THE NEUROLOGICAL ALLIANCE

The Neurological Alliance
The Junction
Station Road
Watford
WD17 1EU
T 01923 882 590
W neural.org.uk

Sir Simon Stevens
Chief Executive Officer
NHS England/Improvement
Email: ce.england@nhs.net

7 July 2020

Dear Sir Simon

The urgent need to restart services for people with neurological conditions

We are writing to you today as organisations working with people affected by brain, spine or nerve conditions, to urge NHS England/Improvement to ensure that services for people with neurological conditions resume as quickly as possible, following months of delay during the COVID-19 pandemic.

Starting and continuing courses of specialist treatments that can delay the progression of neurological diseases has been extremely challenging over the past three months. In many cases, appointments with specialist healthcare professionals have been delayed because these professionals have been redeployed. Access to neurological specialists can reduce unexpected hospital admissions as well as unlock the right treatment and support for many people with neurological conditions. Yet, in a recent survey of more than 1600 people with neurological conditions[i], 72% of respondents reported having had their NHS appointments delayed; 47% of these appointments were with a neurologist and in almost 4 in 10 cases (39%) no replacement date was given. This has left many people with suspected and confirmed neurological conditions in limbo when it comes to their health care.

For some people with neurological conditions, missing out on the right treatment at the right time can have life-changing consequences. For example, advanced drug therapies for Parkinson’s only have a short window during which they can be effective, so some people could *already* have lost their opportunity to have a life-changing therapy. Disease modifying treatments (DMTs) for multiple sclerosis can also stop relapses and slow progression of the condition, allowing people to continue working in some cases and/or delaying their need for a wheelchair. In addition, we have heard from some members that treatments such as the initiation of non-invasive ventilation for people with motor neurone disease, botulinum toxin injections for people with dystonia (a movement disorder in which a person's muscles contract uncontrollably) and therapies for chronic migraine, have in many cases been put on hold, leaving people in pain and with more disabling and distressing symptoms.

For the above reasons, the Neurological Alliance is today launching the briefing **Restarting services for people with neurological conditions after the COVID-19 pandemic - and planning for the longer term** (attached), urging the NHS in England to take the following action as a matter of urgency:

- As soon as it is clinically safe to do so, key services for people with neurological conditions, including diagnostic assessments and tests, MRI scans, the delivery of therapies, rehabilitation services and neurosurgery, must be resumed. We are asking NHS England/Improvement (NHSE/I) to apply the same leadership they have shown to restarting cancer and fertility services, to the restart of services for people with neurological conditions.

- Using Association of British Neurologists (ABN) guidance on recommencing neurology services as a starting point (issued on 21 May 2020) and in consultation with patient groups and the National Neurosciences Advisory Group (NNAG), NHSE/I should urgently set out their priorities for the resumption of hospital and community neurology services.

- Tackling the anticipated backlog of 227,000 neurology and 58,000 neurosurgery appointments by the end of 2020[ii] (even without a second spike in COVID-19 cases), must be prioritised by the NHS to avoid a significant decline in the health and/or mobility of people with neurological conditions, which will result in increased costs to the NHS and social care in the longer term, and a significantly decreased quality of life for those waiting for these services.

- As services resume, people with neurological conditions should be offered a choice of settings (both remote and face-to-face) where possible, given the fact that not all consultations and/or assessments can be carried out safely by telephone or video-conference according to our members, as set out in the attached report. For virtual consultations, capacity must be in place to enable subsequent face-to-face appointments to take place where this is required.

- There must also be adequate support and capacity within NHS mental health services to deal with the immediate mental health needs of people with neurological conditions who are in the ‘shielding’ group or who have been self-isolating because they are clinically vulnerable, reflecting the significant co-morbidity of neurological and mental health conditions.

- The short-term rehabilitation contracts introduced to cope with the COVID-19 crisis, with lower service specifications, should not be rolled over or become permanent. Patients discharged prematurely due to COVID-19 must be regularly reviewed to ensure their mobility and motor function is not deteriorating. Many people with life-changing brain injuries have also had their rehabilitation programmes cut back or cancelled, with no indication as to when they will resume. This is not acceptable as these are the very services that help them to lead an independent life.

