



**THE
NEUROLOGICAL
ALLIANCE**

Restarting services for people with neurological conditions after the COVID-19 pandemic and planning for the longer term

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Summary

The Neurological Alliance is a coalition of more than 80 organisations all committed to improving the lives and outcomes of people affected by neurological conditions. As the COVID-19 pandemic has progressed, we have heard from people with neurological conditions, charities, healthcare professionals and industry, about the profound impact the virus has had on neurological treatment, care and support. Vital treatments that can delay the progression of a neurological condition, or reduce the likelihood of having a relapse, have been delayed; some medicines which alleviate painful and distressing symptoms have been difficult to access; and rehabilitation to support recovery and slow the progression of a condition has been reduced. Many have also been 'shielding' or 'self-isolating' because of the virus and the likely adverse impact of this on mental health and wellbeing cannot be underestimated.

Here we set out our key recommendations for the Government, NHS England and NHS Improvement, commissioners, providers and clinicians, as we collectively seek to return to 'a new normal' – one, we hope, which ensures people with neurological conditions across the country are able to access the right treatment, care and support for them. This report applies to England only.

Acknowledgements

A huge thank you to all of our members and healthcare professionals who shared their valuable expertise in shaping this report. Most of all, we would like to express our huge gratitude to the thousands of people with neurological conditions who shared their experiences with us during these unprecedented times.

Thank you.

Foreword

Accessing the right treatment, care and support to manage a neurological condition makes all the difference. Access to the right medicines could mean exhausting and distressing symptoms like pain and fatigue are more manageable. The right rehab after brain or spinal injury is a fundamental component of recovery, helping people to live as well as possible. The right therapies could reduce relapses and even slow down the progression of a condition. And access to the right specialists unlocks so much of this.

But, during COVID-19, so much of this vital neurological treatment, care and support has been severely disrupted - with devastating impacts. People with neurological conditions are amongst the most impacted by the virus, with many self-isolating, 'shielding', and experiencing high levels of anxiety and loneliness.

In this report, more than 1,600 people with neurological conditions tell us what life has been like for them during this pandemic. The experiences shared here help cast a light and give a voice to the many who are struggling right now. 18% of respondents to our survey told us they felt lonely. One in ten reported feeling hopeless. But their stories also act as a warning of the risks to come if we don't act. We heard examples of people having received a life changing diagnosis, only to receive no follow-up or support. Key procedures and therapies have been delayed.

Neurological health and care professionals have been doing all they can to provide some support during these unprecedented times, often over the phone or via videoconference. However, as redeployment of professionals has taken hold, many medical appointments have been cancelled or delayed – 72% of respondents to our survey told us they had had a medical appointment delayed during the pandemic.

43% of those who had experienced delay didn't know when their appointment had been delayed until – leaving people with neurological conditions or suspected neurological conditions in limbo. This has to change.

And it can change. With the right support and leadership from NHS England and NHS Improvement, together with the passion, drive and expertise of the neurological community, I believe we can turn this around. I've been inspired by the way in which all corners of the neurological community – patient groups, industry, health and care professionals and more – have pulled together during this pandemic, seeking to meet this virus head on.

This collaborative effort has to continue - only by working together will we move to a new, better normal, where people affected by a neurological condition are able to get the right treatment and support, no matter who they are or where they live. I look forward to working with the neurological community, policymakers and everyone else who shares this vision.

Georgina Carr
Chief Executive
The Neurological Alliance

Our key recommendations for the restart of services for people with neurological conditions

- When 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 and rehabilitation services, must be resumed as quickly as possible. NHS England/Improvement (NHSE/I) must apply the same leadership they have shown to the restart of cancer and fertility services, to restarting services for people with neurological conditions. Using Association of British Neurologists (ABN) guidance and in consultation with patient groups and the National Neurosciences Advisory Group, NHSE/I should urgently set out their priorities for a resumption of hospital and community neurology services.
- 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 also be regularly reviewed to ensure their mobility and motor skills are not deteriorating.

