THE
NEUROLOGICAL
ALLIANCE

Together for the 1 in 6:
England findings from My Neuro Survey

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Living with a neurological condition is hard work. We are in it for the long haul and we dearly value the support of our families, friends and carers on a daily basis. But what is critical for us is the input and expertise we receive from the NHS, the Department of Work and Pensions, our Local Authorities and others to enable us to live our best possible lives.

The data and experiences highlighted in this report make for tough reading. Why? Not enough has changed for people with neurological conditions since the previous survey in 2018. The experiences of others affected by neurological conditions that are front and centre of this report demonstrate starkly and frankly what it's like to live with a neurological condition in 2022.

Despite the incredible efforts of NHS staff, this report highlights that there simply isn't the workforce or services necessary to meet people's needs. We are realists – we have to be. We understand the pressures on the NHS and other public services all too well but we also know that co-ordinated improvements will make a difference to our care.

Establishing a Neuro Taskforce would provide the framework and joined up thinking we need to improve services and support. This, alongside implementation of specific recommendations for England set out in this report provide an opportunity to bring about the essential improvements we need.

Action is the most powerful thing Government can do for us. Decision makers must listen to the thousands of people like me who shared their experiences and back the one in six.

Georgina Carr
Chief Executive
The Neurological Alliance

For too long, people affected by neurological conditions have felt ‘invisible’ – invisible to society, invisible to policymakers, invisible to their employer, invisible to Government. That changes today.

At least one in six people live with a neurological condition in England and over 6,000 took the time to share their experiences through ‘My Neuro Survey’. Too often they told us of the battle they faced to access the care and support they need to best manage their condition.

Four in 10 adults reported receiving no information at diagnosis. More than a third of children, young people and adults said their first appointment with a specialist had been delayed in the last year. More than eight out of 10 adults told us their mental wellbeing was made worse by their condition, with little support available. This must change.

The COVID-19 pandemic has impacted all of us, but not equally. People affected by neurological conditions have been amongst the hardest hit with increased isolation, long waits for appointments and ongoing disruption to care.

Our health and care workforce have worked incredibly hard to provide the best care they can at the right time. But there’s a big and growing challenge ahead. As of March 2022, more than 225,000 people were waiting for either neurology or neurosurgery treatment on the NHS. Nearly 100,000 more people are waiting now compared to a year ago.

One respondent told us “I am a very positive, optimistic person. I have lived a full and happy life with several neurological conditions for most of my life. I have always felt well looked after and cared for by the NHS until the last 2 years. Things have changed; I now feel irrelevant and invisible to the NHS.”

I am confident we can turn this around. With new National Clinical Directors on the way, a new strategy for Acquired Brain Injury and other neurological conditions, and more evidence than ever about what needs to change, we have never been in a better position to make the vital case for improvement.

We’re not short of ideas. This report contains 19 recommendations for the Governments, healthcare professionals, commissioners, policymakers and the voluntary sector that would transform the lives of people affected by neurological conditions.

This is a watershed moment for the services and support millions of people rely on. As a community we’re speaking with one voice when we call on the Government to act and back the one in six.

Professor Adrian Williams
Chair of the NHS England and NHS Improvement Clinical Reference Group for neuroscience

This report comes at a time when the NHS is beginning to emerge from the greatest impacts of the COVID-19 pandemic. The extraordinary response from everyone in the NHS, including of course those providing services to people affected by neurological conditions, must be commended.

However, as this report illustrates so starkly, we have some way to go to address unwarranted variation in access to treatment, care and support. I work with clinicians across the country who want to do just that, and the evidence presented here will undoubtedly help us get there.

We are at a critical moment for neuroscience services in England. Nationally, the NHS England and NHS Improvement neuroscience transformation programme, optimum pathways developed through the National Neuroscience Advisory Group (NNAG) and the Getting It Right First Time (GIRFT) programme all provide much needed evidence as to the change required in order to level up service provision.

NHS England and NHS Improvement will soon appoint new National Clinical Directors in neurology and neurosurgery and spinal surgery, representing an opportunity to build on this work, and bring about integrated services for the 1 in 6 people living with a neurological condition in this country.

Importantly, our workforce have faced unprecedented challenges these past couple of years. Coupled with that, many people with neurological conditions describe in this report the challenges they face in accessing the right specialist at the right time. Now is the time for change, and for us to think differently about how we configure services and specialists. This requires stroke, neuroscience and dementia specialists all working collaboratively, to ensure we are maximising expertise, developing efficient rotas, preparing health systems that are fit for innovation, and providing much needed support to one another.

Executive Summary

A lot has changed since we published our "Neuro Patience" report[i] in July 2019. For many of the one in six people with a neurological condition, very little has changed for the better. The impact of the COVID-19 pandemic has exacerbated issues that have affected people with neurological conditions for years. From delays to accessing vital treatments and support to significant unmet mental health and wellbeing needs, this report highlights the experiences, and in many cases frustrations, of our community.

The renewed public and policy focus on health and social care services post-pandemic provides a watershed moment to put in place the joined-up support necessary for people to live well now and in the future.

As well as the challenges facing people with all long-term conditions such as long and growing waiting lists for elective care, an understaffed and overstretched workforce and a lack of adequate social care support, people with neurological conditions face additional challenges to get the support they need and deserve. Longstanding barriers between physical and mental health impacts of neurological conditions mean that in 2022, some of our community continue to be denied access to vital mental health services and support. This must change.

At the time of writing, latest available data[ii] shows 236,122 people waiting for a neurology or neurosurgery appointment on the NHS in England. This is an increase of over 50% from January 2021. 9,250 people have been waiting more than a year for an appointment.

It is unsurprising that many respondents to our survey who had the financial means to do so are increasingly turning to the private sector for support. A growing two-tier system within neuroscience in England flies in the face of the "free at point of need" ethos that underpins our health system. Many of those who cannot afford to access private healthcare continue to wait, and wait, and wait.

There are glimpses of hope despite decades of neglect. National data and service improvement initiatives including the recent Getting it Right First Time (GIRFT) adult neurology report[iii] have provided recommendations for the system which, if properly implemented, would begin to turn the tide on regional variation in quality of and access to services. The incredible campaigning efforts of the brain injury community has led to a commitment to develop a cross-government UK-wide Acquired Brain Injury (ABI) Strategy[iv], a landmark achievement for the sector.

The NHS England and NHS Improvement neuroscience transformation programme provides much-needed focus on ensuring future commissioning frameworks in England are suitable for neurology and neurosurgery services, with significant investment in the development of regional neurosurgery networks to support implementation. The promise of two new National Clinical Directors, for neurology and both neurosurgery and spinal surgery, is also a huge opportunity.

Renewed focus on rare conditions through the UK Rare Disease Framework[v] and hundreds of millions of pounds investment in research into neurodegenerative disease[vi] provide hope for a better future. But without the necessary workforce, coordination and leadership, they will be unable to deliver the change our community needs.

That's why alongside nation specific recommendations we're calling for a UK Neuro Taskforce to bring together key stakeholders and existing service improvement initiatives from across the UK to drive collaboration and sharing of best practice in tackling common challenges in improving access to treatment, care and support.

1 in 6

people in the UK live with a neurological condition

Delays to treatment and care

55%

of adults reported a delay to a routine neurologist appointment in the last 12 months

59%

of children and young people reported a delay to a routine appointment with a specialist for their neurological condition

Information and Support

40%
Adults

33%
Children and young people

reported not being offered or directed to any information about their condition when they were first told about it

England response numbers

5,593
Adults

470
Children and young people

Mental Wellbeing

82%
Adults

89%
Children and young people

reported their neurological condition made their mental wellbeing worse

Transition

84%

of young people were not offered a named worker to support transition between paediatric and adult services but would find this helpful

Our calls to action

Together with Neurological Alliances across the UK we're calling on the UK Government, Scottish Government, Welsh Government and Northern Ireland Executive to:

- **Establish a UK Neuro Taskforce.** The taskforce would bring together relevant Departments, health and social care bodies, professional bodies, people affected by neurological conditions and the voluntary sector to support greater collaboration and sharing of best practice in tackling common challenges in improving access to treatment, care and support for the one in six people in the UK that live with a neurological condition. Full details of the proposed Taskforce are set out in our UK policy report[vii].

As the Neurological Alliance for England, we're also making the following calls.

We encourage people affected by neurological conditions to:

1. Know that you are not alone. There are hundreds of organisations and millions of individuals who are here for you. If you need information or support but don't know where to turn you can find out about our members and the services they offer through our website[viii]

2. Get involved and campaign for change. Together we can help to improve services, boost investment in research and improve outcomes for people with neurological conditions now and in the future. Together, we're stronger.

The Department of Health and Social Care must:

3. Ensure the NHS People Plan delivers a neuroscience and brain workforce fit for the future. Work with the neurological community, including the Neurological Alliance and neuroscience professional bodies to develop the plan.

4. Ensure the Office for Health Improvement and Disparities (OHID) works with health bodies and the neurological community to develop improved data and insight on the prevalence and incidence of neurological conditions, as well as experience of and access to services.

5. Work with the Treasury to fix the current crisis in social care and bring forward a plan to create a fair, effective and sustainable social care system in line with the Care and Support Alliance (CSA) Seven Tests[ix].

The Department for Work and Pensions must:

6. Ensure the welfare system enables people to manage the extra costs associated with their condition, supports employment as appropriate and protects people with neurological conditions from falling into poverty by:

    - Immediately uprating benefits in line with current levels of inflation.

  - Revising assessment regulation and processes to accurately capture the realities of living with a neurological condition and ensure people get the right support first time round – reducing the burden of appeals on individuals and the system.

  - Working with welfare assessment providers and the neurological community to ensure assessors are trained to understand the realities of living with a neurological condition.

We urge NHS England and NHS Improvement to:

7. Implement and track the recommendations made by the Getting it Right First Time (GIRFT) national report for adult neurology[x] including:

   - Recommendation 2 – Embed neurology liaison services to allow timely access to neurologist advice at all sites.

   - Recommendation 14 - Develop clinically led subspecialty regional networks, starting with epilepsy and MS, with links to local multi-disciplinary teams (MDTs).

   - Recommendation 20 - Review the organisation and roles of neurologists and neurology trainees to better meet patient needs and maximise training quality

   - Recommendation 25 – Create a neurology dashboard to enable monitoring of key metrics to support continual quality improvement.

8. Recruit National Specialty Advisers (NSAs) for neuropsychology and neuropsychiatry to lead and coordinate national service improvement efforts alongside the incoming National Clinical Directors (NCDs) for neurology and neurosurgery and spinal surgery.

9. Ensure people are given the choice of a face-to-face, video or telephone appointments where appropriate.

Those planning, commissioning and delivering services must ensure:

10. Every Integrated Care Board (ICB) works with the neurological community in their area to map current service provision for people affected by neurological conditions and set out plans to address shortcomings in care.

11. Every ICB has a clinical and patient lead for services for people affected by neurological conditions in their area.

12. Every Integrated Care Partnership (ICP) includes people affected by neurological conditions or a representative from the neurological VSCE sector.

13. Trusts, provider collaboratives and ICBs work together to implement common features of neuroscience pathways, including named care coordinators, access to mental wellbeing support and timely access to specialists, alongside other best practice recommendations included in:

- National Neurosciences Advisory Group (NNAG) Optimum Clinical Pathways[xi]
- NHS RightCare Toolkits & Pathways[xii] on progressive neurological conditions, headache and migraine and epilepsy
- Relevant NICE Guidance and Quality Standards[xiii]

14. NHS Trusts review their local Mental Health Commissioning Policies, to ensure that these facilitate access to specialist mental health support for everyone with a neurological condition.

15. NHS Trust contracts plan for conversations about mental wellbeing in consultations, with referrals and signposting where necessary.

16. ICBs and NHS Trusts map current mental health and wellbeing support available in their area for people affected by neurological conditions. Appropriate triage, referral routes and a matched care approach must be available in every area, ensuring people can access support according to their needs.

17. ICBs and NHS Trusts provide transition support to every young person with a neurological condition and their parents or guardians, including a named worker.

18. ICBs and NHS Trusts work with the voluntary sector and local people to understand local need and implement coordinated and integrated care for people affected by neurological conditions.

19. NHS Trusts provide every person diagnosed with a neurological condition with information in a format that is accessible and appropriate for them, including written information.

20. NHS Trusts build in the time and resource necessary to provide follow-up appointments with an appropriate specialist for all newly diagnosed people to discuss their treatment and care options.

21. NHS Trusts conduct an audit of the support available for people newly diagnosed with neurological conditions including 'Newly Diagnosed' courses and address any gaps, including through collaboration with the voluntary sector.

We urge the voluntary sector to:

22. Work together to ensure we are hearing from, supporting and representing a diversity of people with neurological conditions. This includes sharing approaches to embedding equity, diversity and inclusion in our work.

About the report

This report focuses on the experiences of the 5,593 adults and 470 children and young people who responded to My Neuro Survey and reported living in England. Our colleagues across the UK are developing similar reports to highlight the experiences of respondents living in Scotland, Wales and Northern Ireland. For further detail about the methodology and data, please see the accompanying technical report[xiv].

People affected by neurological conditions often need a range of treatment, care and support – including primary, secondary, tertiary, quarterney and community services, as well as support to retain financial independence and manage extra costs associated with their condition. That means they are often the people who have the best understanding of how different parts of the health and care system work together. This, combined with the fact that there is a lack of routinely collected data related to services for people with neurological conditions, makes the survey and these reports even more important.

Summary of UK key themes

1 in 6 people in the UK live with a neurological condition but there simply isn't the workforce or services in place to provide the support they need and deserve. From delays to lifechanging treatment and care to a lack of mental health and wellbeing support, over 8,500 people across the UK shared their experiences as part of My Neuro Survey. UK responses and key themes are explored in more detail in the UK report[xv] but we've included a summary of the key UK below:

Mental Wellbeing

The right support for your mental health and wellbeing is critical when you live with a neurological condition – yet 6 out of 10 adults told us they hadn't been asked about their mental wellbeing by a healthcare professional in the past three years.

Delays to treatment and care

Despite the best efforts of services and healthcare professionals across the UK, there are serious delays to treatment and care with more than half experiencing delays to a routine neurologist appointment.

Information and support from diagnosis

Finding out you have a neurological condition is scary and confusing. Receiving the right information and support can make a real difference. Despite this, a fifth of all UK respondents reported not being given an explanation when they were diagnosed. 4 in 10 adults and a third of children and young people said they were not offered or directed to any information.

This must change. We're calling on Governments across the UK to establish a Neuro Taskforce to drive collaboration and sharing of best practice in tackling the crisis in services and support for the one in six people with a neurological condition and plan services fit for the future.

From "Neuro Patience" to now

"Neuro Patience" was the title of the report[xvi] that followed the 2018/19 National Neurological Patient Experience Survey policy report. There were three key messages drawn from the experiences of those who responded. It called for care and support for people with neurological conditions to be:

- **Accessible**, the speed of access to specialists must improve overall and should not vary depending on where you live.
- **Personalised** and tailored to the needs of each individual.
- **Holistic**, addressing people's mental health, social care needs, and their financial security.

