musculoskeletal Alliance found that:

* 55% of respondents reported a significant increase in demand for their services – this includes things such as peer support networks, helplines, online information and support groups.
* Just under 30% of respondents reported that it was either very likely, or extremely likely, that their organisation would be forced to suspend or reduce support as a result of financial difficulties due to COVID-19.
* **Telemedicine must not become the new normal ‘by accident’, but only where it is a clinically safe and effective option for patients. Patients should also have a choice about how services are delivered that best meets their needs.**
* **Any wider use of telemedicine must not have the effect of further widening health inequalities in people with neurological conditions**
* **Charities must also be recognised for the vital support they offer to people with neurological conditions and for taking pressure off NHS frontline services; it is vital that they can continue to offer their regular services to beneficiaries during and after the peak of the COVID-19 pandemic.**

1. **References**

   The Neurological Alliance website. Accessed here <https://www.neural.org.uk/about-neurological-conditions/>, 7 May 2020. [↑](#endnote-ref-1)
2. The Neurological Alliance, NEURO PATIENCE: Still waiting for improvements in treatment and care - Neurological Alliance, 2018/19 National Neurology Patient Experience Survey. Accessed here <https://www.neural.org.uk/wp-content/uploads/2019/07/neuro-patience-2019-1.pdf>, 7 May 2020. [↑](#endnote-ref-2)
3. Association of British Neurologists, COVID-19 Guidance and Advice. Accessed here <https://www.theabn.org/page/COVID-19>, 7 May 2020. [↑](#endnote-ref-3)
4. Epilepsy Action and University of Sheffield, Epilepsy Specialist Nurses The Evidence (ESPENTE): a Systematic Mapping Review, July 2019. Accessed here <https://www.epilepsy.org.uk/sites/epilepsy/files/research/The%20ESPENTE%20Study%208.7.19%20Version%201.pdf>, 7 May 2020. [↑](#endnote-ref-4)
5. Ling Mao; Huijuan Jin; Mengdie Wang et al, Neurologic Manifestations of Hospitalized Patients With Coronavirus Disease 2019 in Wuhan, China, JAMA Neurol. Published online April 10, 2020. doi:10.1001/jamaneurol.2020.1127. Accessed here <https://jamanetwork.com/journals/jamaneurology/fullarticle/2764549>, 1 May 2020. [↑](#endnote-ref-5)
6. Association of British Neurologists website, RaDAR. Accessed here <https://www.theabn.org/page/radar?&hhsearchterms=%22radar%22&#rescol_6214908>, 7 May 2020. [↑](#endnote-ref-6)
7. Catherine J Mummery and Christopher M Kipps on behalf of the Association of British Neurologists, UK neurology response to the COVID-19 crisis, Clinical Medicine 2020 Vol 20, No 3 May 2020, Accessed here <file:///C:/Users/judya/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/IF3M59U4/abn%20covid%20(002).pdf>, 1 May 2020. [↑](#endnote-ref-7)
8. Final report of the National Clinical Audit of Specialist Rehabilitation following major Injury.

   NCASRI Project team, Lead: Turner-Stokes L. Northwick Park Hospital. London, 2019. Accessed here <https://www.kcl.ac.uk/cicelysaunders/about/rehabilitation/nhs-audit-report-v9-rgb.pdf>, 7 May 2020. [↑](#endnote-ref-8)
9. HSJ, 100,000 people incorrectly told they needed to self-isolate because of coronavirus, 5 May 2020. Accessed here <https://www.hsj.co.uk/coronavirus/100000-people-incorrectly-told-they-needed-to-self-isolate-because-of-coronavirus/7027575.article>, 7 May 2020 [↑](#endnote-ref-9)
10. Catherine J Mummery and Christopher M Kipps on behalf of the Association of British Neurologists, UK neurology response to the COVID-19 crisis, Clinical Medicine 2020 Vol 20, No 3 May 2020, Accessed here <file:///C:/Users/judya/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/IF3M59U4/abn%20covid%20(002).pdf>, 1 May 2020. [↑](#endnote-ref-10)