“I was very recently diagnosed with MND. I hadn't even met with my care team when the lockdown started and [my] appointments were cancelled.

“I have missed out on post-operative care. Brain surgery is a big deal and I have had no face to face after care or treatment since leaving hospital.

- In order to achieve a restart of services, the specialist neurology staff redeployed to COVID-19 wards, should be brought back to restore staffing in neurology departments to the levels seen prior to the pandemic.
- As services resume, people with neurological conditions should be offered a choice of settings (both remote and face-to-face), where possible. For remote consultations, capacity must be in place to enable a subsequent face-to-face appointment where this is required.
- There must 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 due to the common coexistence of neurological and mental health conditions.
- Tackling the anticipated backlog of 227,000 neurology and 58,000 neurosurgery appointments anticipated by the end of 2020ⁱ needs to be prioritised by the NHS to avoid a significant decline in the health, mobility and quality of life of people on these waiting lists - and increased costs to the NHS and social care in the longer term.
- The needs and preferences of people with neurological conditions must be central to any 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 greater use of digital technology in delivering care. The Alliance's membership is well placed to support people with neurological conditions to be involved in such decisions.
- The welcome progress that has been made in recent years in redesigning NHS neurology services and clinical pathways, for example through the NHS Neurology Transformation Programme, must be resumed as quickly as possible.

What are neurological conditions?

There are now an estimated 16.5 million cases of neurological conditions in England, at least 1 in 6 people are now living with one or more neurological condition(s)ⁱⁱ.

There are over 600 types of neurological conditions – conditions of the brain, spine and/or nerves; some which are comparatively common such as multiple sclerosis and Parkinson's and others which are rare. Neurological conditions can be sudden, fluctuating, progressive and/or lifelong and have a range of different causes including genetic factors, traumatic injury and infection - although the causes of some neurological conditions are still not well understood. Anyone can be affected by a neurological condition, no matter their age.

Neurological conditions can result in significant challenges to a person's mobility and/or cognitive function and/or cause considerable pain, having a significant impact on their quality of life and wellbeing; in some cases neurological conditions can lead to premature, avoidable death. Deaths associated with a neurological condition in England are 35% more likely to be prematureⁱⁱⁱ.

In people with neurological conditions, the interactions between their physical health, their cognitive function and their emotional wellbeing can be complex and challenging because of the complexity of the brain. For example, depression and anxiety often co-exist alongside the physical and cognitive symptoms experienced by people with a neurological condition; in turn, these mental health problems can adversely impact their neurological condition, making it worse - or even triggering it. In other cases, apparent mental health problems may, actually, reflect an undiagnosed neurological condition. Getting the right support for people with neurological conditions, both physical and emotional, is therefore essential.