These themes are as relevant today as they were almost four years ago. This report once again highlights the issues people continue to face around timely access to treatment, care and an accurate diagnosis. Mental health and wellbeing are also a key message in 2022, rather than improving there is evidence to suggest that people feel their mental wellbeing needs are being met less now than they were then.

"Neuro Patience" was written with intended irony in 2019 but in 2022, it is more akin to a cruel joke. The patience of the neurological community has long run out. For many, frustration has turned to resentment and anger – this was clear in the thousands of experiences shared in response to My Neuro Survey.

It would not be possible or indeed desirable to cover even the toplines of everything of note that has happened in the last four years. There are, however, some events that continue to have such a profound impact including on people affected by neurological conditions that this report would be weaker if they were not referenced.

COVID-19

Early 2020 saw the first cases of coronavirus reported in the UK. This quickly became a pandemic of the likes not seen for a generation impacting every part of people's daily lives. While the pandemic affected everyone, it did not impact everyone equally.

Data from the Office for National Statistics (ONS)[xvii] showed that people with disabilities were more likely than non-disabled to report that the pandemic made their mental health worse. An impact that is supported by data from My Neuro Survey.

People with some neurological conditions including Parkinson's, motor neurone disease (MND) and Multiple Sclerosis (MS) were identified[xviii] as being at moderate risk of complications due to COVID-19 and some with comorbidities were part of the cohort advised to "shield" by the Government.

> **Initial diagnosis excellent. But lockdown and change of consultant with need to "shield" for most of 18 months due to steroids followed by immunosupression drugs during a pandemic linked to another chronic condition (diabetes) has been stressful. This stress has been discounted then ignored by the medical profession. I am fortunate to be in remission.**
>
> - Adult with a neurological condition

The pandemic has also had a significant impact on access to health and care services including for people with neurological conditions as discussed in more detail in the following sections. The National Neurosciences Advisory Group (NNAG) report[xix] on lessons learnt from the pandemic highlighted some of the impacts of COVID-19 on neuroscience services in England:

- A growing number of long-covid patients, increasing demand for neuroscience services.
- A slowdown in referrals with specialist centres for MND experiencing an estimated 30-50% drop in referrals, leading to delays in diagnosis and support.
- Redeployment to COVID-19 wards and increased pressure to reduce waiting lists had a significant impact on the mental health of health and care professionals. Risk of losing much needed specialist expertise after COVID-19.

The impact of the pandemic on people and services continues to be felt. What this means for people with neurological conditions in England is a key theme of this report.

Cost of living

As we emerge from the worst of the pandemic many are facing a very challenging financial situation with rising energy prices and inflation fueling a cost-of-living crisis. As with the COVID-19 pandemic, the impacts of rising costs are not felt equally and again it is people with disabilities and long-term conditions who are often hit the hardest.

Financial difficulties often contribute to or exacerbate mental health and wellbeing challenges. Some people with neurological conditions rely on welfare support yet benefits have seen real terms cuts despite rising prices and fixed costs.

> **Life costs more for disabled people and their families, spending more on essential goods and services like; heating, insurance, equipment and therapies. These extra costs mean disabled people have less money in their pocket than non-disabled people, or simply go without.**
>
> - Scope, Extra Costs[xx]

> **I live in poor quality private rental flat. Limited options to move due to lack of local housing. The wintertime worsens MS symptoms because of flat being inadequately managed, insulated and building damp/ general disrepair issues. Very concerned about affording ever increasing Gas & electric / food and clothing. Worsening stress / anxiety and MS symptoms.**
>
> - Adult with Multiple Sclerosis

Workforce

Patient organisations, professional bodies and the health system itself all highlight the workforce challenge that continues to blight neurosciences in England.

It's not just a chronic shortage of neurologists but all allied health professionals, specialist nurses, neuropsychiatrists, neuropsychologists, care workers and almost all other health and care professionals. The compounding impact of the pandemic on an already overstretched health and care workforce cannot be overstated, including on mental health and wellbeing, burnout and retention[xxii].

The complexity of neurological conditions means people often require the support of multiple services to manage their condition, but we know that too often the specialists people need simply don't exist in the NHS.

The distribution of our workforce is also a key issue– around a third of neurologists, for example, are based in the South East of England[xxiii]. Again, this is recognised by the system and others but we're yet to see meaningful action to address it.

An understaffed and overstretched workforce is a key contributor to almost all the challenges highlighted in this report. The often-heroic efforts of health and social care colleagues in the most difficult of circumstances alone cannot sustain the system. A long term and properly funded workforce plan for neurosciences must be at the heart of efforts to build services fit for the future.

> **The UK was ranked 44 out of 45 European countries for number of neurologists per population with only Ireland being worse.[xxi]**
>
> - ABN Neurology Workforce Survey, 2018-19

The Health and Care Act

April 2022 saw the Health and Care Act[xxiv] enter the statute books in England. It is a wide-ranging piece of legislation that will have a significantly change how health and care services are delivered in England.

One of the most notable changes is the establishment of Integrated Care Systems (ICSs), that will split the country into 42 health footprints. Many services for people affected by neurological conditions, including much of neurology, neurosurgery, neurophysiology and specialised rehabilitation will now be commissioned at an ICS level. It is yet to be seen what this will mean for services people with neurological conditions rely on.

The decision to delegate responsibility for commissioning some specialised services previously commissioned centrally by NHS England to individual ICSs is a significant change. Many people with neurological conditions rely on these services and there is a risk that devolving commissioning responsibilities could exacerbate existing regional variation in access and quality. There is also a clear opportunity for change. The establishment of Integrated Care Boards (ICBs) and Integrated Care Partnerships (ICPs), for example, could enable greater coordination around planning and delivery of care.

Neuroscience Service Improvement Initiatives (2019 – 2022)

Despite the significant turmoil experienced in the past three years, several service improvement initiatives have been retained, although their pace has been slowed by the pandemic.

- **The Getting it Right First Time (GIRFT) national report for adult neurology**[iii] was published in September 2021. It represented the first systematic national analysis of neurological services in England. The report made a total of 26 recommendations focusing on access to care, outpatient clinics and care pathways. The report also highlights significant variation in access to services and patient care along with workforce challenges.
- **Getting it Right First Time (GIRFT)** have also produced reports on spinal surgery[xxv] in January 2019 neurosurgery and stroke[xxvi] in April 2022. These specialties are closely interconnected with neurosciences making them relevant for reference here.
- NHS England and NHS Improvement **Neurosciences Transformation Programme**[xxvii] seeks to support emerging regional teams as well as ICS level commissioners in the NHS, through establishing 'what good looks like' for specialised neuroscience services for a local population. There are two main workstreams to the programme: adult neurosurgery and specialised neurology services for adults. Six optimum models of care have been developed – on MS, epilepsy, neuroautoimmune disorders, subarachnoid hemorrhage, brain tumours and pituitary surgery.
- NHS England and NHS Improvement **Outpatient Transformation Programme**[xxviii] was launched during the pandemic. In neurology, new guidance is being developed on the use of triage, advice and guidance, as well as remote consultations. The Neurological Alliance has worked closely with the programme, resulting in their support of our guidance on 'Patient Initiated Follow-Up' (PIFU).
- NHS England and NHS Improvement Delivery plan for tackling the COVID-19 backlog of elective care[xxix] ("**Elective Recovery Plan**") was published in February 2022 and sets out how the health service plans to tackle

the backlog of elective care and reduce waiting times. This includes action to address backlogs in neurosurgery[xxx].

- The National Neurosciences Advisory Group (NNAG) has continued to act as a key forum to enable collaboration across neuroscience:

- **Optimum Clinical Pathways**[xi] have been developed across MND and neuromuscular conditions, movement disorders, traumatic brain injury (TBI), functional neurological disorders (FND) and migraine, headache and facial pain. Pathways covering key themes of care, on genetics, rehabilitation, mental health and wellbeing and transition between paediatric and adult care are also in development.

- **Lessons learnt from the COVID-19 pandemic:** Priorities in care for people with neurological conditions after the pandemic[xix], April 2021.

- **Neurology Outcomes Discussion**[xxxi], September 2021. Recognising the importance of clear, defined outcomes of good neurological care, the discussion brought together the community to assess what is required and next steps.

Responses

The more than 6,000 people in England that responded to our surveys shared a huge amount of information about their lives. Below we explore their responses in more detail, including:

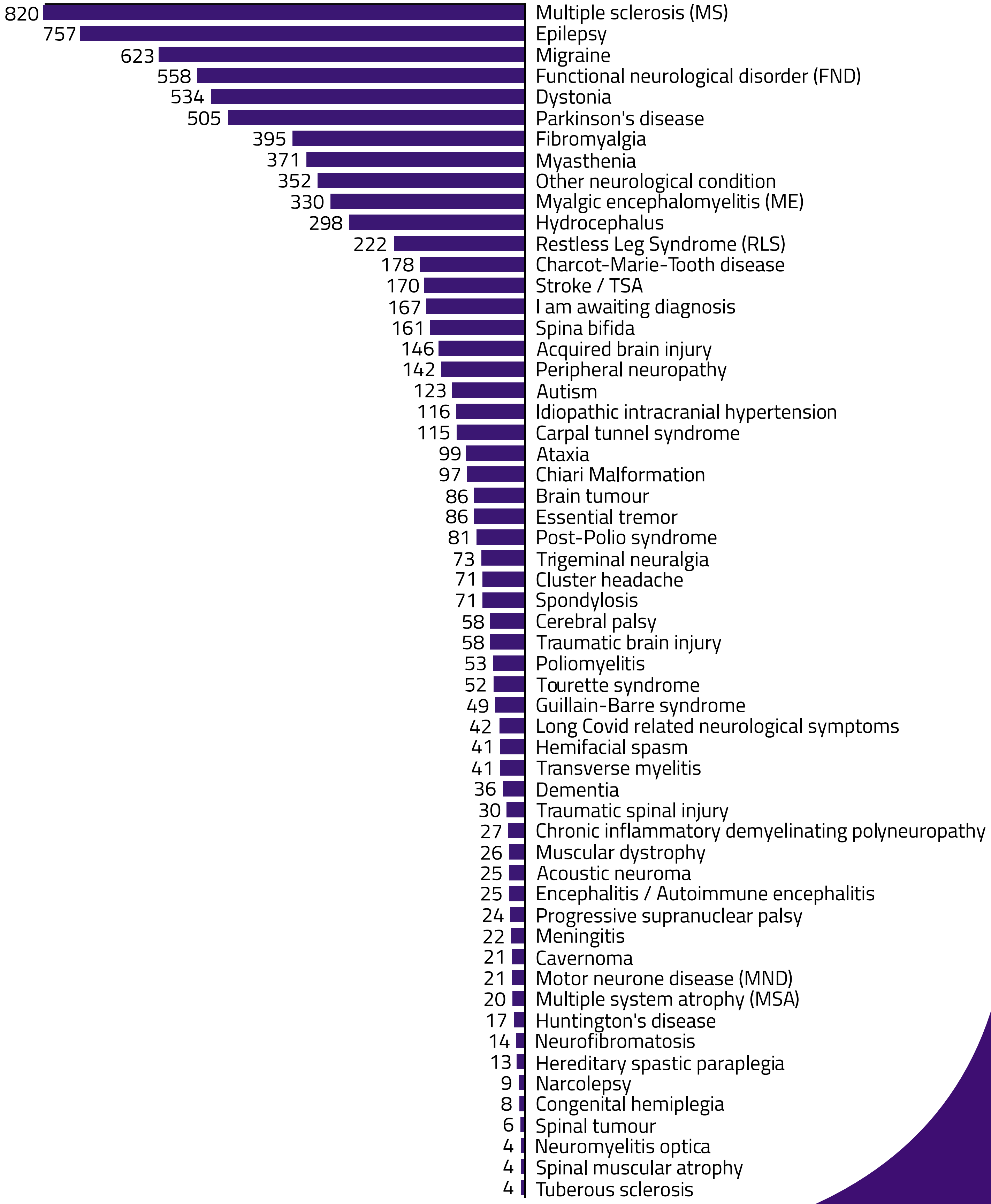
- The impact of living with a neurological condition
- Experience and information at diagnosis
- Access to treatment and support
- Remote consultations
- Going private
- Mental health and wellbeing
- Access to social care
- Access to financial support
- Access to education and employment

Data from key questions will be presented in each section sitting alongside the experiences of people who shared more information with us. The data is important, but the people behind it are what really matters. We've made every effort to put our community front and centre of this report.

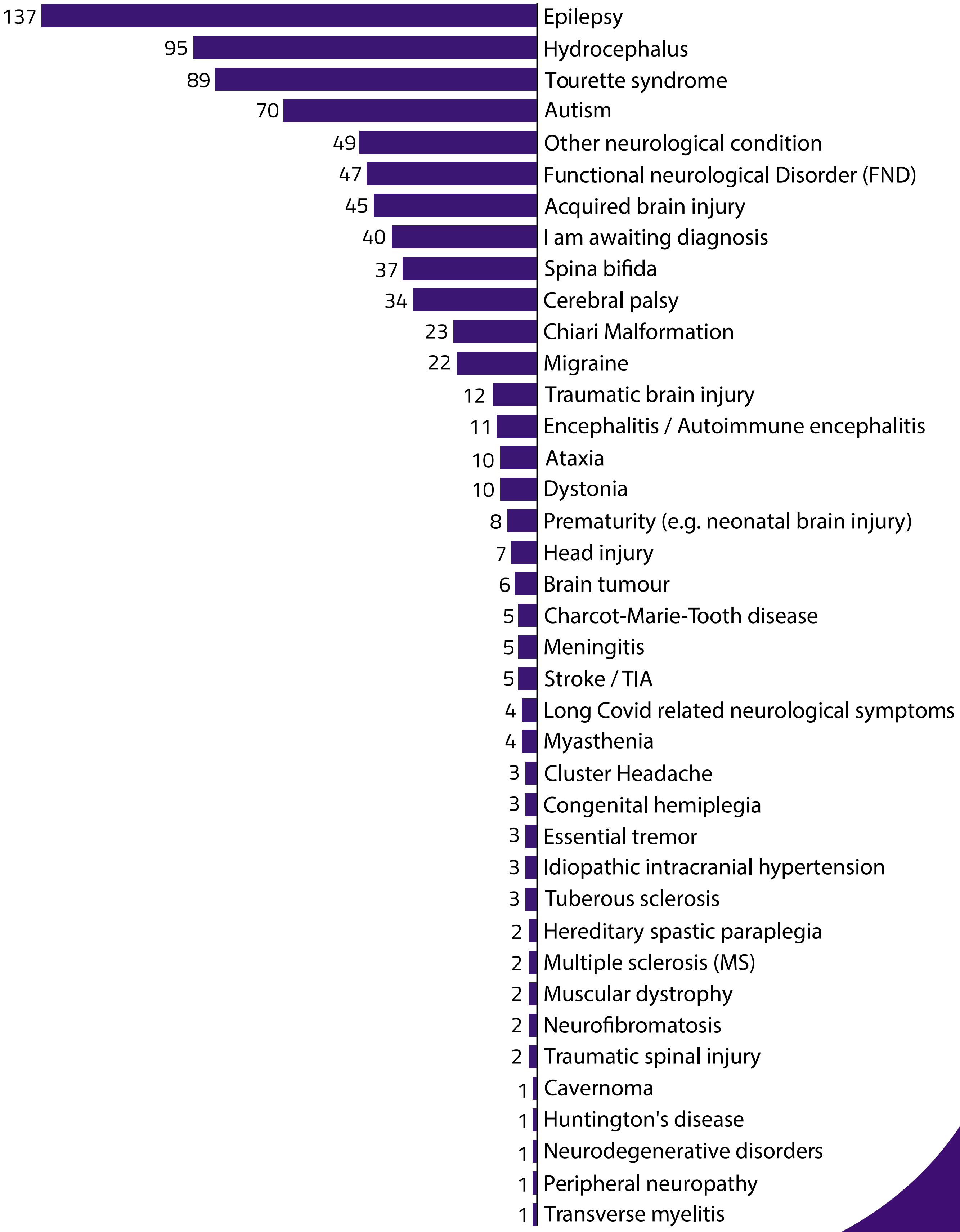
One in six people in the UK live with a neurological condition. There are over 600 known conditions varying from those that are relatively well-known such as epilepsy and MS to more rare conditions including the Ataxias and Transverse Myelitis.

