

Effects of COVID-19 pandemic on people with neurological conditions and their access to health and care services; and the steps being taken to restart specialist neurology services

– Short Debate tabled by Baroness Gale – Briefing for members of the House of Lords

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Briefing produced jointly by the Neurological Alliance, MS Society, Parkinson's UK, Motor Neurone Disease Association, the UK Acquired Brain Injury Forum and the Royal College of Speech and Language Therapists (RCSLT).

Overview

Approximately 1 in 6 people in the UK are living with a neurological condition. The COVID-19 pandemic has highlighted and exacerbated existing gaps and unwarranted variation in care for people with neurological conditions across the UK. Although many have redoubled their efforts to bring services in line with provision pre-pandemic, gaps in support and capacity remain.

Before the pandemic, people with neurological conditions reported worse experiences of care compared to other long term conditions. For example, more than 83% of people with cancer were given sufficient information at time of diagnosis, compared to just 42% of people with neurological conditions. Epilepsy was reported as the sixth most frequently recorded cause of death in people with learning disabilities and the second most frequently reported potentially treatable cause of death (2018-9).

However, our ability to treat, support and manage neurological conditions has progressed significantly in the past two decades. In multiple sclerosis (MS), the number of treatments available on the NHS to manage relapses and slow progression has doubled in the past decade alone. Three new treatments for migraine have been approved in the past 18 months, despite the pandemic. We are understanding more about neurological conditions every day - we need to ensure that services are able to ensure that scientific successes reach those who could benefit, starting with the right support and strategy for services for neurological conditions to recover from the impacts of the pandemic.

1. The impact of COVID-19 on waiting for specialist neurology services

In February 2020 prior to the first lockdown, just 38 people had been waiting more than a year for a neurology appointment, 169 for a neurosurgery appointment. However, by March 2021, according to recent NHS England and NHS Improvement data, more than 150,000 people were waiting for a neurology appointment and more than 60,000 for a neurosurgery appointment. More than 10,000 have been waiting for more than a year.

At the same time referrals to neurology services have dipped in many areas. This has profound implications, and could mean delays to diagnosis and treatment.

Delayed diagnosis and referral has concerning implications for access to treatment and support. For example, specialist Motor Neurone Disease centres saw a 30-50% reduction in referrals in 2020. Without access to specialist expertise patients cannot receive a confirmed diagnosis and begin accessing treatment and support for this complex and often rapidly progressive condition. In multiple sclerosis (MS), delayed diagnosis could mean a delay to access treatments which could slow or even stop the progression of the condition.

The NeuroLifeNow platform asked more than 250 people with neurological conditions what their experience of care was like in April. 16% of respondents experienced delays to care. This group were more likely to have accessed emergency support last month, as well as report feeling anxious or hopeless.

In a survey of more than 3000 people with epilepsy, supported by SUDEP Action:

- 40% of people with epilepsy had worsening health during the first wave of the pandemic
- 87% reporting increasing mental strain
- 33% of people with epilepsy are experiencing issues in accessing care
- 25% having difficulties accessing their vital anti-seizure medication prescriptions

As the COVID-19 threat level is lowered, the Government must work with NHS England and NHS Improvement, commissioners, healthcare professionals, professional bodies and patient groups to ensure that services are restored to their pre-pandemic levels as soon as possible.

COVID-19 has shone a harsh spotlight on the serious shortage of neuroscience specialists, including experts in neurorehabilitation and specialist nurses. The Government must use this year's Autumn Spending Review to provide long term investment alongside a workforce plan to ensure we have a health and care workforce that meets the needs of people with neurological conditions, now and in the future.

2. Adoption of digital services and remote consultations.

There has been widespread adoption of remote consultations, new triage and advice and guidance models. For some groups of neurological patients, virtual consultations have meant the welcome access to a consultant or specialist nurse, reducing the costs and logistics of travelling distances for follow up appointments faced pre-pandemic. However, virtual assessments are not clinically appropriate in all cases and some symptoms and deterioration of health cannot be picked up virtually. There is also a risk that they can lead to lower thresholds in referral to diagnostic services.

DHSC and/or NHSE/I must evaluate the effectiveness of the digital delivery of rehabilitation services during the pandemic, including

examining user experience and digital inequalities. Best practice and innovation in rehabilitation delivery needs to be more effectively shared across the nations, while the limitations of digitally-delivered rehabilitation also needs to be recognised and mitigated.

3. The urgent need for a social care plan that works for all

The pandemic has exposed longstanding barriers to social care that people with neurological conditions and their families face. Challenges accessing and navigating social care have been intensified as stress and pressure on unpaid carers has increased under lockdown restrictions. The Government has committed to bring forward proposals this year to tackle the social care crisis. Many people with neurological conditions need to access social care at a younger age, so it is essential that any proposals address the needs of working aged adults, as well as older people.