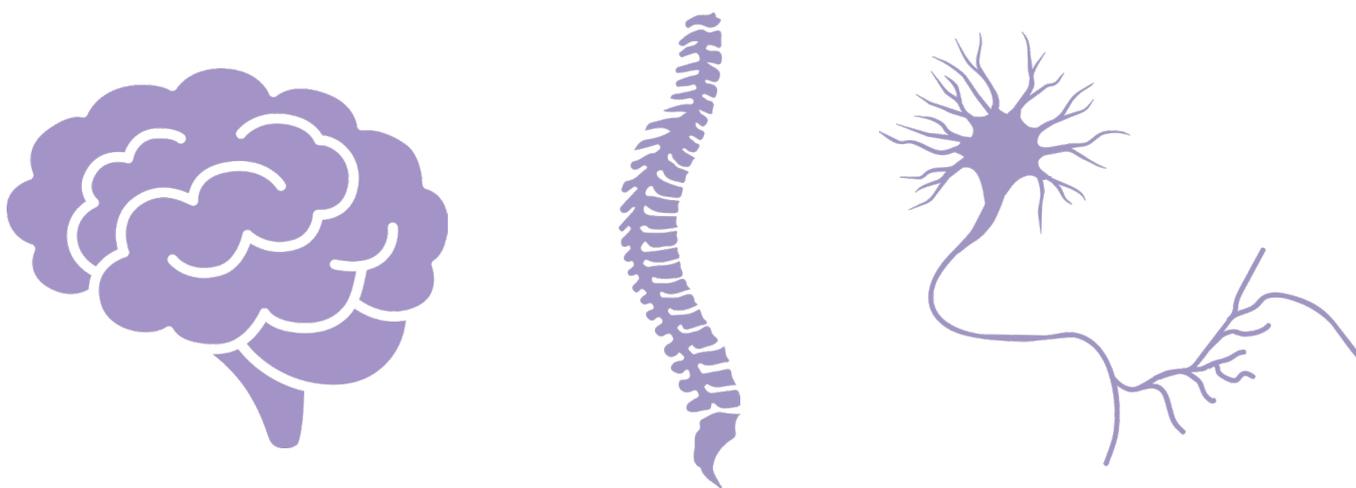


Fig 1. Neurology: the branch of medicine dealing with the brain, spine and nerves

Health and care services have not always met the needs of people with neurological conditions

There is currently an unacceptable variation across the country when it comes to people with neurological conditions being able to access the right treatment, care and support^{iv}. This directly affects their ability to live independently and experience the best possible quality of life. NHS services for people with neurological conditions have, historically, been under-prioritised compared to other medical conditions such as cancer and heart disease. This is despite the 14.7 million cases of neurological conditions in England, now affecting 1 in 6 people (some people have more than one condition) and the significant impact that disorders of the brain, spine and nerves can have on a person's quality of life. In the Neurological Alliance's recent Patient Experience Survey of over 10,000 people with neurological conditions, almost half of those responding (46%) reported that their condition impacted on their quality of life 'to a great extent.'^v

Pre-COVID-19, many people experienced long waits to see a specialist and/or did not feel their care was tailored to their specific needs. The same Patient Experience Survey^{vi} revealed that almost 4 in 10 respondents (39%) saw their GP five or more times before being told they needed to see a neurologist, while 55% of respondents said they experienced delays in accessing healthcare services. Those living in areas of higher deprivation also had longer waits to see a specialist compared to those living in areas with lower levels of deprivation.^{vii} These factors can create further disillusionment and a sense of isolation in an already vulnerable group, with significant impacts on their mental health.

For every four neurologists in Germany there is also only one in the UK^{viii}, underlining the scarcity of specialist neurological expertise in the NHS workforce. Likewise, across Europe as a whole, the research spent on understanding brain disorders lags significantly behind that spent on other conditions such as cancer^{ix}.

Problems around access to health care, specialists and new therapies inevitably affects the outcomes of people living with neurological conditions. The number of deaths in England as a result of having a neurological condition rose steadily in the decade to 2014 according to Public Health England, rising from around 23,000 deaths (23,051) in 2001 to around 32,000 (31,925) deaths in 2014, an increase of almost 40% over that period^x. Brain Research UK reports that around 140,000 people die each year in the UK as a result of neurological conditions – one fifth of all deaths; this much higher figure includes people with dementia, brain tumour and stroke^{xi}.

Mental health care for people with neurological conditions has also, all too often, been an afterthought. Just 42% of respondents in our recent Patient Experience Survey reported having been asked about their mental wellbeing, suggesting person-centred care is a long way from being a reality for people with neurological conditions^{xii}.

Furthermore, providing specialist rehabilitation for the people with neurological conditions that need it, such as those who have had a brain injury, must be more highly prioritised. Having a neurological condition is normally life-long and patients' needs change over time. The current provision of rehabilitation is inadequate to meet these changing needs with long waits for services. An NHS rehabilitation service specification is needed, setting out how people with neurological conditions can access rehabilitation along their whole care pathway, backed up by increased NHS funding allocated to the delivery of such services^{xiii}.

How has COVID-19 affected the health and care of people with neurological conditions?

The COVID-19 pandemic has been extremely challenging for many people living with neurological conditions and for those closest to them.