We received responses from people affected by more than 60 different neurological conditions. The graphs below show how many responses we received from people with different neurological conditions in England.

Adult conditions



Child/ young person conditions



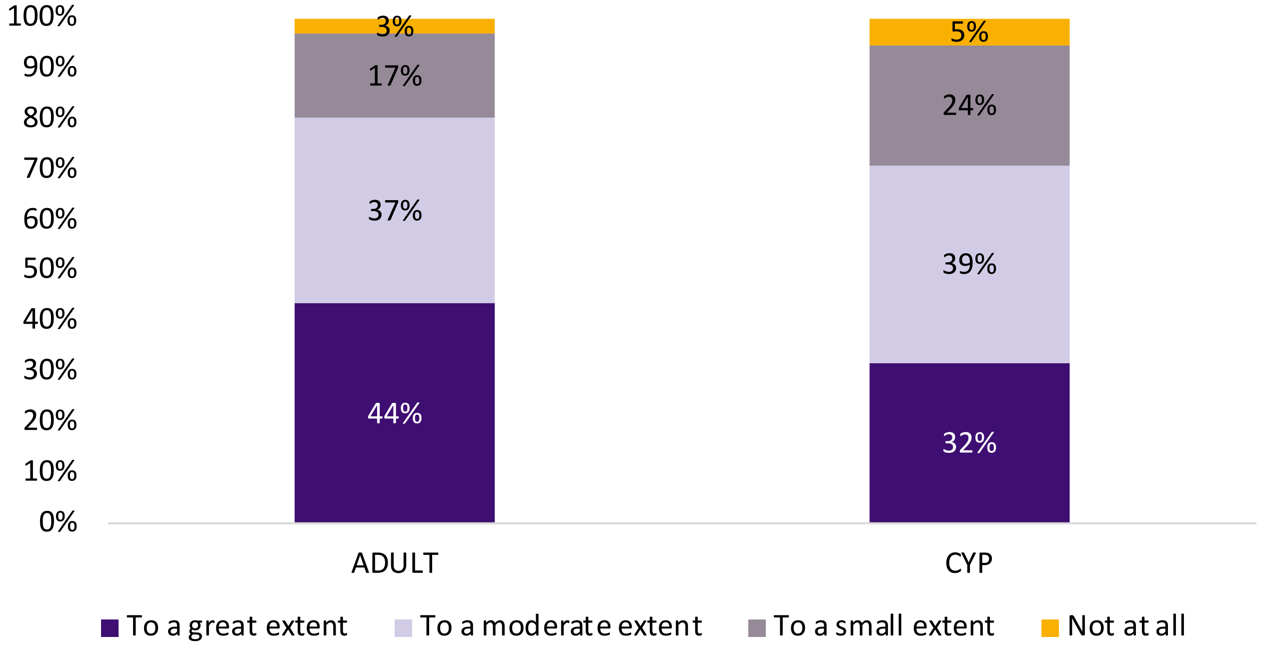
The impact of living with a neurological condition

Neurological conditions can and do impact every aspect of life, from eating and sleeping to working and playing. Too often the impact of these conditions is not well known or understood by wider society. This must change.

A better general understanding of how, and how much, neurological conditions can affect people is vital. For some, it would mean the difference between having to fight for the support they need at work or school and having that support available to them from the start. For everyone affected, it would make life that little bit easier.

> **The devastating effect of migraine is not realized at all. People do not understand the condition or have any idea of the profound affect upon every aspect of a sufferers life.**
>
> - Adult with migraine

To what extent overall does your neurological condition(s) impact your quality of life?

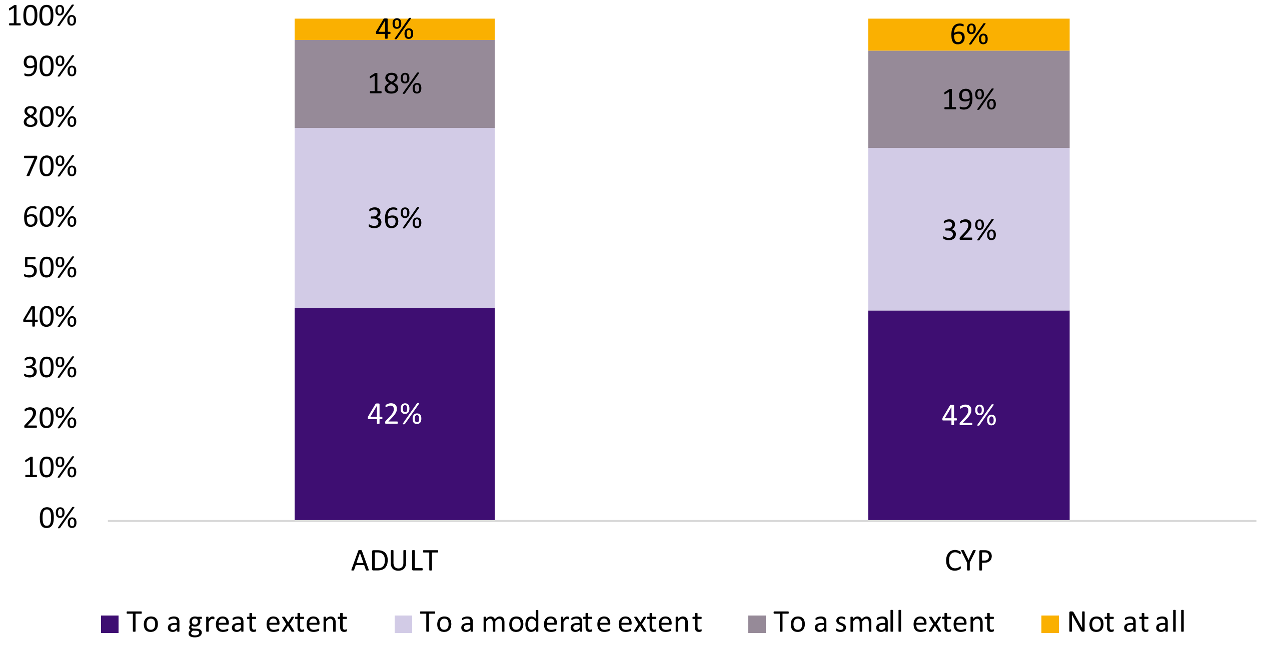


CYP: Child/young person

Neurological conditions can have huge consequences on quality of life. A lack of or limited understanding and awareness of neurological conditions and how they can impact people can often makes a challenging situation even worse. 81% (n=4,454) of adults in England reported their condition impacted their quality of life to a great or moderate extent, the same percentage as in 2018/19 suggesting there has been no improvement. 71% (n=328) of children and young people said the same.

> **I have several seizure types daily. It greatly affects my quality of life. I love my school and they are very helpful and understanding. I wish there was more awareness of epilepsy and more research into finding a cure.**
>
> - Child/young person with epilepsy

To what extent does your neurological condition(s) affect your day to day activities?



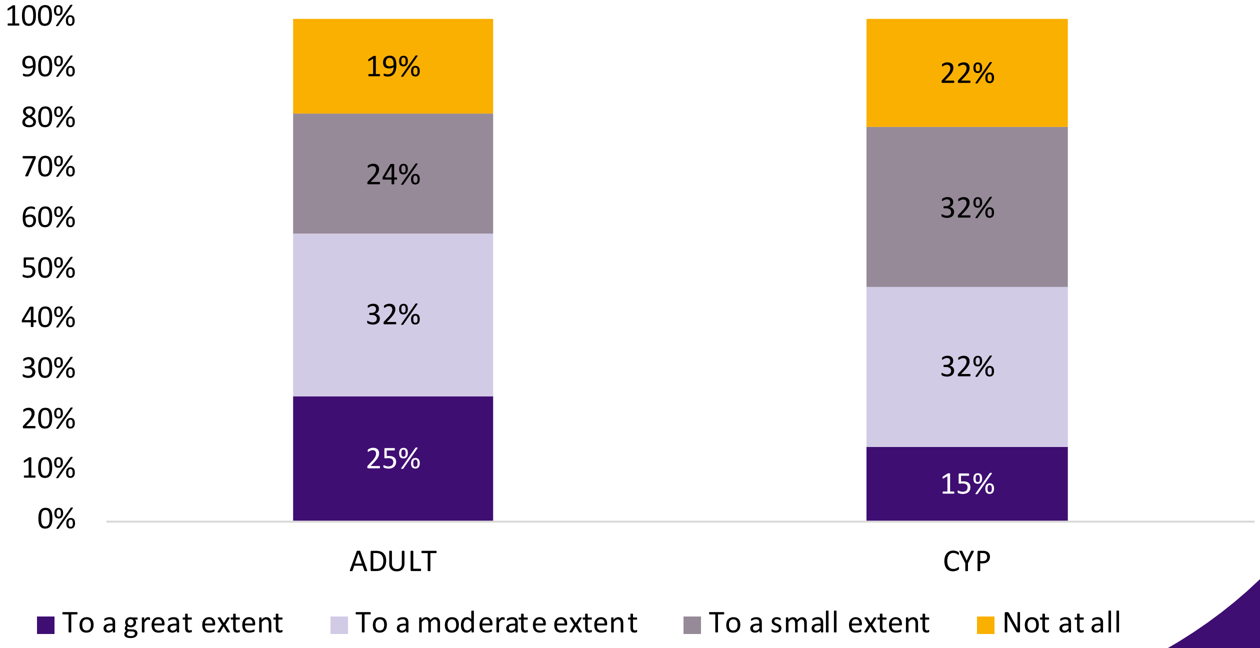
CYP: Child/young person

Things that people without a neurological condition might take for granted can be made much harder or even impossible for some people as a result of their condition. The impact on every part of a person's life came through clearly.

78% (n=4,345) of adults and 74% (n=344) of children and young people reported that their condition affected day to day activities to a great or moderate extent compared to 77% of 2018/19 respondents. A slight worsening compared to the previous survey for adults.

> **"Severe Restless leg syndrome [RLS] is an affliction that affects every part of daily life. I no longer feel safe to drive due to lack of sleep. Days out are a nightmare because of RLS on the journey home. I dread holidays. Evenings watching the tv are disturbed. I dread going to bed even though I am exhausted...I have suicidal feelings in the past because of this affliction but for the most part it is not treated seriously by the medical profession.**
>
> - Adult with Restless Leg Syndrome (RLS)

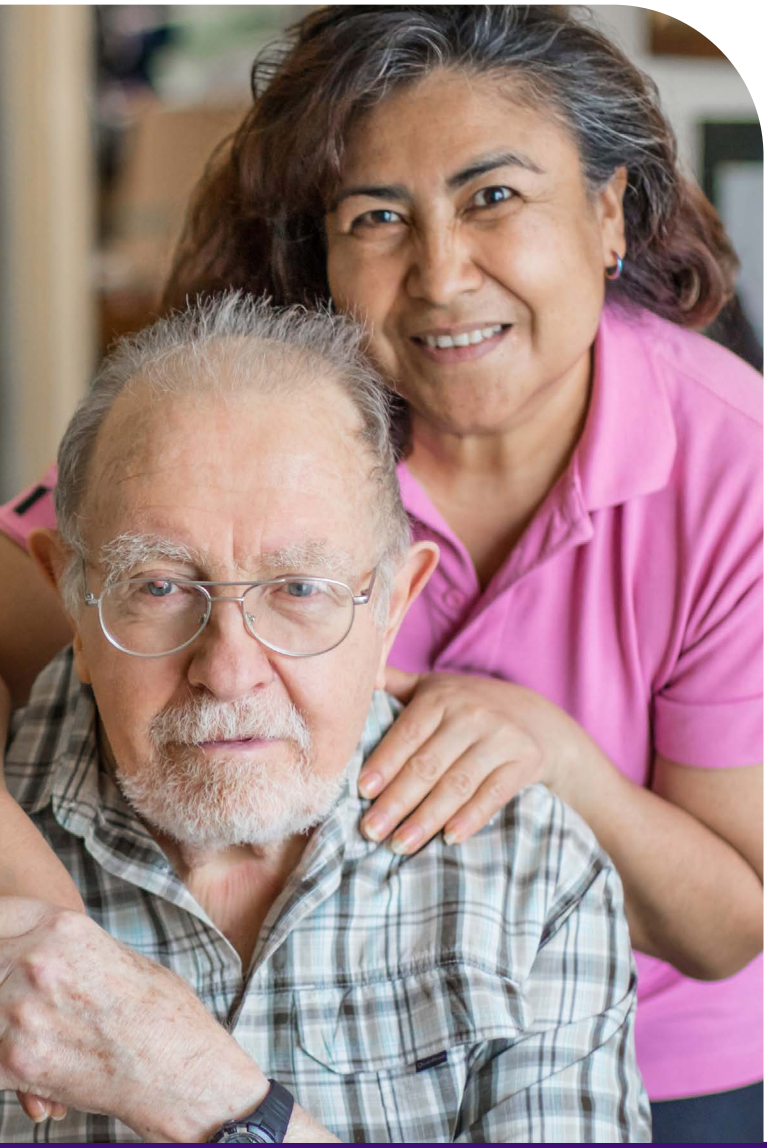
To what extent overall does your neurological condition(s) cause you pain?



CYP: Child/young person

Some neurological conditions or symptoms can cause people significant pain. There were many references to pain in free text comments and It's clear that for some, their pain management is inadequate. Others mentioned that they have access to a pain clinic or pain specialist, but many more do not have this option.

Delays to accessing tests and seeing specialists can exacerbate symptoms of neurological conditions, including pain.



> **Ataxia is a complex condition … I suffer with pain, digestive problems, insomnia, incontinence, disturbed vision, poor balance, fatigue. An annual short consultation is not sufficient to address all these problems.**
>
> - Adult with Ataxia

> **I have been in constant pain now for 6 months and only avoided even further delay in seeing the pain specialist because we paid privately for a MRI scan rather than wait 'many months' for a NHS MRI scan.**
>
> - Adult with a neurological condition

Experience and information at diagnosis

Getting an accurate diagnosis as quickly as possible is the first step towards getting the necessary treatment, care and support. Amongst other things, a timely diagnosis can enable people to access treatments or specialists necessary to slow the progression of a condition, manage symptoms or provide adaptations to maintain independence or allow for optimal planning for end-of-life care.