Finally, the needs and preferences of people with neurological conditions should be central to decisions made about reconfiguring NHS services, particularly when considering the wider use of telemedicine and digital tools, to ensure that no one is excluded as a result of the wider adoption of digital technology, which could drive further health inequalities. In the longer term, the Neurological Alliance is calling for a National Plan for Neurology, to put neurological conditions on the same footing as the key conditions prioritised in the NHS Long Term Plan. People with neurological conditions have been left behind for too long.

The Neurological Alliance and its members are keen to work with you to achieve these goals, and to find solutions that enable us to address the current gaps in neurological treatment, care and support.

We look forward to your response.

Yours sincerely

Georgina Carr
Chief Executive
Neurological Alliance

Sue Millman
Chief Executive Officer
Ataxia UK

Jon Spiers
Chief Executive Officer
Autistica

Peter Cornell
Chair
Black Country Neurological Alliance

Marc Smith
Chief Executive Officer
Brain and Spine Foundation

Caroline Blakely
Chief Executive Officer
Brain Research UK

David Mitchell
Chair
British Polio Fellowship

Simon Bull
Chief Executive Officer
Charcot-Marie-Tooth United Kingdom

Glenys Marriott
Chair
Cumbria Neurological Alliance
Chair
Headway South Cumbria

Helen Matthews
Deputy Chief Executive
The Cure Parkinson's Trust

Sara Garland
Founder and Chief Executive
The Daisy Garland

Austin Willett
Chief Executive Officer
Different Strokes

Dr Elizabeth Corcoran
Chair
Downs Syndrome Research Foundation UK

Chris Bradshaw
Chair
The Dystonia Society

Maxine Smeaton
Chief Executive Officer
Epilepsy Research UK

Dawn Golder
Executive Director
FND Hope UK

Deb Troops
Chair
Greater Manchester Neurological Alliance

Caroline Morrice
Chief Executive Officer
Guillain-Barre & Associated Inflammatory Neuropathies

Philip Lee
Chief Executive Officer
Epilepsy Action

Anne Meader
Chair
Hampshire Neurological Alliance

Cath Stanley
Chief Executive Officer
Huntington’s Disease Association

Shelly Williamson
Chair
IIH UK (Idiopathic Intracranial Hypertension)

Emma Williams
Founder/Trustee/Chief Executive Officer
Matthew’s Friends Charity Global

Sally Light
Chief Executive Officer
Motor Neurone Disease Association

Frank Ludlow
Chair
MS National Therapy Centres

Nick Moberly
Chief Executive Officer
MS Society

David Martin
Chief Executive Officer
MS Trust

Karen Walker
Chief Executive Officer
Multiple System Atrophy Trust

Sarah Cuthell
Chief Executive Officer
Myaware

Matt O'Neill
Chair
Narcolepsy UK

Joanne Cole
Head of Operations
Neuro Key

David Garmon-Jones
Trustee
Neurological Alliance

Steve Ford
Chief Executive Officer
Parkinson’s UK

Donald Gordon
Cofounder and Chair
Ring 20 Research and Support UK

Gaynor Edwards
Chief Executive Officer
Spotlight YOPD

Jane Hanna OBE
Chief Executive Officer
SUDEP Action (Sudden Unexpected Death in Epilepsy)

Heidi Travis
Chief Executive Officer
Sue Ryder

Suzanne Dobson
Chief Executive Officer
Tourettes Action

Sally Rodohan
President
Transverse Myelitis Society

Adrian Hale
Chief Executive Officer
Trigeminal Neuralgia Association UK

Chloe Hayward
Executive Director
The United Kingdom Acquired Brain Injury Forum (UKABIF)

cc Rt. Hon. Matt Hancock MP, Secretary of State, Department of Health and Social Care
Prof Stephen Powis, National Medical Director, NHS England
John Stewart, National Director, Specialised Commissioning, NHS England

Attached: Restarting services for people with neurological conditions after the COVID-19 pandemic and planning for the longer term (Neurological Alliance, July 2020).

---

[i] [1] From to 9 to 20 June, the Neurological Alliance surveyed 1672 people with a total of 62 neurological conditions on the Impact that COVID-19 had had on their care. The results are available on the Neurological Alliance's website https://www.neural.org.uk/

[ii] Medbelle NHS Waiting List Estimation Tool. Accessed here https://www.medbelle.com/waitlist/, 2 July 2020