'Shielding' has had a significant impact on people with neurological conditions

- Many people with neurological conditions were advised to 'shield', being at risk of severe illness if they contracted COVID-19 (i.e. in the clinically extremely vulnerable group). Others were advised to go out as little as possible as they were clinically vulnerable. Due to inadequacies in NHS neurological datasets, identifying those at heightened risk of the virus was extremely labour intensive for many clinicians and led to unfortunate delays in people with neurological conditions receiving the necessary advice to 'shield'.
- In a recent Neurological Alliance survey of more than 1,600 people, asking how they had been affected by COVID-19, which closed on 20 June 2020^{xiv}, 49% said they had found the Government's communications on 'shielding' unclear; 31% of respondents also told us that they had experienced problems accessing food during the lockdown. A summary of the survey results are set out in the panel on page 11.
- Alliance member organisations have reported a significant rise in the need for mental health and befriending support as the impacts of self-isolation have taken hold, with reduced social contact and increased anxiety about the risk of infection. At the same time, access to mental health services has been restricted during the pandemic.

“ [My] mental health issues [have been] exacerbated by inability to access [my] usual social outlets (yoga class, group gatherings)^{xv} ”

- The Government has now announced that 'shielding' will be relaxed from 6 July and paused from 1 August. This has given rise to concern in people with neurological conditions who have been 'shielding' about the risk this poses as they start to go out more; they need better information to be able to assess their own personal risk if they catch COVID-19. A potential risk stratification tool being developed by Oxford University in association with ten other UK universities, the DHSC, NHS Digital and other agencies, will not be available until September 2020 at the earliest, leaving people who are still 'shielding' uncertain and anxious about what to do for the best from 1 August.

Access to treatments and therapies has been disrupted and/or delayed

- Starting, altering and/or continuing courses of treatment can delay the progression of neurological diseases and/or reduce relapses, but this has been extremely challenging during the pandemic. In many cases such treatments have simply been cancelled with no indication as to when they will resume, causing great concern to the people affected. In the Alliance's COVID-19 survey, 72% of respondents reported having had their NHS appointments delayed; 47% of these appointments were with a neurologist and in 39% of cases, no replacement date was provided. This has left many people with suspected and confirmed neurological conditions in limbo when it comes to their health care.

“ I was due to receive plasma exchange due to an acute MS relapse however due to COVID-19 this was cancelled. I am certain that had this treatment gone ahead, I would have got my symptoms under control sooner... ”

How has COVID-19 affected the health and care of people with neurological conditions?

- 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. Certain Disease Modifying Treatments (DMTs) for multiple sclerosis (MS), which reduce relapses and slow the progression of the condition - in some cases delaying the need for a wheelchair - have also been delayed or cancelled in some NHS clinics. Cancelled and/or delayed treatments will often leave people with increased social care needs in the longer term. Some treatments like botulinum toxin injections for dystonia (a movement disorder in which a person's muscles contract uncontrollably) and therapies for chronic migraine have also been cancelled, leaving people in pain and with more disabling symptoms. People recently diagnosed with motor neurone disease have also not been able to start non-invasive ventilation to support their breathing.

“I need regular botox injections every 9 weeks. Up until COVID-19 I have received this treatment without fail for some 16 years. Now my treatment has stopped my condition is returning to how it was some 16 years ago

- Access to therapies for common, but hugely distressing and exhausting symptoms like pain, fatigue, seizures and muscle weakness, have been disrupted or delayed. In some cases, this has been due to the need for carers to pick up specialised treatments from the hospital during the pandemic, or because homecare deliveries have been compromised.

“I have regressed to how I was 2 years ago and am bed bound again - my mood is low and I have needed to rely on my mum as no one has offered any support.

There has been disruption and change to specialist neurology support

- Many neurologists, specialist nurses and allied health professionals have been redeployed during the COVID-19 pandemic. Because of this and the risk of infection, almost all routine face-to-face neurology appointments have been delayed or cancelled. For people with neurological conditions this may mean they do not have access to the same level of support to help prevent an emergency admission to hospital, to receive early interventions when new symptoms arise, or to get a swift diagnosis.