Delays to getting a diagnosis often impact on a person's mental wellbeing. Persistent symptoms alongside a lack of clarity over what is causing it and often no treatment or support can cause worry and distress as highlighted by a person living with MS.

> **I felt like when I was diagnosed with RRMS [Relapsing Remitting Multiple Sclerosis] it wasn't handled professionally at all and found it very upsetting and hard to take. It came across so casually from the neurologist when he told me... I was just told in-front of the rest of the ward. To him it might of been something he tells people but to me it's the rest of my life I have to deal with and it's still upsetting to me this day 3 years later on....**
>
> - Child/young person with MS

> **I first experienced symptoms in April 2020 and finally been diagnosed with MS in Jan 2022. The time taken to get to this point and time taken to get scans, Lumbar Puncture and appointments to see specialists has been completely unacceptable, causing me distress and worry unnecessarily.**
>
> - Adult with MS

When asked about the length of wait experienced between first experiencing symptoms to getting a diagnosis:

- 35% (n=1,931) of adult respondents reported waiting more than 12 months.
- 14% (n=784) reported waiting 7-12 months and 3-6 months (n=788)
- 19% (n=1,063) reported a wait of less than 3 months.
- 9% (n=493) responded as "don't know/ can't remember" and
- 7% (n=394) that the question was not applicable to them, this is likely to include those who are still awaiting a diagnosis.

Responses to the same question from the children and young people's survey show less people waiting more than 12 months, although there is still significant room for improvement:

- 24% (n=109) of children and young people respondents reported waiting more than 12 months between first experiencing symptoms and getting a diagnosis.
- 15% (n=71) reported waiting 7-12 months and
- 14% (n=67) reported waiting 3-6 months.
- Waits of less than 3 months were reported by 33% (n=154) of children and young people respondents.
- 2% (n=10) responded as "don't know/ can't remember"
- 11% (n=52) that the question was not applicable to them, this is likely to include those who are still awaiting a diagnosis.

> **"After 2 years of being passed from pillar to post I was eventually seen by a Physiotherapist who recognised my symptoms and referred me to see a Neurologist who after just 10 minutes diagnosed me with Parkinson's disease. If I had been diagnosed 6 months earlier I might have been able to keep working but without the correct medication I just couldn't function.**
>
> - Adult living with Parkinson's

For children and young people and those who care for them, the impact of being unable to get an accurate diagnosis can be severe. A respondent whose son has Tourette's Syndrome highlighted the challenges they have faced when trying to get a diagnosis, with different specialists and services unable or unwilling to see them or provide a confirmed diagnosis:

Finding out that you have a neurological condition can be life changing. This set of questions were asked to respondents who indicated they received their diagnosis within the last 10 years.

We asked people whether their diagnosis was handled sensitively with 69% (n=2,122) of adults reporting yes, either definitely or to some extent. 32% (n=980) of adults reported their diagnosis was not really handled sensitively or not at all. When asked how well their diagnosis was handled, 59% (n=209) of children and young people reported it was good or excellent while 41% (n=148) reported it was average or poor.

As well as a need for healthcare professionals to handle such news sensitively, it is vital people are given an explanation that they and those close to them understand. By their nature neurological conditions are often complex making an explanation from a specialist even more important.

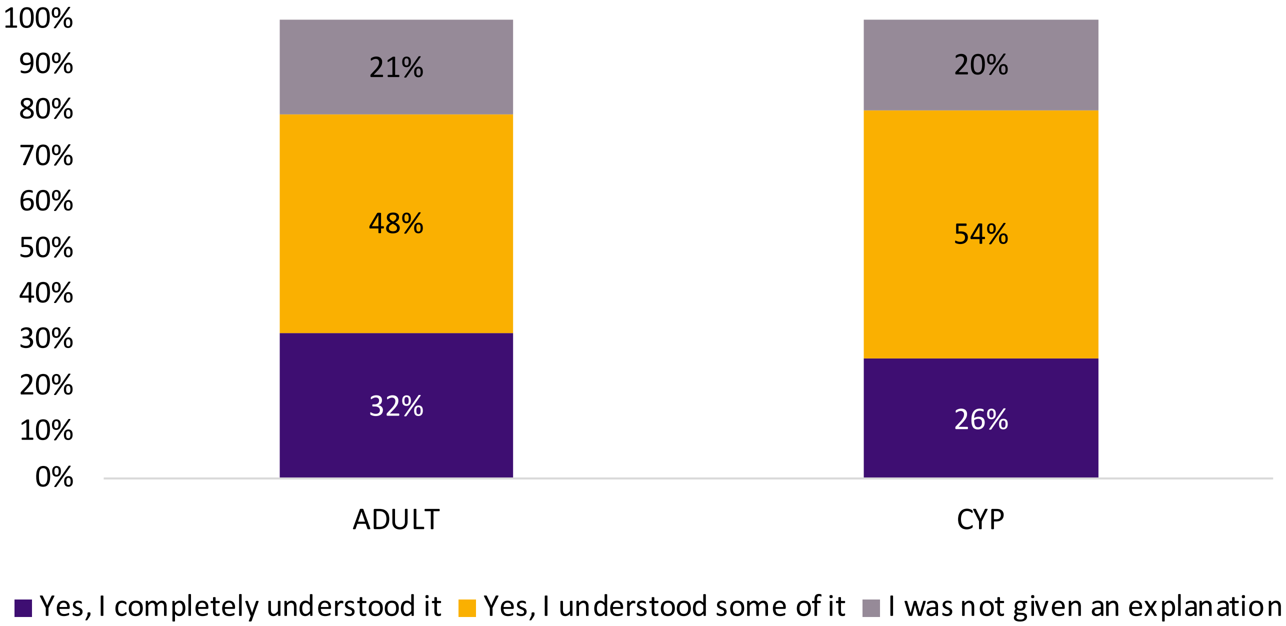
We asked people whether they understood the explanation given to them at their diagnosis or when they were first told about their condition. 80% of respondents across both surveys reported either completely understanding the explanation given to them or understanding some of it. Of particular concern was the 20% of children and young people respondents (n=67) and 21% of adult respondents (n=633) who reported not being given an explanation.

> **“My son's Tourette's is getting worse we are being passed from pillar to post trying to get a diagnosis. GP was unhelpful until a complaint was made then he sent the referral which has since been rejected by the paediatric neurologists and told to refer to CAMHS who will most likely say they don't diagnose Tourette's syndrome and that we should see a neurologist. All whilst my 10 year olds tics are becoming more complex and frequent. He suffers from pain in his neck from all the head jerking, he has night terrors and sleep walks often, his anxiety is increasing, he has outbursts of rage, and is embarrassed by his vocal tics. Getting a diagnosis would help him own his condition and help him understand what it is and be easier to access support.**

> **I had a three minute appointment with a neurologist [REDACTED] in a corridor and he told me I have [Functional Neurological Disorder] with no testing apart from and MRI scan. I asked him to explain the condition and he told me to google it.**
>
> - Adult with Functional Neurological Disorder

> **Diagnosis of Tourette's was a line added in paediatric report. No discussion or explanation with patient (age 9 at time) or parent. No support or advice offered even 4 years later.**
>
> - Child/young person with Tourette's Syndrome

Did you understand the explanation given to you at your diagnosis / when you were first told about your condition?



CYP: Child/young person

It is concerning that something so important as an explanation when receiving a diagnosis is reportedly not happening for one in five respondents.

There is potentially a difference in understanding between healthcare professionals and people receiving a diagnosis around what constitutes an explanation in this context – a perception gap. While this is something that merits consideration, what matters is whether a person feels they have received and understood the explanation of their diagnosis. More research and engagement between people affected by neurological conditions and healthcare professionals is needed to ensure everyone receiving a diagnosis receives an explanation they recognise and understand.

Finding out that you have a neurological condition can lead to you having countless questions. Despite this, appointments with specialists are often short and infrequent and people can struggle to contact their specialist in between appointments. This makes access to high quality written information vital – ensuring that people have information to refer to.

Some neurological conditions can also affect cognition and memory making it more difficult to remember information that might be given verbally during a diagnosis. There is often a need to explain your diagnosis to others including family, friends or wider support networks making access to high quality written information about your condition even more important.

NICE Guidelines – Information at Diagnosis

The National Institute for Health and Care Excellence (NICE) recognises the importance of information at diagnosis, including written information.

Information at the time of diagnosis - MS[xxxii]

1.2.2The consultant neurologist should ensure that people with MS and, with their agreement their family members or carers, are offered oral and written information at the time of diagnosis.

Information and support after a first seizure – Epilepsy[xxxiii]

1.1.8After a first seizure, give the person, and their family and carers if appropriate, information about...

1.1.9After a first afebrile seizure in a child, explain to their parents or carers how to self-refer the child urgently if they have a further seizure.

Communication with people with Parkinson's and their carers – Parkinson's[xxxiv]

1.1.3 Because people with Parkinson's may develop impaired cognitive ability, communication problems and/or depression, provide them with:

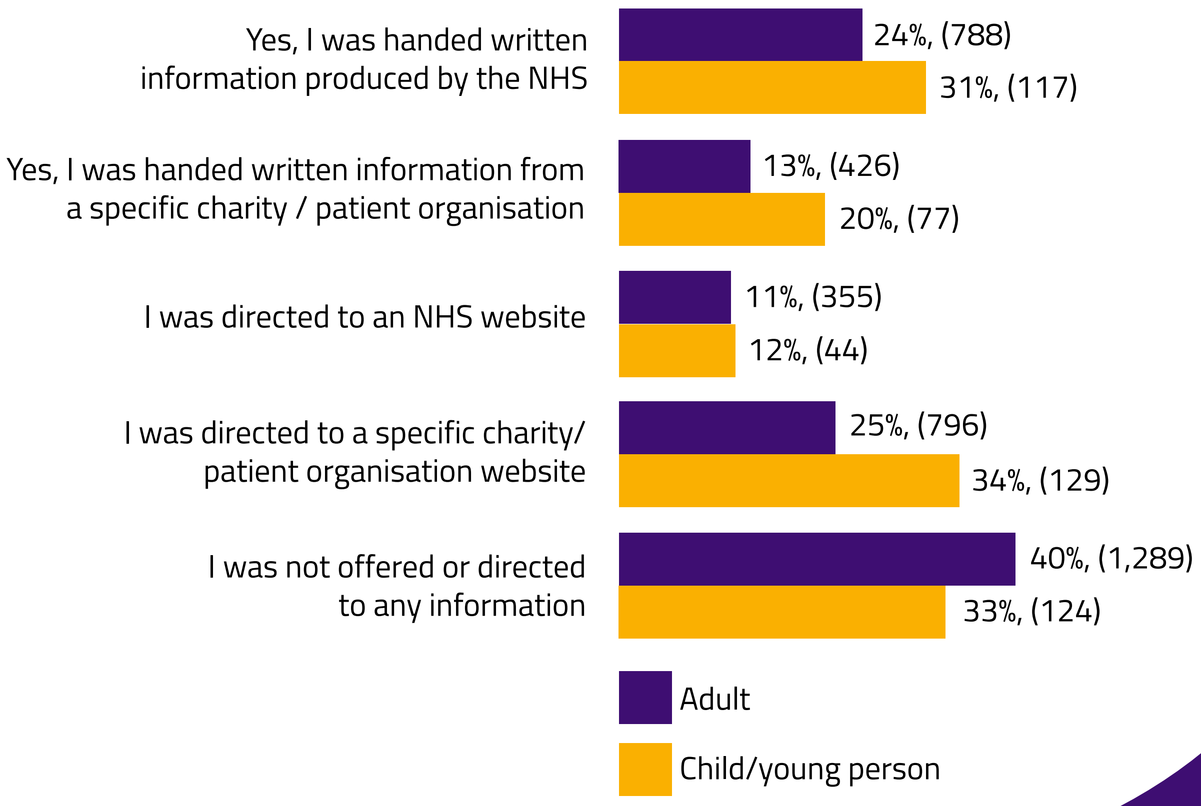
- both oral and written communication throughout the course of the disease, which should be individually tailored and reinforced as necessary
- consistent communication from the professionals involved. **[2006]**

Despite its importance, 40% of adult respondents (n=1,289) and 33% of children and young people (n=124) reported not being offered or directed to any information about their condition when they were told about it. This must change.

A lack of information about a condition or the impact it could have on a person's life can make a difficult situation even harder. It can also mean people do not have the information they need in order to make informed decisions about their treatment and care.

> **“We have had to fight for support for our child and left hospital following brain surgery with little or no information and certainly no ongoing support. We have had to find everything ourselves and it's hard.**
>
> – Child/young person with a neurological condition

When you were told you had a neurological condition, were you given written information about it? Please tick all that apply



Charities and patient organisations, including many Neurological Alliance members, are an important source of information for people with neurological conditions and are often signposted to by healthcare professionals. 34% of children and young people (n=129) and 25% of adults (n=796) reported being directed to a specific charity or patient organisaiton website. 20% of children and young people respondents (n=77) and 13% of adult respondents (n=126) reported being handed written information from a specific charity or patient organisation.

Issues around access to information at diagnosis were also highlighted in our 2018 report but should be eminently solvable. We're committed to working with healthcare professionals, professional bodies and people affected by neurological conditions to address gaps and ensure everyone receives an explanation and information they understand.

> **“Since [my] diagnosis I feel I have just been overlooked and not received very much guidance, information or signposting from NHS services. As I was an HGV driver before I feel a bit more explanation and justification would of been useful to enable me to understand my condition and the consequences on my life.**
>
> - Adult with epilepsy

Access to treatment and support

We know that access to the right specialist at the right time can make all the difference. Many people who took the time to respond to the survey spoke of the excellent care they had received from specialist neurologists, nurses, allied healthcare professionals and others involved with their care.

However, we know that many people's experiences are not so positive. According to the latest available data[iii], in March 2022 there were 181,967 people waiting for an NHS neurology appointment in England, over 60,000 more people than in March 2021. 3% of them, or 5,459 people, had been waiting more than a year for an appointment, up from 2% a month earlier.