The Department of Health and Social Care (DHSC) must work with the Care and Support Alliance, Association of Directors of Adult Social Services and others to better understand and ensure resources are in place to meet long standing unmet need in the social care system. These must fully address the needs of working aged adults.

4. Access to rehabilitation services

Rehabilitation services, both in hospital and in the community, play a key role in the recovery, support, symptoms management and function of people with neurological conditions. There is strong evidence that rehabilitation in the community improves long-term outcomes and can help to reduce hospital readmissions.

The redeployment of community based therapists and influx of new referrals to neuro rehab units have compounded existing pressures. NHS data shows there were 20,695 fewer outpatient appointments with a rehabilitation consultant across all neurological conditions between March and June 2020 compared to the same period the previous year – a reduction of 28 per cent.

A report published by the RCSLT in March 2021 of people's experiences of accessing speech and language therapy during the first UK-wide lockdown revealed that:

- 48% of people living with neurological conditions had less speech and language therapy during lockdown.
- 80% of people living with neurological conditions had no face-to-face speech and language therapy since June 2020.
- 40% of people living with neurological conditions said their needs got worse.
- People living with neurological conditions told us that having less speech and language therapy was bad for their social life and friendships (59%), home and domestic life (52%) and mental health (52%).

A funded, national strategy is required to improve rehabilitation in the four nations. We recommend a new national leadership role for rehabilitation in the NHS to drive forward this agenda.

5. Impact on medical research into neurological conditions

Neurological research has been significantly disrupted and risks compromising future innovation and advancement of treatment options for people with neurological conditions. Medical research charities invested £1.9 billion in medical research in the UK in 2019, and half of publicly funded medical research nationally. Charity research funders have experienced huge downturns in their income, which has led to the suspension of their research grant funding. The Association of Medical Research Charities estimates that 70% of clinical trials and studies funded by its member charities were stopped, paused or delayed in 2020. This means that many people with neurological conditions face delays in access to innovative new treatments for their conditions.

The UK Government must clarify if and how recent spending commitments to support UK research will contribute towards neurological research and provide financial support for medical research charities.

6. Impact on mental health

Coping with the impact of the diagnosis and symptoms of a neurological condition can lead to depression and anxiety. However, the interplay between neurological conditions and co-morbid mental health conditions is often far more complex than this. Changes in the brain can directly affect emotions and cognitive functioning; psychiatric symptoms can exacerbate neurological symptoms, and neurological medications can have side effects that include mental health problems. In some cases, a patient presenting with psychiatric symptoms may have an underlying neurological condition and, conversely, neurological symptoms may not reflect a neurological disorder but a functional disorder secondary to emotional difficulties.

Before the pandemic, 4 in 10 respondents to the National Neurological Patient Experience Survey said their mental health needs were not being met at all. The National Neuroscience Advisory Group (NNAG) recently reported a troubling outlook for people with co-morbid mental health and neurological conditions including a lack of joined up care, the absence of care planning, and an inability to access mainstream mental health services.

Lockdown and uncertainties concerning wellbeing, access to health care, treatment management and other social factors have had a detrimental impact on the mental health and wellbeing. Increased depression, anxiety, suicidal thoughts and social isolation have been widely reported. Some services are now reporting a three year wait for access to support. Complex in-patient, specialised neuropsychiatry services have, in some areas, stopped as a result of the pandemic.

The neuropsychological and neuropsychiatric impacts of COVID-19 itself are not yet fully understood. However, case studies have revealed neurological problems

in severely affected COVID-19 patients in particular, that may require support from neuropsychiatry. These include cognitive deficits, hallucinations, as well as things like delusions and paranoia in patients with no previous history of mental health issues.

NHS England and NHS Improvement must support the roll out of effective and appropriate screening for mental health needs, and the collection of data to support service delivery and improvements in place.

DHSC, NHS England and NHS Improvement should ensure that NHS reforms support the integration of mental health and neurological care.

Potential questions to ask the Health Minister:

- Could the Minister confirm NHS England and NHS Improvement's proposed recovery strategy for services for people with neurological conditions?
- What is the Minister's assessment of how many people with neurological conditions have missed out on treatment/surgery?
- How does the Minister intend to improve the provision of mental, emotional and cognitive support for people with neurological conditions?
- Will the Minister commit to improving NHS and care activity data for neuroscience services?
- Will the Minister commit to re-appointing a National Clinical Director for neurology?
- Will the Minister ensure a national strategy is in place for neuro-rehabilitation within NHSE/I, with a national leadership position in place?

If you have any questions about the information in this briefing, please contact Joseph.Brunwin@mssociety.org.uk