How has COVID-19 affected the health and care of people with neurological conditions?

- Where possible, telephone or video (telemedicine) consultations have been used instead of face-to-face consultations. Telemedicine consultations can be an important tool in helping people to access the right support and it has enabled at least some contact with neurology specialists to continue during the pandemic. In some cases, however, making an accurate assessment of how a neurological condition is affecting a person and being able to observe their physical function virtually, can be extremely challenging or even pose a significant risk in some cases. For example, swallow assessments carried out virtually by speech and language therapists might not be accurate and therefore pose a potential risk to clients. Also, some people with neurodevelopmental conditions (NDCs) such as autism can struggle to engage and communicate effectively about their symptoms during virtual as opposed to face-to-face consultations. For some neurological conditions it is only a full clinical assessment that allows a diagnosis to be made as diagnostic tests are not available.

“I felt quite anxious and on edge trying to describe my symptoms over the telephone

Access to rehabilitation services and physical therapies has been significantly reduced

- Many people with life-changing brain injuries have had their rehabilitation programmes cut back or cancelled with no indication of when these may resume. These are the very services that help them to return to living a more independent life.
- Therapies that help people with progressive neurological conditions such as Parkinson's and MS to manage their pain on a daily basis, or to stay mobile and independent, such as 'hands on' physiotherapy and physical activity, have been cancelled, sometimes because they are held at

facilities in the community which have closed. The impact of removing a person's opportunity to progress towards achieving physical rehabilitation goals can have a significant impact on their physical and mental health. Some neurological conditions can deteriorate rapidly without specialised rehabilitation.

“I cannot access the swimming pool, so my pain and stiffness have affected me more

There has been restricted access to social care

- Some people have experienced reductions in social care in the community, sometimes due to shortages of Personal Protective Equipment (PPE), meaning care workers cannot attend and/or people do not feel safe receiving care. This has left many unpaid carers overstretched and exhausted, including some parents and families providing 24/7 care for children with neurological conditions.

“I requested that the carer who will take over from the current carer has a COVID test before coming, but the agency refused

The disruption to daily life has been especially challenging for some

- For people with neurological conditions, particularly neurodevelopmental conditions like autism, the societal changes caused by COVID-19 - for example, complying with social distancing - has been very challenging and the huge disruption to their lives has triggered intense stress and emotional upset.

How has COVID-19 affected the health and care of people with neurological conditions?

Key Findings from the Neurological Alliance's survey on COVID-19 (June 2020)

- 49%** of people who answered the question (718 people) said the Government's advice on whether to shield was unclear.
- 31%** (526 people) said they had experienced difficulties accessing their normal food supplies.
- 23%** (390 people) said they had had difficulty accessing their regular medication.
- 72%** (1194 people) said they had had medical appointments delayed during the pandemic.
- 47%** Of the appointments delayed, 47% (584 people) said their delayed appointment had been with a neurologist.
- 43%** (527 people) had not been given a new date for their delayed appointment.
- 47%** (763 people) had had virtual (telemedicine) instead of face-to-face appointments, 81% of which were by phone and 9% by videoconference.
- 58%** (491 people) said their virtual appointments had been either very, or reasonably, effective.
- 31%** (525 people) said the COVID-19 crisis had very significantly, or significantly, affected their neurological condition.
- 36%** of people said they currently felt anxious and 19% felt lonely.

*To the nearest 1% - in each case the % relates to the number of people who answered the question.

There were 1672 responses to the survey held between 9 and 20 June, representing people with more than 62 different neurological conditions, in addition to people waiting for a diagnosis

What needs to happen now?

We have seen widespread disruption to neurological treatment, care and support. Therefore, when it is clinically safe to do so, key services for people with neurological conditions must be resumed as quickly as possible. NHSE/I must apply the same leadership they have shown to the restart of cancer and fertility services, to restarting NHS services for people with neurological conditions. Using Association of British Neurologists (ABN) guidance^{xvii} and in consultation with patient groups and the National Neurosciences Advisory Group, NHSE/I should set out the priorities for a resumption of hospital and community neurology services as quickly as possible.