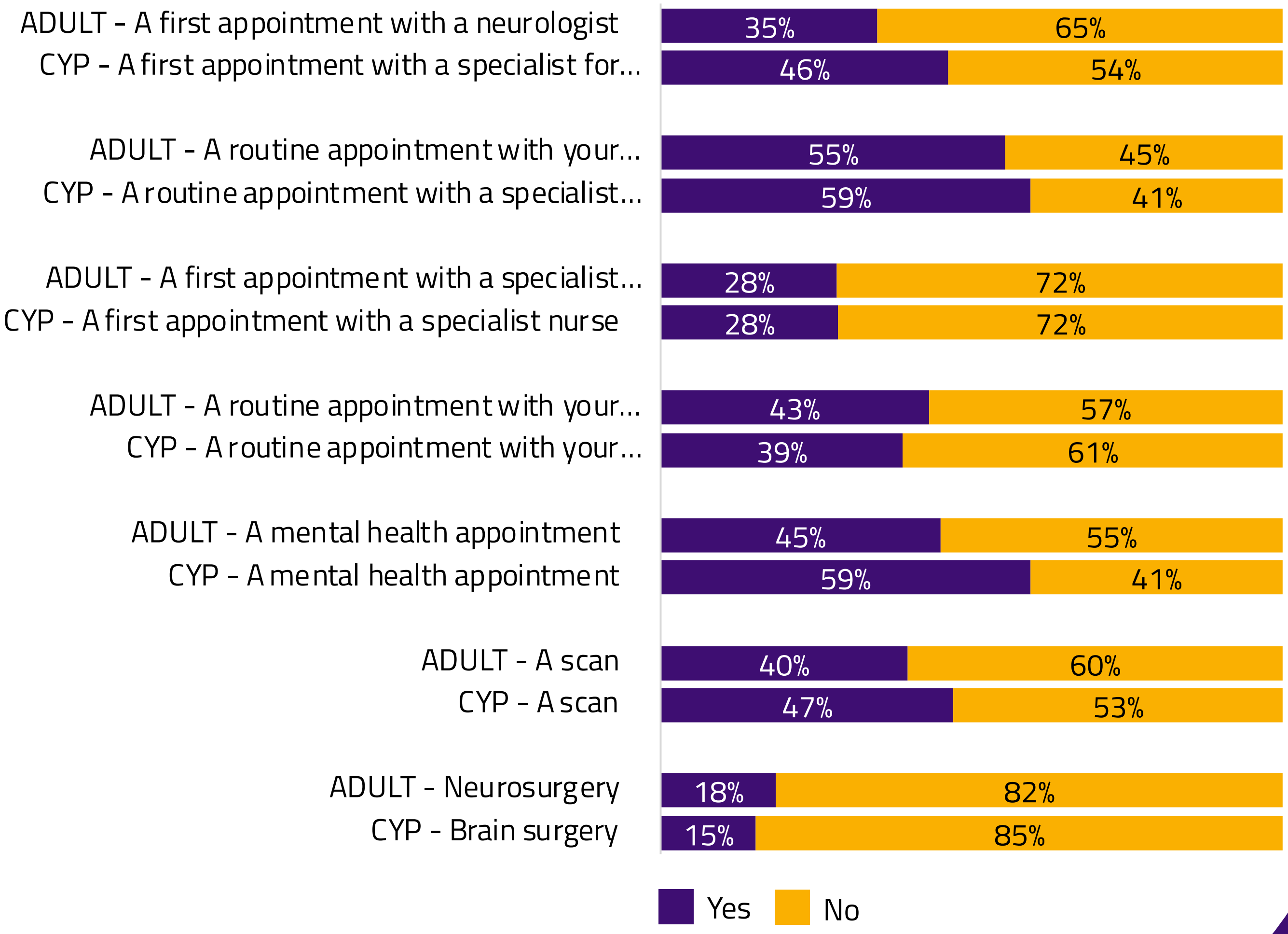
March also saw 54,155 people waiting for an NHS neurosurgery appointment, over 10,000 more people than were waiting in March 2021. Of those, 3,791 or 7% had been waiting for more than a year.

> **“Excellent care and appointments were arranged really quickly with reasonable waiting times. Considering we are in a pandemic that was nothing short of amazing. Can't praise the NHS neurology service, scans, eye hospital etc highly enough.**
>
> - Adult with a neurological condition

Long waits to see specialists and access services are not new for people with neurological conditions but the pandemic has made a bad situation even worse. In 2018/19 55% of respondents reported experiencing delays in accessing healthcare services. This is what people told us about delays to treatment and care in 2021/22.

> **I have been waiting nearly 3 years for treatment for NEAD and this has an impact on my overall health after my ABI.**
>
> - Adult with ABI & Non-Epileptic Attack Disorder (NEAD)

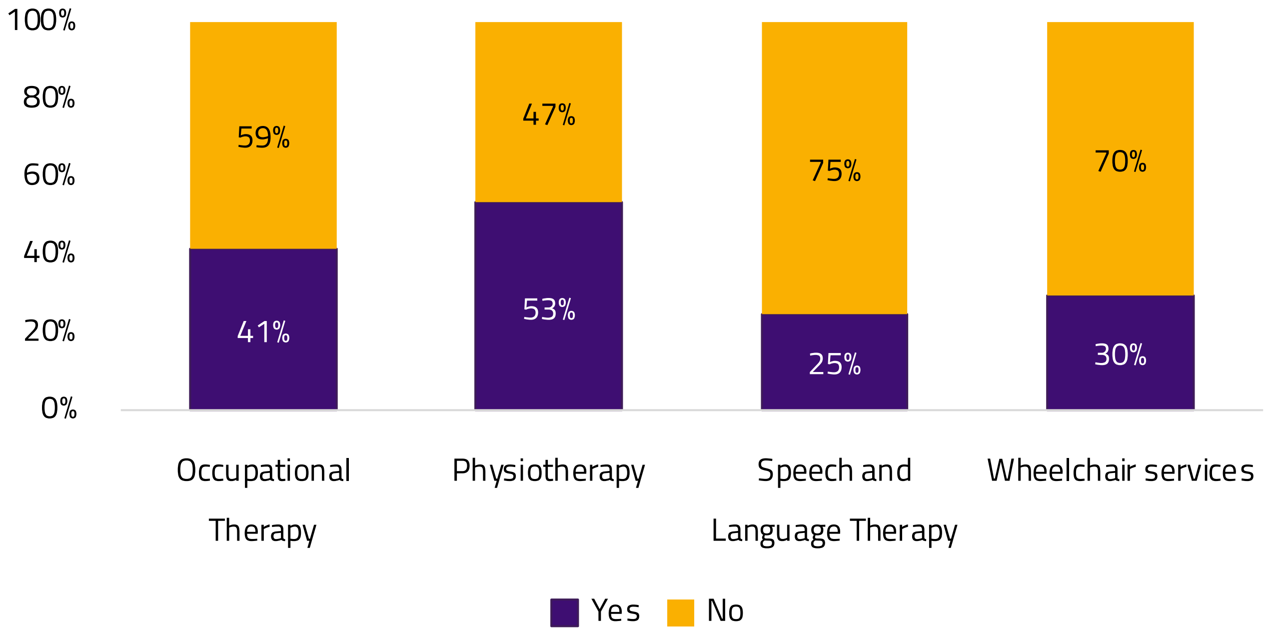
Have you experienced delays to your neurological care or treatment in the past 12 months?



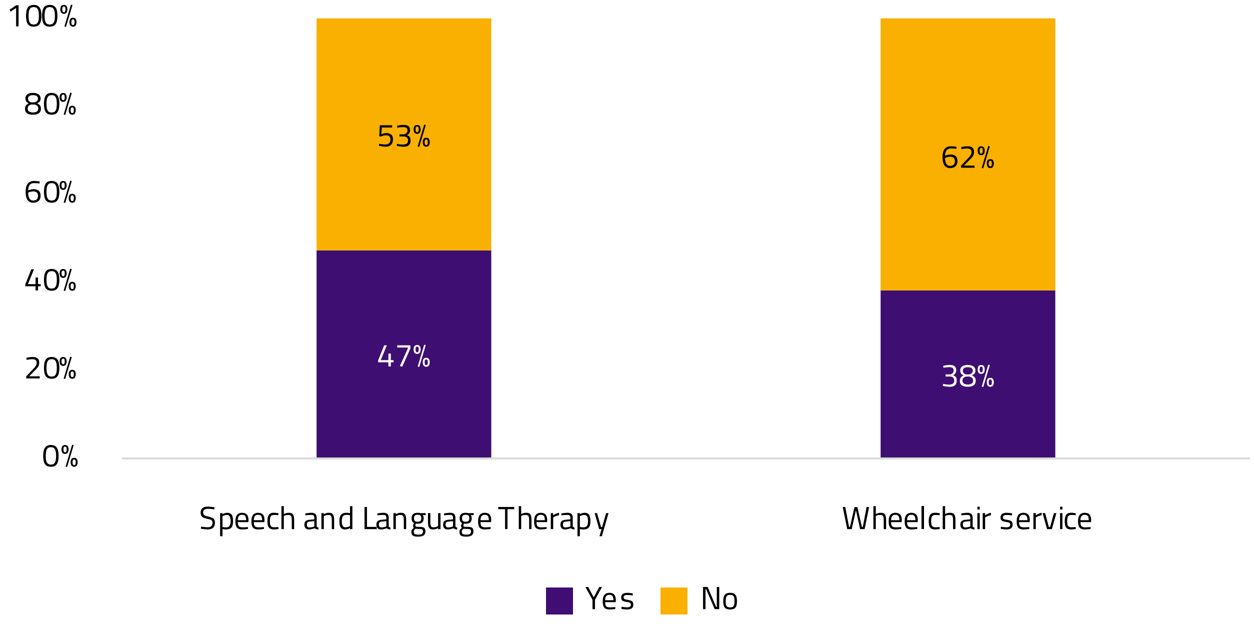
CYP: Child/young person

Have you experienced delays to your neurological care or treatment in the past 12 months?

Adult



Child/young person



While many are frustrated with delays to accessing services they rely on, others told us that there were specialists and services that they would like to access but are simply unable to. Living well with a neurological condition often requires access to multiple services, treatments and therapies. From allied health services including physiotherapy, occupational therapy, dietetics, speech and language therapy and audiology to mental health support, the best all round care and support is often a team effort.

People indicated that they weren't always being offered the services they believed could help them to live independently and best manage their condition. Many also told us that they were aware of service limitations in their region, such as a lack of neuropsychiatrists, which meant they were not able to get the support they need. The graphs below show the proportion of respondents who would find specific support helpful but have not been offered.

Delays to treatment and care can have a significant impact on a person's condition and quality of life including worsening mental health and wellbeing or a deterioration of their condition. For some, delays can mean the difference between slowing the progression of a condition or not.

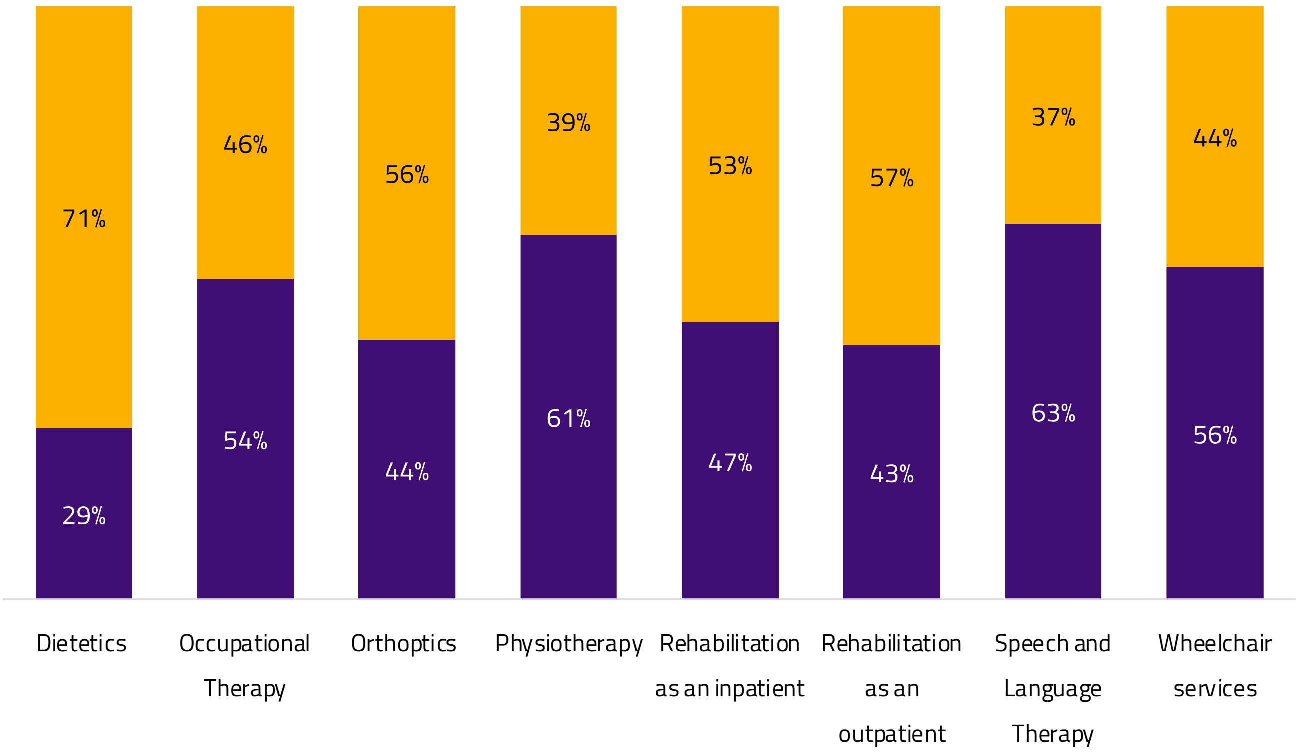
> “ **The lack of physiotherapy services through the pandemic has cost me the ability to walk.**
>
> - Adult with a neurological condition

> “ **Multiple referrals have been made for more support and assessments to understand conditions and support needs but massive waiting lists have become even longer with Covid.**
>
> - Child/young person with a neurological condition

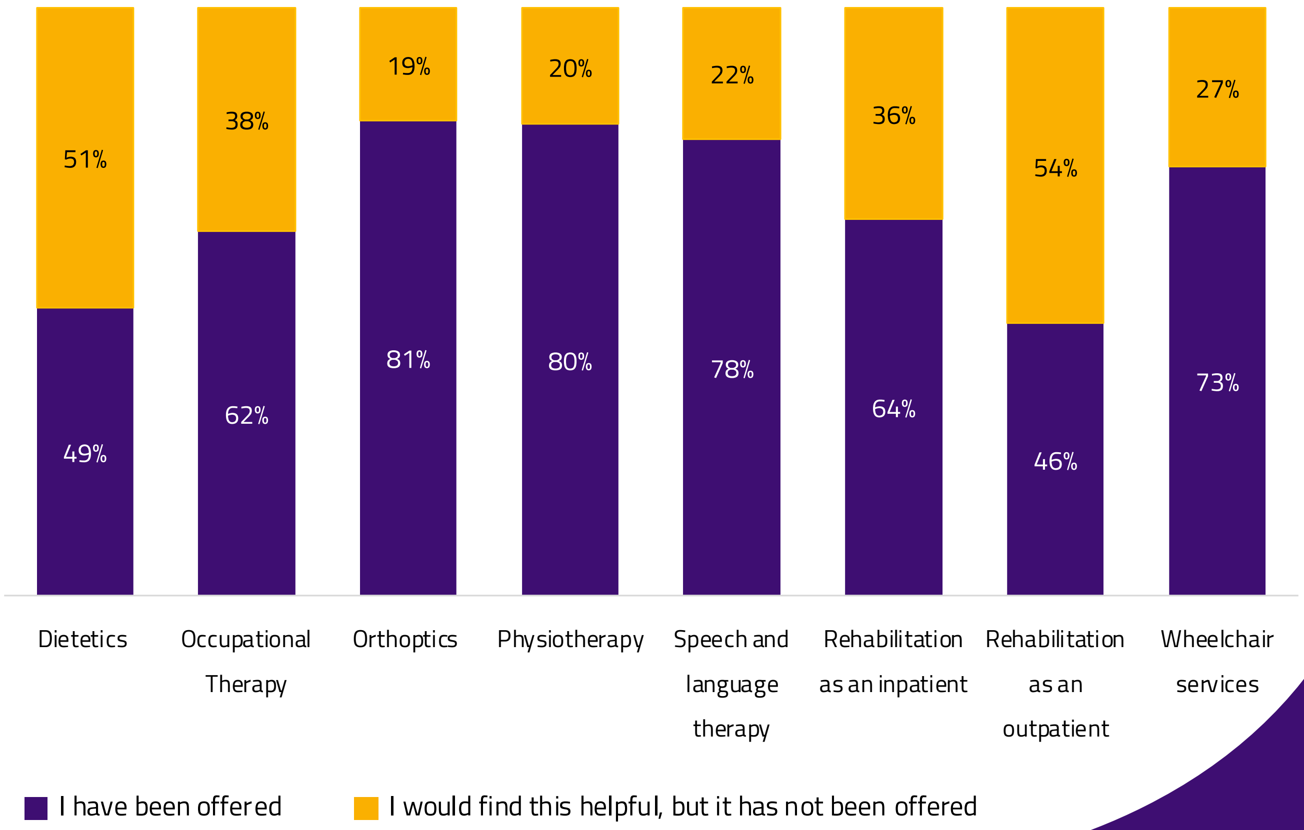
> “ **Due to the Pandemic all treatment clinics stopped. It has been almost 2 years since I last had an appointment. My condition has worsened to the extent that I am struggling to carry out my job… . I fear now that my condition has developed so much that the previous treatment I received will no longer have an effect.**
>
> - Adult with a neurological condition

