

Written evidence submitted by MS Society (CBP0092)

Neurology and MS services

Note: this submission contains survey evidence which will be published as part of our upcoming campaign on MS and neurology services on 6th October. We ask that the Committee does not publish this response until then.

Overview

The pandemic compounded existing challenges facing NHS neurology services and people with MS, and underlined the need for urgent action ensure a sustainable future for these services.

Considering the key challenges, we need to see:

1. Increased investment in training more neurology professionals and a development of a long-term workforce strategy;
2. Immediate investment and support to enable services to adopt more efficient and effective models of care and ways of working which make the best use of existing professionals;
3. Support to self-manage consistently offered to patients and better communication with patients while they are waiting for appointments; and
4. Specific guidance on appropriate use of digital and virtual appointments in neurology in the NHS.

About MS

Multiple sclerosis (MS) is a neurological condition that affects more than 130,000 people in the UK. It's unpredictable and different for everyone. It's often painful, exhausting and can cause problems with how people walk, move, see, think and feel.

About the MS Society

We're the MS Society. We're here by your side through the highs, lows and everything in between. Together we fund world-leading research. We provide information and services so everyone can live well with MS. We make our voices heard and campaign for everyone's rights. And we support one another so no one has to feel alone. Together we are a community. And together we will stop MS.

The impact of the pandemic on access to neurology and MS services

In England, over 149,285 people were waiting to start treatment with a neurologist in July 2021 compared to just over 120,000 in April 2020, at the start of the pandemic, and this number has continued to grow since May 2020. Although the overall number of people waiting over a year is relatively small, it rose 9068% from February 2020 to March 2021.¹

We surveyed 746 people living with MS in August 2021. 33% had experienced delays or cancellations to healthcare appointments at some point during the pandemic. Most respondents (67%) who had appointments via telephone or video, received some or all of the support and information they needed. This is very encouraging, although of course it is concerning that a significantly minority did not get the support they needed.

¹ NHS England, Consultant-led Referral to Treatment Waiting Times

We also surveyed 196 healthcare professionals in August 2021 including nurses and physiotherapists working with people with progressive neurological conditions (such as MS, Parkinson's and Motor Neurone Disease). More than half (53%) said waiting times for their service have increased since March 2020. Of those, nearly a quarter (22%) estimated it could take 1-5 years to return to pre-pandemic waiting times.

Impact on people with MS

Disrupted access to neurology services has clearly had a negative impact on many people with MS. Our survey of people living with the condition found over half (53%) said a reduction to the specialist support they received before the pandemic contributed to their symptoms getting worse to some or a great extent.

Professionals also believe capacity challenges are having a negative impact on patients. Our recent survey of neurology healthcare professionals found over 3 in 5 (63%) professionals said they were finding it 'very challenging' or 'extremely challenging' to provide a good service for everyone already on their caseload. Whereas, only 1 in 3 (31%) said that that was the case pre-pandemic. Of those who were finding it challenging to some degree:

- 4 in 10 (42%) said they have had to compromise the quality of care they would normally deliver.
- 7 in 10 (73%) have been unable to see everyone who needs to access to their service in a timely way.
- 32% said they are concerned that the safety of some of their patients may be compromised.

Capacity to address the neurology backlog and approaches to manage it

Dealing with the backlog and continuing to see growing numbers of new patients, will be challenging for neurology services. Our survey of 196 healthcare professionals working with people with progressive neurological conditions in August 2021, found that, among those who said waiting times have increased since the pandemic (53%), nearly a quarter (22%) estimated it could take 1-5 years to return to pre-pandemic waiting times.

Lack of staff and staff burnout will undermine the ability of services to address the backlog. 29% of professionals said their service has fewer staff than before the pandemic, and of those who were finding it to some degree challenging to provide a good service, 3 in 5 (60%) were concerned about staff burnout. We also asked professionals, in the next 5 years, what they think the challenges will be for services for people with progressive neurological conditions. 88% said increased caseloads and 65% said specialist staff leaving the workforce.

Before the pandemic, there was already a serious shortfall of neurology professionals. An audit of 51 UK MS services in 2020 suggested a sensible caseload for a neurologist of 615 people with MS, but found on average neurologists had caseloads of 1,815 patients. For MS nurses, caseloads of 315 per nurse are considered optimal, but the audit found on average they were in fact 1,757. Estimates suggest at least 200 more MS nurses and over 100 more neurologists are needed for MS services' caseloads to be sustainable.²

In terms of how to overcome the challenges services are facing, we recommend:

² * Hobart J, Rog D, Matthews J (2020) MS Audit Presentation at Raising the Bar for MS conference. November 2020

1. Investment in the Spending Review in training more neurology professionals and the development of a long-term workforce strategy to ensure the current situation is not markedly worse in decade's time.
2. In the immediate term, neurology services need investment and support to enable them to adopt of best practice models of care and ways of working which make the best use of existing professionals, and are more efficient and effective. The recent NHS England 'Getting it Right First Time' neurology report made a series of recommendations on models of care services should move towards, including training advanced practitioners to free up specialists' time and introducing electronic triage systems.³ There is clearly a present challenge in developing and implementing new models. When we asked professionals, in the next 5 years, what they think the challenges will be for services for people with progressive neurological conditions, 78% said a lack of funding for future service developments. Professionals clearly identified opportunities over the next five years, including access to virtual groups/training (84%) and increased/more effective use of virtual/telephone appointments (76%).
3. We also need to see support to self-manage consistently offered and better communication with people, while they are waiting for appointments. Technology has great potential to help people to live better with long-term conditions including people with MS. Our survey of people with MS found 96% of those who had experienced delays or cancellations to appointments had not received information and support on self-management, representing a missed opportunity to prevent deterioration. Yet professionals surveyed (68%) identified greater use of self-management technology as a key opportunity over the next five years. We also want to see every NHS Trust act on the guidance about good communication with patients which NHS England produced with National Voices (of which we are a member).⁴
4. To ensure people who are digitally excluded are not left behind and that digital approaches meet the needs of people with neurological conditions, NHS England must work with them and with neurological charities to produce specific guidance on appropriate use of digital and virtual appointments in neurology.

³ NHS England, Getting it Right First Time, September 2021. Available with login credentials: <https://www.gettingitrightfirsttime.co.uk/medical-specialties/neurology/>

⁴ NHS England, Good communication with patients waiting for care, 25 May 2021. Available: <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/01/C0855-i-good-communication-with-patients-guidance-v2.pdf>