There have also been dramatic interruptions to rehabilitation services. Short term in-patient rehabilitation contracts introduced to cope with the COVID-19 crisis should not be automatically rolled over. These short-term changes also need to be assessed to ascertain whether they are working, not only for NHS providers, but more importantly, for the people concerned. Rehabilitation services in the community must be reviewed and increased, to factor in the neurological impact of COVID-19 on patients. Also, support and capacity within NHS mental health services must be made available to deal with the immediate impacts of 'shielding' and of limited social contact on the mental health of people with neurological conditions – people who, even before the pandemic, were dealing with significant mental health challenges, often without the NHS mental health support they needed.

Above all, the needs and preferences of people with neurological conditions must be central to any 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. In terms of a greater reliance on telemedicine, which has become a particularly pressing issue, inequalities exist in the ability and capacity of people with neurological conditions to utilise telephone or video consultations. In some cases, use of these services is not appropriate, and so should not be adopted as the 'norm' in the longer term. One of our members told us that in a survey of their members, half of people reported preferring letter to email communications^{xviii}.

“ Sometimes I find speaking difficult and can express myself better in person

Known challenges for people with neurological conditions which affect the possible efficacy of 'virtual' consultations include:

- not having access to a quiet space at home to host a private consultation with a specialist neurologist or nurse;
- struggling to access remote services because of health issues linked to cognition, hearing or sight loss or motor difficulties e.g. difficulty holding a telephone/using a computer;
- not having access to the digital technologies themselves (e.g. a smart phone, computer or laptop); and
- internet access and connectivity problems.

“ [It was] more relaxed as I didn't have to leave my house and go out in public

What needs to happen now?

There should therefore not be a default position that outpatient appointments can be done virtually unless there is sound medical evidence to support this. In the longer term, research that seeks to understand the impact of 'virtual consultations' on health outcomes should be supported and prioritised. The Alliance's membership is well placed to support people with neurological conditions to be involved in decisions about their care.

“It was hurried and due to lack of rapport some things were misinterpreted

The utility of some digital approaches to care has been set out in the NHS RightCare Pathway for Progressive Neurological Conditions^{xix}, and it provides a useful basis for service improvement, now and in the future.

Planning for the future - securing high-quality services for people with neurological conditions in the long term

In the longer term, the Neurological Alliance is urging NHSE/I, Health Education England, NHSX, NHS Digital and health and care bodies across the country to work with the wider neurological community to develop and deliver a new National Plan for Neurology. The Plan should, firstly, ensure that people with neurological conditions are not left behind in the wake of COVID-19. It should also set out how the

NHS plans to commission and deliver comprehensive, personalised and holistic physical and mental health and care services for people with neurological conditions and to build a thriving health and care neurology workforce. The Plan should have at its heart addressing the current, unwarranted variations in treatment, care and support that people with neurological conditions still experience every day.