Please tell us which treatments and therapies you have been offered, or you believe may help you to manage your neurological condition(s)

Adult



Child/ young person

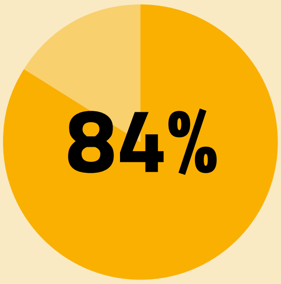


We also asked children and young people about the support available to them during the transition from paediatric to adult services. Changing specialists and moving to a different service can often be challenging and worrying for those involved.

In recognition of the difficulties that people can experience when moving from paediatric to adult services, the National Institute for Health and Care Excellence (NICE) Quality Standard on transition[xxxv] notes- Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.

When asked whether respondents had a named worker to support their transition between paediatric and adult services 84% (n=182) of those to whom it was applicable reported they had not been offered a named worker but would find this helpful.

More needs to be done to support young people with neurological conditions when moving to adult services. Poor transition support can lead to people not accessing adult care pathways which in turn can lead to poor management of their condition.



of children/ young people were not offered a named worker to support transition between paediatric and adult services but would find this useful.

> **With the transition to adult services it is extremely troubling to her anxiety levels.**
>
> - Children and young people respondent with Paediatric Acute Neuro-Psychiatric Syndrome (PANS)

Going private

Another theme that emerged in dozens of free text responses to both surveys was the use of private healthcare services in response to challenges with accessing services and appointments in the NHS. While it is an individual decision whether to use private healthcare services, this is an option that is not available to people who don't have the financial means to access services privately. It is vital that healthcare is available according to need and not according to wealth.

The impact of delays to accessing specialists, waiting lists and an overstretched workforce is an increasingly two-tier health system with those who can afford it accessing private healthcare services while those who can't often face unacceptable waits.

Beyond diagnoses and general neurologist appointments, respondents to both surveys reported accessing other health services privately including MRI scans, physiotherapy, mental health support, speech and language therapy and treatments such as Botulinum toxin. The reason given for people feeling that they need to access these services privately is often an inability to access them in a timely manner through the NHS.

> **The only reason the most recent diagnosis (autism) was achieved within 3-6 months was because we paid to go private. NHS waiting list 4 years. 3 years since last MRI.**
>
> - Child/young person with Autism

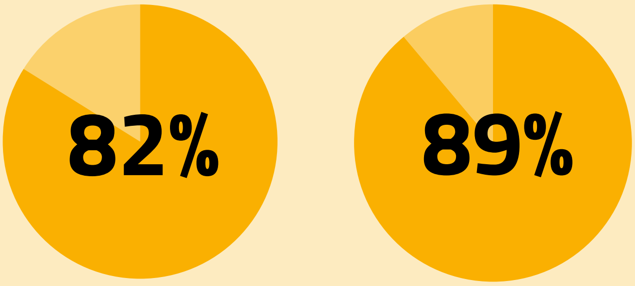
> **I had to go private to get my diagnosis, so, whilst I did get diagnosed less than 3 months after my first symptoms, the neurologist I saw on the NHS wanted me to wait for a year to see if anything else happened, rather than diagnosing me based on an MRI which clearly showed demyelination (I had 11 separate lesions). I have a family history of MS and was not prepared to chance waiting ... I was lucky enough to have access to private healthcare, but was very conscious of the fact that not everyone is so lucky.**
>
> – Adult with MS

> **I have to pay privately for my own physiotherapy. No one seems to coordinate my management. I really feel that I would be so much better if my case was looked at via a multidisciplinary meeting. It is me that is having to initiate solutions to my problems. I feel terribly let down.**
>
> – Adult with a neurological condition

Mental health and wellbeing

Neurological conditions often have a significant impact on mental health and wellbeing. Alongside the mental health impact of having a long-term condition there is a complex and comparatively poorly understood interplay between the physical and psychiatric impact of many neurological conditions. This can and does lead to people being refused access to either service as a result of the perceived primacy of a person's physical or mental health condition. This is something that is largely unique to living with a neurological condition and continues to have a significant impact on some people. It must change.

For many, the pandemic has made their mental health even worse. Data from the Office of National Statistics[xxxvi] showed people with disabilities were more likely to report that the pandemic has made their mental health worse. My Neuro Survey data also highlights adults who live in more deprived areas of England being more likely to report that their mental health has worsened due to the pandemic (i.e. those considered living in areas of deprivation quintile 1).



of adults

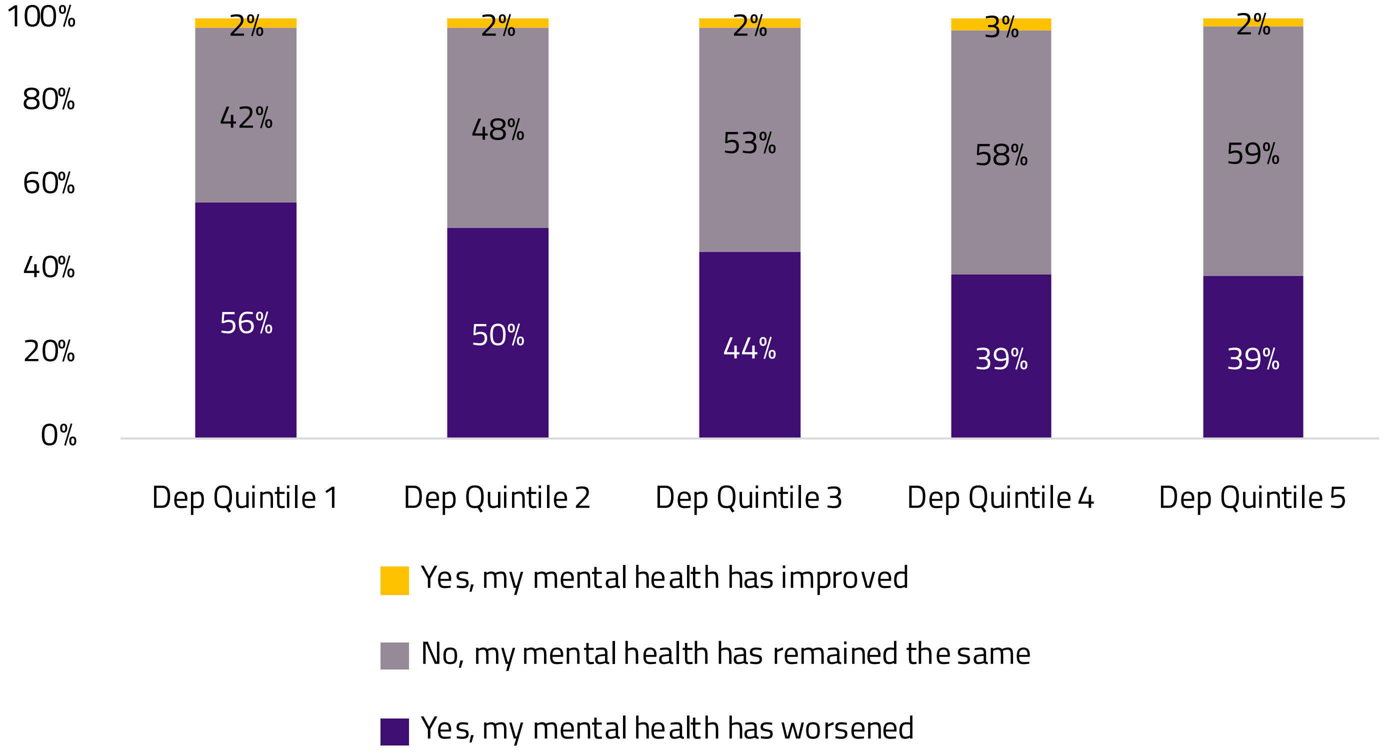
of children and young people

reported their neurological condition makes their mental wellbeing worse.

> **I have been trying to get help with my mental health since leaving hospital in June 2020, all I have to show for it is a waiting list and links to other websites.**
>
> – Adult with a neurological condition

> **I was told by the CAMHS team (children's mental health) that Tourette's is not a mental health condition and is a neurological condition. But our gp has tried to refer us to a neurologist and they won't see us and tell us Tourette's is a mental health condition.**
>
> - Child/young person with Tourette's Syndrome

Have you experienced a change in your mental health needs due to Covid-19?



Conversations about mental wellbeing and referrals or signposting to support are vital for everyone with a long-term condition. For those with neurological conditions, the complex interplay between physical and mental health makes them even more important. The first step towards getting the right support is being asked about your mental wellbeing by a health or social care professional. Despite this, over half of children and young people's respondents (52%, n=221) and 61% (n=3,141) of adults reported not being asked about their mental wellbeing by a health or social care professional within the last three years.

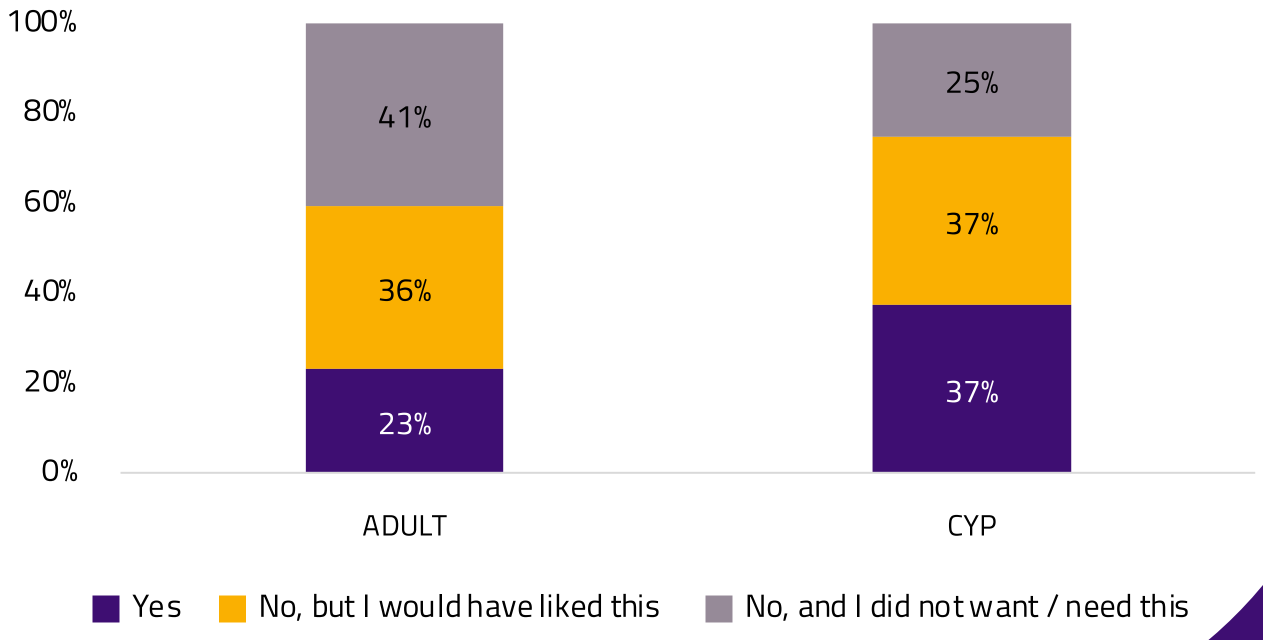
> **"The pandemic has not helped as when I retired (symptomatic but before diagnosis) I was hoping to travel & thoroughly enjoy life while I was able, but got locked down instead. The pandemic has made me wonder whether I will ever get the chance to do some of my "bucket list" things or whether the Parkinson's will take over before the pandemic restrictions are lifted.**
>
> - Adult with Parkinson's

We also asked people whether they had been referred or directed to support for their mental wellbeing by a health professional in the last three years. Over a third of adults (36%, n=1,900) and children and young people (37%, n=164) respondents reported that they had not been but would have liked this.

> **I have given up trying to get better treatment for dystonia and my mental health.**
>
> – Adult with Dystonia

> **I have never had any treatment or ongoing support for my health issues both mental and physical as a result of Guillain Barre Syndrome 16 years ago. I feel this is not acceptable.**
>
> – Adult with Guillain Barre Syndrome

Have you been referred or directed to support for your mental wellbeing by a health professional within the last three years?

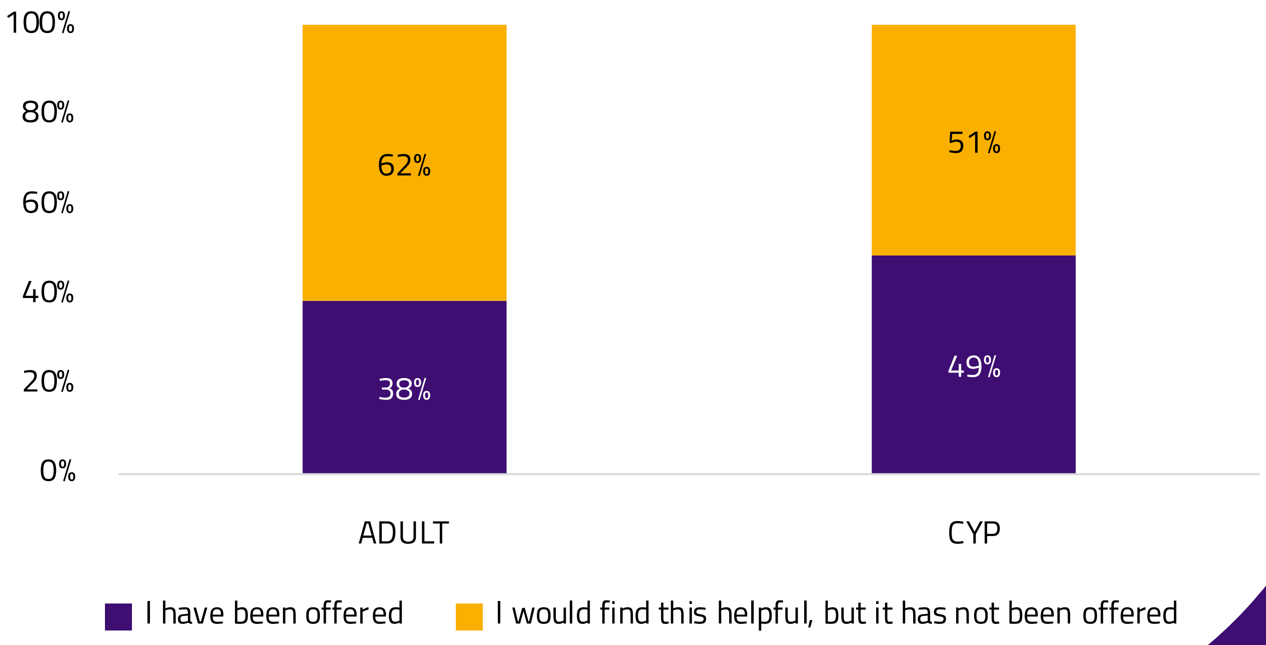


When people are referred or directed to support for their mental wellbeing, they often reported it made them feel better or more positive but there is room for improvement. 61% (n=596) of adults reported that the support they received helped them feel better overall while 39% (n=378) reported that it did not.

Some people require support from neuropsychologists or neuropsychiatrists to meet their mental health needs. These vital services and the professionals who work in them are hugely overstretched and under resourced leading to a postcode lottery for access and support. Of those who thought neuropsychology or neuropsychiatry support may help them to manage their condition, 62% (n=930) of adults reported that these services had not been offered.

> **It is a shame that neuropsychology services are not available nationwide, my postcode means I have been told I do not fall into the right area to qualify for support.**
>
> – Adult with a neurological condition

Have you been referred or directed to support for your mental wellbeing by a health professional within the last three years?



Remote Consultations

The COVID-19 pandemic had a significant impact on health and social care services. This continues to be felt, particularly by those with long term conditions who use these services on a more regular basis. As well as questions about delays to routine treatment and care such as appointments with specialists and accessing therapies, we also asked people a series of questions about remote consultations.

Remote consultations are appointments that take place over the phone or through a video call instead of face-to-face. While they predate the pandemic, during the COVID-19 pandemic they were used as a way of reducing the risk of infection associated with a visit to a hospital or health or care setting. They have continued to be used particularly in outpatient settings with ambitions from NHS England for at least 25% of outpatient appointments to be delivered remotely, this is equivalent to 40% of appointments that don't require a procedure[xxxvii].

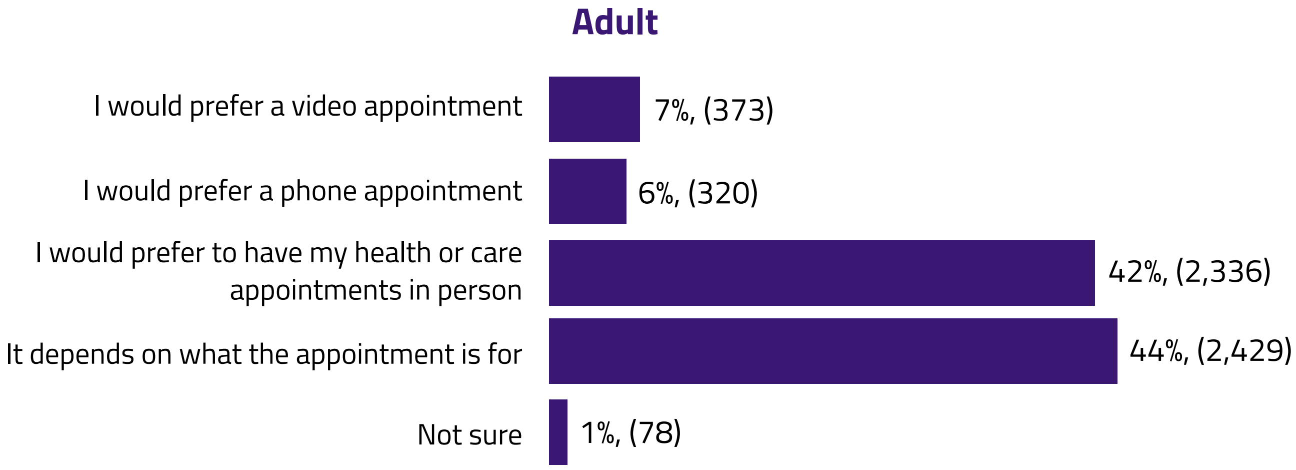
Remote consultations can include telephone or video appointments and for some people and in some circumstances, they can be a welcome alternative to face-to-face appointments.

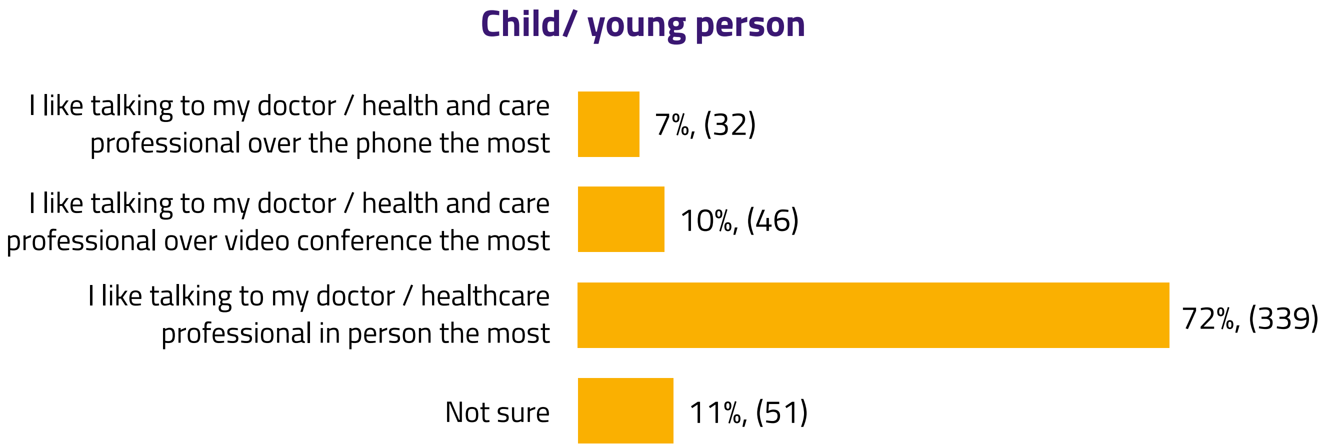
However, there is a lack of high-quality research into the outcomes associated with remote consultations compared to face-to-face appointments. There is also limited evidence around what people affected by neurological conditions think and value about consultations with their specialist, including via remote consultations.

> **“ I have really appreciated the access to remote appointments. My specialists are all over the country so travelling to routine appointments is a time and money sink. Being able to have these appointments over the phone or via video chat to monitor the situation without any physical assessments has improved my care.**
>
> – Adult with a neurological condition

> **“ I find what few phone appointments I have been involved with have always meant that I have forgotten to say something which I felt was important. There is always an element of dissatisfaction at the end of the phone call which I have never felt at an in-person appointment.**
>
> – Adult with a neurological condition

More health and care appointments are now being delivered remotely (this could be by telephone or video conference). How do you feel about this?





44% (n=2,429) of adult respondents noted that how they felt about remote consultations was dependent on what the appointment was for. Free text comments highlighted that some people saw benefits of remote consultations for routine appointments or simple enquires or discussions with healthcare professionals.

42% (n= 2,336) of adult respondents reported preferring to have their health or care appointments in person while 72% (n=339) of children and young people reported liking talking to their doctor or healthcare professional in person the most.

> **“ As a preliminary chat fine but not instead of face to face and not as an excuse for delaying face to face.**
>
> – Adult with a neurological condition

Given the significant variances in peoples experiences of and feelings towards remote consultations people should be given the choice of a face to face, video or telephone appointment wherever appropriate.

Particular consideration also needs to be given to groups for whom remote consultations may present additional challenge to reduce the risk of worsening existing health inequalities. This includes people with communication challenges or with additional or complex needs including learning disabilities.

It also includes people with specific types of conditions such as progressive neurological conditions whose condition may be deteriorating, albeit in ways difficult to assess remotely.

There was significant cross over between free text responses around remote consultations and the challenges some people face with travelling to appointments. The unequal spread of neurologists and specialist neuroscience centres around England can lead to people having to travel many miles for appointments. Some neurological conditions can also impact your eligibility to hold a driving license[xxxviii].

When asked how difficult they found travelling to the majority of appointments for their neurological condition 27% (n=1,444) reported finding it difficult and 15% (n=814) reported finding it very difficult. For children and young people, 22% (n=97) reported finding it difficult and 10% (n=43) found it very difficult.

> **As an autistic Person I find telephone and video very upsetting and can't process the info we end up having to follow up anyway.**
>
> – Autistic Adult

> **As Parkinson's Dementia progresses it is extremely important that I am seen in person so that I can be assessed as a whole person.**
>
> – Adult respondent with Parkinson's

> **We have to travel to London (Kings) for scans and then a few weeks later for the consultant appointment, so having the consultant appointment by phone has been useful as we have less travel and it is appropriate for the purposes of that appointment. I may feel differently if we were at a more acute stage of care.**
>
> – Child/young person with a neurological condition

The circumstances and needs of every person with a neurological condition are different and as such any one size fits all approach is bound to fail some in our community. Options and flexibility, including around how people access health and care services, are vital to best support people with neurological conditions and this must be the starting point for future discussions.

> **I get confused about technology but also can't drive far so options are helpful.**
>
> – Adult with a neurological condition

Access to Social Care

Many people with neurological conditions rely on social care services as much as health care services to live well. In an indication of how poor data is in this area, the most up to date figures[xxxix] on social care expenditure on care services for people with neurological conditions are from 2013. At that time the figure was approximately £2.4 billion, almost 14% of total adult social care spending. Despite this, too many people report that social care services fail to meet their needs.

When asked whether the social care people received met their overall needs, 39% (n= 835) of adults and 43% of children and young people (n=102) disagreed. A further 38% (n=827) of adults and 41% (n=98) of children and young people neither agreed or disagreed leaving just 23% (n=490) of adults and 16% (n=37) of children and young people agreeing with the statement.

A reliance on unpaid care and support from family, friends or wider support network was also apparent in free text responses and elsewhere. 48% (n=2,676) of adults and 55% (n=258) of children and young people reported receiving unpaid help with their day-to-day life at home. 4% (n=198) of those adult respondents reported this help came from someone under the age of 18.

Social care is vital for many in our community, but responses indicate that too often services are not meeting their needs and there is a heavy reliance on unpaid help to get by. Planned changes to the social care system including the introduction of a cap on the total costs a person will incur for social care during their lifetime are unlikely to help working age adults or less well-off older people who require support.

> “ **Impossible to contact professionals. Waiting lists are months and months just for initial appointments. Equipment taking 6-12 months. No support with echo/special needs school admissions. Professionals don’t communicate with each other. Council just as bad, no social care support available.**
>
> – Child/young person with a neurological condition

> “ **Social care have taken over a year to arrange access in and out my home. I was originally told that they couldn’t do anything and that it was unfortunate I couldn’t get round my home.**
>
> – Adult with a neurological condition

More needs to be done to "join up" health and social care services. Too often these systems work in isolation leading to people being unable to access the support they need. A more integrated approach to health and social care is a central focus of the recent Health and Care Act[xxiv] and the Integration white paper . It is critical that investment and support is in place to ensure these initiatives succeed in joining up these vital services.

> **He [my partner] is my carer, he drives me everywhere, looks after me when I have my partial seizures - many times a week. This is the only reason why I find getting to my appointments and work easy. Of course he is free, he's my partner. Without him I would find life very difficult, I would have to move. I have no public transport from where I live...**
>
> – Adult with epilepsy

> **I was advised to have a shower put in as I cannot use the bath easily and the hospital sent a letter to my council [Name of Council Removed] asking for help on this but the council refused it. So I struggle everyday with washing needs but I get by but not sure what will happen when I get older... as money is tight I cannot do this.**
>
> – Adult with a neurological condition

Access to financial support

Living with a neurological condition can often mean that life is more expensive than for someone without. For some people, it can prevent them from working or make getting and keeping a job harder. 2022 continues to see prices rise including for food, fuel and energy as well as sharp increases in inflation. As we begin to emerge from the pandemic people are facing an increasingly challenging financial situation.

When asked how they were coping with their household finances 39% (n=1,564) of adults reported having enough money to get by but being dependent on using their savings. In response to a sperate but related question, 23% of adults (n=952) reported they were struggling to cover their costs. When asked whether they had enough money to cover basic needs, 11% (n=443) of adult respondents reported that they did not.

Concerns about how people were going to manage financially going forward were evident in several free text responses. Financial concerns often add more stress and worry for people who are already experiencing challenges related to their neurological condition. As well as contributing to worsening mental health and wellbeing, stress can exacerbate conditions such as epilepsy with some people experiencing an increase in seizures.

Ongoing concerns were raised about the assessment process for some benefits such as Personal Independence Payments (PIP) – non-means tested support intended to help with the extra costs of living with a disability or health condition.

> “ **We currently have enough money to support ourselves but we are very careful how we spend money, living very simply. I am very worried about money and how the planned benefit system changes will affect our ability to cover our costs.**
>
> – Adult with a neurological condition

> “ **I just wish, more than anything in the world, that there was more help out there for someone like me. Because I’m able to hold a conversation, I think professionals just assume that I’m managing fine. But I’m not. As well as being disabled myself, I’m a carer for my mum, who is even more disabled. We both pool all our money together and pay a friend to look after us, but sometimes, it’s not quite enough.**
>
> – Adult with a neurological condition

42%(n=2,272) of adult respondents reported that they or someone who cares for them were receiving PIP or Disability Living Allowance (DLA), the legacy benefit that PIP was bought in to replace. Concerns about the application and decision-making process were raised on multiple occasions in free-text comments.

> **“ I have had pd [Parkinson’s] for nearly 24 years, and have just recently had to apply for benefits this last year, I have never felt so agitated, upset and panicky that I would miss something out which would prevent me from getting much needed assistance, also a feelings of depression at admitting there were things my Parkinsons prevented me from doing. I also felt totally humiliated at having to write all this information down some of it was of a very personal nature which I wouldn’t even share with my family and here I am having to write it all down and send it to a complete stranger to judge whether I can claim benefits for my illness...,**
>
> – Adult with Parkinson’s

Inconsistency in decision making was also highlighted including one respondent querying why their PIP renewal had been unsuccessful despite the impact of their condition getting worse.