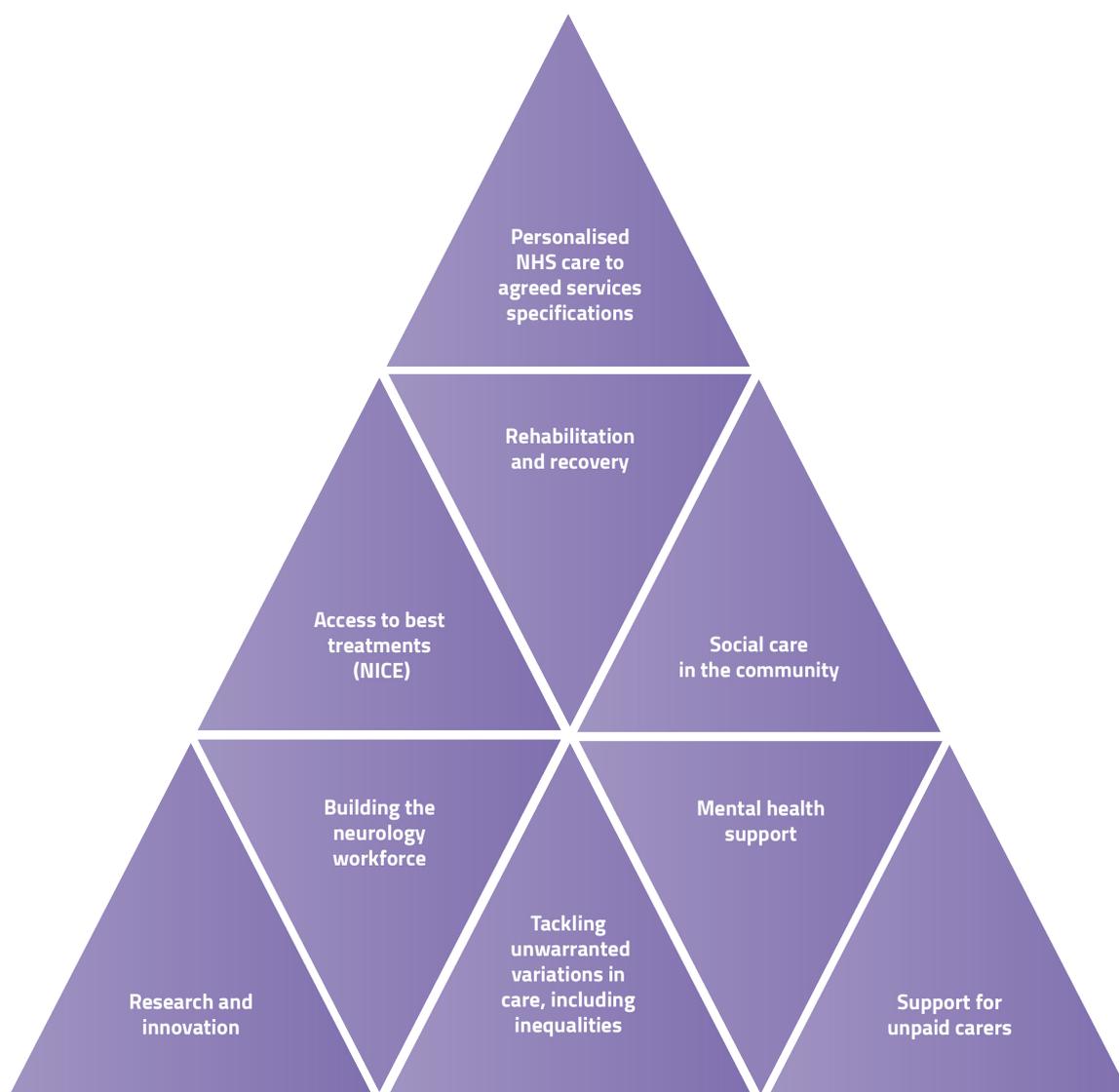


Fig 2. The key elements of a National Plan for Neurology

Planning for the future - securing high-quality services for people with neurological conditions in the long term

In greater detail, a new National Plan for Neurology should include the following key elements:

- NHSE/I and Public Health England should work closely with the National Neurosciences Advisory Group and the Neurological Intelligence Collaborative **to improve the outcomes for people with neurological conditions and to reduce avoidable deaths**, with improved data collection to allow progress and outcomes to be more easily evaluated, including for the management of rare conditions. NHSE/I must ensure that NHS neuroscience service specifications reflect the need for comprehensive and coordinated treatment, care and support across the whole neurological pathway.
- There needs to be **integrated commissioning of services and improved care planning and co-ordination** with a named health care professional responsible for every person's care as part of the NHS's commitment to delivering more personalised care^{xx}. All people with neurological conditions should have access to the support of a multidisciplinary team. Some neurological conditions such as functional neurological disorders (FNDs) and rare neurological conditions do not yet have an applicable NHS service specification, a recommended treatment pathway or applicable NICE Guidelines - a situation which needs to be addressed.
- Research is needed to understand **how care pathways, workforce models and services have changed in response to COVID-19** and the impact this has had on service users, staff and health and care organisations. In particular, research into the impact of different telemedicine and digital tools on the health and care outcomes and experiences of people with neurological conditions should be supported. NHS England/Improvement should work with local NHS organisations to embed this learning from COVID-19 equitably across the country, providing investment in new models of care where appropriate.
- To reflect any move towards more services being delivered via telemedicine, the NHS Tariff should be redesigned to ensure that there is adequate **financial reimbursement of specialist neurology services for virtual consultations**, reflecting the time and support required to deliver these services effectively. This should include the provision of information and guidance to people with suspected or confirmed neurological conditions by clinicians and those making referrals to specialist services.
- Research and action must be undertaken to unearth and **address the pervasive inequalities in health outcomes for people with neurological conditions**, including of Black and Ethnic Minority communities.
- **High-quality neurorehabilitation** is essential to speed recovery, maximise restoration of function and achieve the best possible quality of life for people with neurological conditions such as brain injury - across the whole pathway not just at the front end. Indeed, there is now a substantial body of trial-based evidence and research to support both the effectiveness and cost-effectiveness of specialist rehabilitation^{xxi}. Additional provision must be made for in-patient rehabilitation beds in order that people with acute neurological conditions can continue to receive the neurorehabilitation they urgently need, alongside the needs of new COVID-19 patients.
- **Community rehabilitation services** must also be expanded to reflect the observed neurological impact of COVID-19 on patients. However, the rehabilitation needs of people with existing neurological conditions must not be overlooked; the Alliance is hearing that some people with existing conditions have been discharged from community rehabilitation services and put onto waiting lists that include people recovering from COVID-19. This is not acceptable.

Planning for the future - securing high-quality services for people with neurological conditions in the long term

- Given the low number of neurologists in England compared to many other countries in Europe, a **neurology workforce plan** is urgently required to address this shortage. This should include the training of specialist nurses and allied health professionals to work in the multi-disciplinary teams (MDTs) needed to serve local neurology populations across the country.
- Addressing the **mental health needs** of people with neurological conditions is integral to their care as neurological and mental health conditions so often co-exist. Functional neurological disorders (FNDs), for example, are classed as both neurological and psychiatric conditions. Therefore there needs to be an explicit pathway for people with neurological conditions to be able to access mental health services, including support that is sensitive to their condition, in order to achieve parity of esteem/outcomes for the mental and physical health of people with neurological conditions.
- Many people with neurological conditions need **consistent social care** to help them manage their day-to-day lives. This should not be considered as an 'add-on extra' - it is essential for maintaining their health and wellbeing and to support the many unpaid carers caring for people with neurological conditions. Social care should be properly funded as part of the Government's new plan for social care.
- There is a need for **higher research spending** on developing new therapeutic treatments for neurological conditions. Research spending on neurological conditions from all sources is relatively low compared to some other conditions, and it fell as a proportion of all research spending from 11.6% in 2004/05 to 9.7% in 2018^{xxii}. The pandemic has also had a disproportionate impact on medical research charities that do not provide frontline services as they have not been eligible for COVID-19 related Government support. Yet some of these condition-specific neurological research charities provide vital funding for research, often into rare neurological conditions, which should continue to be supported through agencies such as the National Institute for Health Research (NIHR).
- Research into **understanding the longer-term neurological consequences of COVID-19** should be prioritised as evidence is rapidly emerging that a significant number of people who are hospitalised with COVID-19 go on to experience new neurological symptoms^{xxiii}.

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THE NEUROLOGICAL ALLIANCE

About us

The Neurological Alliance is a coalition of 80 organisations working together to transform outcomes for the millions of people in England with a neurological condition. We campaign for high quality care and support to meet the individual needs of every person with a neurological condition, at every stage of their life. Our work is shaped by the experiences of people with neurological conditions and aims to address the causes of poor care.

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