For some, the perceived challenges with the application and assessment process have acted to prevent them from applying for support to which they could be entitled.

> **“I was awarded Pip for the first 2yrs after my diagnosis but it was then refused at my next assessment at renewal. I did appeal in writing to the decision but to no avail I couldn’t understand why they had refused the renewal when I was suffering more than when I was awarded it from diagnosis.**
>
> – Adult with a neurological condition

> **“I am trying to apply for a blue badge but it is very difficult to make sense of the forms, the difficulties in applying have meant I have been put off applying for PIP or ESA. It is likely that in the next six months I will have to give up working as my condition continues to deteriorate.**
>
> – Adult with a neurological condition

A respondent noted that the experiences of others who have applied for certain support had led them to believe that going through the process themselves could impact their mental health condition and increase the risk of self-harm.

When welfare support is reduced or removed, people often face difficult choices. For those who are unable to work or to increase their hours due to the condition it can be an impossible situation.

> **I believe that I am entitled to PIP, and previously Attendance Allowance but have never applied for either. I am scared to apply for PIP/Attendance Allowance because going by the experience of others I am terrified that by existing depression would worsen again and quite possibly cause me to attempt to take my own life.**
>
> – Adult with a neurological condition

> **Following an assessment for PIP/DLA I was deemed fit for work without any benefit. I lost DLA and Tax Credits. I work part time and unable to increase my hours due to Dystonia. Now my wage is very low and not enough to cover all my outgoings.**
>
> – Adult with Dystonia

Access to education and employment

Having a neurological condition can make getting and keeping a job or staying in school more challenging. The discussion around employment should be considered alongside the preceding section on financial wellbeing, particularly with respect to the challenges many people face with accessing welfare support.

We asked adult respondents whether they agreed or disagreed with the statement "I have stopped working because of my neurological condition symptoms". 57% (n=2,142) agreed with the statement, 9% (n=332) neither agreed nor disagreed while 34% (n=1,263) disagreed. Some people also mentioned having to reduce their working hours to better manage their symptoms.

> **"I have to work as a cleaner. I am exhausted. I have to work to eat. My incapacity benefit was stopped.**
>
> – Adult with a neurological condition

> **"I have been sacked on 2 occasions for 'not fulfilling my duties' as I have had seizures before work 5 times in 8 weeks. I am often ignored after interview when they hear of my epilepsy. I have been rejected for PIP as I walk, dress myself & have a degree. They ignore the fact that I have advance seizures many times every day which makes it dangerous for me to cook, iron, shower, cross roads alone...I am not eligible for Universal Credit as I live with my partner however his pay doesn't cover our rent, fares & bills & neither does he really want to support me. I hate being dependant on him & my parents.**
>
> – Adult with epilepsy

Employers have a legal duty to make reasonable adjustments to ensure people with disabilities can continue to access things including employment and education. Simple changes such as allowing someone to work from home can make a real difference to a person's quality of life.

We also asked people whether they had been discriminated against at work due to attitudes towards their neurological condition. 33% (n=1,057) of adult respondents indicated they had faced this kind of discrimination, 16% (n=519) neither agreed nor disagreed while 50% (n=1,606) indicated they had not experienced discrimination of this type. It is concerning that in 2022, one third of respondents to the above question agreed that they had experienced discrimination at work due to attitudes towards their condition.

> “ **I have reduced my work hours over the last couple of year because of my FND symptoms. Having time to work from home during 2020, I noticed the benefits of not going out to work every day (less stress, less tiring). I have recently reduced my hours to have a compromise of still working and earning a little bit, but having more time.**
>
> – Adult with Functional Neurological Disorder

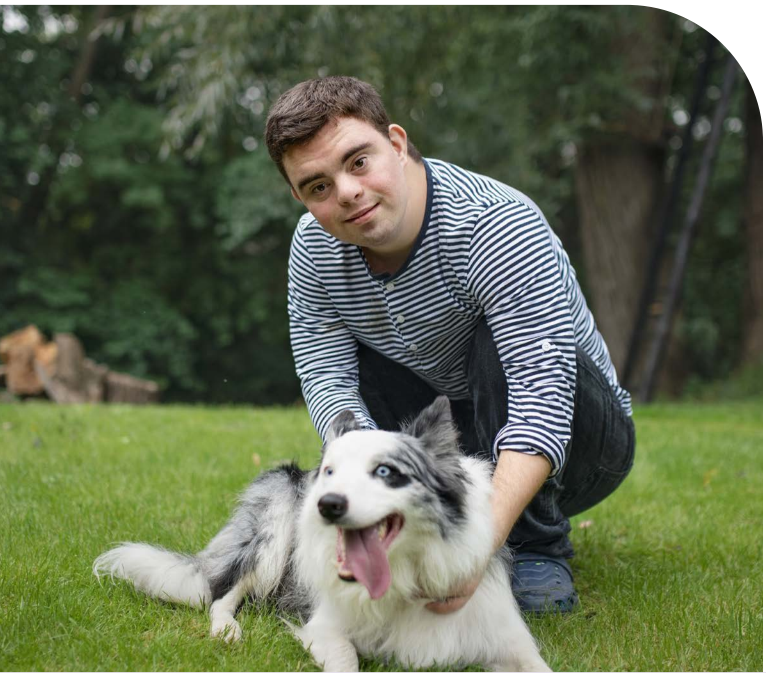
> “ **My employer has been massively supportive of me and recently agreed to allow me to work from home permanently.**
>
> – Adult with a neurological condition

> “ **I have been off sick from work this year due to bullying/ harassment and discrimination over my condition by my manager.**
>
> – Adult with Tourette's Syndrome

Several respondents noted that they were concerned about disclosing their neurological condition when applying for jobs because of previous negative experiences with not hearing back from employers when they disclosed their condition. This must change.

The children and young people's survey included questions about experiences of education. We asked people whether their attendance at school had been affected due to their neurological condition. 71% (n=305) of respondents agreed that their attendance had been affected by their condition, 11% (n=47) neither agreed nor disagreed while 18% (n=76) disagreed.

Being out of school for prolonged periods of time can have an impact on things other than education. One respondent noted that they had missed out on access to therapies including occupational therapy, physiotherapy and speech and language therapy because their condition meant they were unable to regularly attend school.



> **“ Employer's still seem to discriminate against Parkinson's disease because when a potential employer finds our I have Parkinson's I don't hear anything back.**
>
> – Adult with Parkinson's

> **“ My condition means that I am generally housebound these days and I am missing out on a lot of fun and opportunities. I have fallen through the net with education as there is not a formal process to education children like me who are too poorly to attend school. As a result, health services that work through school forget about me too (such as physio and OT, Speech and Language).**
>
> – Child/young person with a neurological condition

Better awareness and up-to-date information about specific conditions could mean the child or young person quoted below can attend school safely and regularly when possible.

As well as impacting on development, there is also a mental health impact associated with being out of education for prolonged periods. When combined with the impact of a person’s neurological condition it can have a significant impact on many parts of a child or young person’s life.

> **“ My school has told me I cannot attend until they are able to have a first aider with me at all times. Obviously, with the nature of non-epileptic seizures, this is completely the wrong thing to do and has a negative effect of worsening both the seizures and my mental health...This has significantly disrupted my education, A-levels, friendships, social communication skills and isolated me.**
>
> – Young person with a neurological condition

Calls to action

Together with Neurological Alliances across the UK we're calling on the UK Government, Scottish Government, Welsh Government and Northern Ireland Executive to:

- **Establish a UK Neuro Taskforce.** The taskforce would bring together relevant Departments, health and social care bodies, professional bodies, people affected by neurological conditions and the voluntary sector to support greater collaboration and sharing of best practice in tackling common challenges in improving access to treatment, care and support for the one in six people in the UK that live with a neurological condition. Full details of the proposed Taskforce are set out in our UK policy report[xlii].

As the Neurological Alliance for England, we're also making the following calls.

We encourage people affected by neurological conditions to:

1. Know that you are not alone. There are hundreds of organisations and millions of individuals who are here for you. If you need information or support but don't know where to turn you can find out about our members and the services they offer through our website[xliii]
2. Get involved and campaign for change. Together we can help to improve services, boost investment in research and improve outcomes for people with neurological conditions now and in the future. Together, we're stronger.

The Department of Health and Social Care must:

3. Ensure the NHS People Plan delivers a neuroscience and brain workforce fit for the future. Work with the neurological community, including the Neurological Alliance and neuroscience professional bodies to develop the plan.
4. Ensure the Office for Health Improvement and Disparities (OHID) works with health bodies and the neurological community to develop improved data and insight on the prevalence and incidence of neurological conditions, as well as experience of and access to services.
5. Work with the Treasury to fix the current crisis in social care and bring forward a plan to create a fair, effective and sustainable social care system in line with the Care and Support Alliance (CSA) Seven Tests[xliv].

The Department for Work and Pensions must:

6. Ensure the welfare system enables people to manage the extra costs associated with their condition, supports employment as appropriate and protects people with neurological conditions from falling into poverty by:

    - Immediately uprating benefits in line with current levels of inflation

    - Revising assessment regulation and processes to accurately capture the realities of living with a neurological condition and ensure people get the right support first time round – reducing the burden of appeals on individuals and the system.

    - Working with welfare assessment providers and the neurological community to ensure assessors are trained and understand the realities of living with a neurological condition.

We urge NHS England and NHS Improvement to:

7. Implement and track the recommendations made by the Getting it Right First Time (GIRFT) national report for adult neurology[xlv] including:

    - Recommendation 2 – Embed neurology liaison services to allow timely access to neurologist advice at all sites.

    - Recommendation 14 - Develop clinically led subspecialty regional networks, starting with epilepsy and MS, with links to local multi-disciplinary teams (MDTs).

    - Recommendation 20 - Review the organisation and roles of neurologists and neurology trainees to better meet patient needs and maximise training quality

    - Recommendation 25 – Create a neurology dashboard to enable monitoring of key metrics to support continual quality improvement

8. Appoint National Specialty Advisers (NSAs) for neuropsychology and neuropsychiatry to lead and coordinate national service improvement efforts alongside the incoming National Clinical Directors (NCDs) for neurology and neurosurgery and spinal surgery

9. Ensure people are given the choice of a face-to-face, video or telephone appointments where appropriate.

Those planning, commissioning and delivering services must ensure:

10. Every Integrated Care Board (ICB) works with the neurological community in their area to map current service provision for people affected by neurological conditions and set out plans to address shortcomings in care.

11. Every ICB has a clinical and patient lead for services for people affected by neurological conditions in their area.

12. Every Integrated Care Partnership (ICP) includes people affected by neurological conditions or a representative from the neurological VSCE sector.

13. Trusts, provider collaboratives and ICBs work together to implement common features of neuroscience pathways, including named care coordinators, access to mental wellbeing support and timely access to specialists, alongside other best practice recommendations included in:

    - National Neurosciences Advisory Group (NNAG) Optimum Clinical Pathways[xlvi]

    - NHS RightCare Toolkits & Pathways[xlvii] on progressive neurological conditions, headache and migraine and epilepsy

    - Relevant NICE Guidance and Quality Standards[xlviii]

14. NHS Trusts review their local Mental Health Commissioning Policies, to ensure that these facilitate access to specialist mental health support for everyone with a neurological condition.

15. NHS Trust contracts plan for conversations about mental wellbeing in consultations, with referrals and signposting where necessary.

16. ICBs and NHS Trusts map current mental health and wellbeing support available in their area for people affected by neurological conditions. Appropriate triage, referral routes and a matched care approach must be available in every area, ensuring people can access support according to their needs.

17. ICBs and NHS Trusts provide transition support to every young person with a neurological condition and their parents or guardians, including a named worker.

18. ICBs and NHS Trusts work with the voluntary sector and local people to understand local need and implement coordinated and integrated care for people affected by neurological conditions.

19. NHS Trusts provide every person diagnosed with a neurological condition with information in a format that is accessible and appropriate for them, including written information.

20. NHS Trusts build in the time and resource necessary to provide follow-up appointments with an appropriate specialist for all newly diagnosed people to discuss their treatment and care options.

21. NHS Trusts conduct an audit of the support available for people newly diagnosed with neurological conditions including 'Newly Diagnosed' courses and address gaps, including through collaboration with the voluntary sector

We urge the voluntary sector to:

22. Work together to ensure we are hearing from, supporting and representing a diversity of people with neurological conditions. This includes sharing approaches to embedding equity, diversity and inclusion

Acknowledgments

For the first time ever, we have worked across the UK to provide an unparalleled insight into the experiences of people with neurological conditions accessing treatment, care and support. More than 8,500 people took the time to respond to 'My Neuro Survey' and more than 35 clinics took part across the UK. Over 100 voluntary sector organisations, professional bodies and regional groups worked tirelessly to promote the survey. The Association of British Neurologists (ABN), Royal College of Psychiatry Faculty of Neuropsychiatry, Association of Chartered Physiotherapists in Neuroscience (ACPIN) and the British Paediatric Neurologist Association (BPNA) all endorsed and promoted the survey. Twelve people with neurological conditions have advised on the tone and approach taken for our wider campaign.

We'd also like to thank our steering group members for their time, input and support with the survey and subsequent reports.

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About My Neuro Survey

This is the fourth iteration of the National Neuro Patient Experience Survey. The survey was previously run in England in 2014, 2016, and 2018/19. The methodology was updated in 2018/19 - gathering responses in neurology clinics as well as via an online survey. This methodology was repeated again in 2021/22, and also included physiotherapy and rehabilitation clinics.

There were some important firsts for the 2021/22 survey. For the first time the survey was UK-wide and run in collaboration with the Neurological Alliance of Scotland, Wales Neurological Alliance and the Northern Ireland Neurological Charites Alliance (niNCA). There was also a version of the survey produced specifically for children and young people. Taken together, this means My Neuro Survey was open to everyone affected by a neurological condition in the UK – a landmark achievement.

The Neurological Alliance (England) engaged survey company Quality Health/IQVIA to undertake the survey. The Neurological Alliance and Quality Health/IQVIA worked in close partnership, together with a Steering Group of people affected by neurological conditions, UK neurological alliances, patient groups and healthcare professionals to develop and test the methodology and survey questions, as well as to analyse and report on the data.

Data was collected between 25 October 2021 – 6 February 2022. The survey was promoted:

- By members of the Neurological Alliance's across the UK on their social media channels and via direct email
- Via a hyperlink shared in clinic letters and as part of remote consultations in participating clinics
- In some clinics, a ballot box was used to collect paper responses – this was not widely used due to infection control restrictions in clinic
- Via paid advertising on social media

People could respond to the survey via the website, via a language telephone line (if they would prefer to respond in a language other than English), by using an Easy Read questionnaire or through a paper-based questionnaire completed in clinic or posted directly to IQVIA.

If a carer, parent or guardian was filling out a questionnaire, we asked that they respond based on the experiences of the person with a neurological condition.

For more details about the data and the survey please see the accompanying technical report.

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THE
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ALLIANCE

The Neurological Alliance (England)

We are a coalition of over 80 organisations working together to transform quality of life for people with neurological conditions. Together we campaign to ensure people affected by neurological conditions can access high quality, joined up care and support to meet their individual needs, at every stage of their life.

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