THE NEUROLOGICAL ALLIANCE

Act for the 1 in 6

England findings from My Neuro Survey 2024

June 2025

Contents

Foreword

At least one in six people in the UK live with a neurological condition, millions more love and care for someone who does. Neurological conditions are everyone's business.

In 2022, we published the findings of the previous My Neuro Survey and launched our #BackThe1in6 campaign, calling on government to establish a UK Neuro Taskforce. Alongside the 8,500 people who shared their experience, that call was supported by over 19,000 individuals and more than 100 organisations who demanded change.

The cover image of this report is a powerful mosaic created by people affected by neurological conditions, made up of hundreds of personal images, of people all calling for change and better care across the country.

THE NEUROLOGICAL ALLIANCE

Act for the 1 in 6

England findings from My Neuro Survey 2024

June 2025

Since then, there have been six Health Secretaries, four Prime Ministers and one General Election. But what has changed for the neurological community?

Following the campaign, in November 2024 the UK Government announced the creation of the UK Neuro Forum – the first UK-wide initiative focused on improving services and support for people with neurological conditions. It is early days, but this progress shows the power of collective action.

Still, the reality for many has not improved – and in some cases, has worsened.

Too many people continue to wait too long, travel too far, and fight too hard to get the care they need. They feel let down by a system that doesn't understand their condition, meet their needs, or plan for their future.

At the same time, changes to the health system - including the abolition of NHS England and cuts to Integrated Care Board (ICB) budgets - risk further destabilising already overstretched neurological services. It is currently unclear what national clinical leadership for neurological services will look like under new health system architecture. Key initiatives – including the NHS England National Neuroscience Transformation Programme, which have been so critical in driving improvements in care – may not continue.

But we know what good care looks like. We hear it every day, the difference joined-up care, trusted professionals and life-changing support can make. These must become the norm, not the exception.

There is still time to get this right. But it requires political will, leadership and investment. This is why we are calling on the government to act for the one in six.

Let's move from crisis to change. Let's build a system that works for everyone.

Georgina Carr
CEO, The Neurological Alliance

Executive summary

There are over 600 known neurological conditions impacting millions of people in England - affecting everything from how you move to how you think, feel, and connect with others. Once again, My Neuro Survey reveals a system that is often failing to meet the needs of people affected by neurological conditions.

More than 6,000 adults and over 800 carers who reported living in England took part in the 2024 survey, making it the largest source of insight into the realities of living with a neurological condition in the country. Their experiences are clear: the system is under pressure, and people are paying the price.

People affected by neurological conditions are still waiting too long, travelling too far, and being let down too often. Many feel dismissed, misunderstood, or forgotten. Despite dedicated professionals and positive pockets of care, the overall picture is of a fragmented and overstretched system.

Key findings

Just 1 in 3 people agreed that the care they receive from healthcare services meets their needs.

Almost half do not feel supported by the health system.

69% of those who needed neuropsychiatry couldn't access it. **62%** said the same about neuropsychology.

Over a quarter of people couldn't access a neurologist or specialist nurse in the past year.

More than 4 in 10 said they don't know who to contact between appointments.

Three quarters said their condition impacts their ability to work or study; **6 in 10** are struggling financially.

Recommendations: Act for the 1 in 6.

To build a system that works for the one in six, we are calling on the government to:

- Ensure the NHS 10 year plan is supported by a specific implementation plan for services for people affected by neurological conditions.
- Tackle critical workforce shortages in neuroscience and associated specialties in the forthcoming workforce plan.
- Build a health system architecture that provides much needed clinical leadership and delivers transformation of services for people affected by neurological conditions. Draw from the extensive work undertaken within the NHS England national neuroscience transformation programme, National Neuro Advisory Group optimal clinical pathways of care and relevant Getting It Right First Time programmes.
- Implement NHS guidance that seeks to ensure no-one is turned away from mental health services due to their neurological diagnosis.
- Rethink and reverse planned cuts to the health and disability benefits system and ensure any changes do not negatively impact people affected by neurological conditions.
- Unlock the potential of the UK Neuro Forum by providing dedicated, time-limited government funding to support its coordination and engagement activities.

Thank you

More than 10,000 experiences were shared via My Neuro Survey in 2024. This report focusses on the experiences of 6,196 adult respondents to My Neuro Survey who reported living in England. It also reports on the experiences of 819 respondents to the carers' version of My Neuro Survey who reported living in England.

We would like to thank everyone who shared their experiences or supported My Neuro Survey. This report and its recommendations would not have been possible without your insights and experiences.

What are neurological conditions?

Neurological conditions are conditions that affect the brain, spinal cord or nerves.

There are over 600 known neurological conditions.

Neurological conditions affect at least one in six people across the country. [1]

Because these are the systems that control your mind and body, they can impact every part of life – your physical and mental health, how you think, how you feel and how you interact with the world.

Neurological conditions are the leading cause of disability globally. [2]

Neurological conditions cost an estimated £96bn to the UK economy in 2019 taking into account the direct and indirect economic impact. [3]

About My Neuro Survey

This is the fifth iteration of our national neurological patient experience survey. The survey was previously run in England in 2014, 2016, 2018/19 and 2021.

The survey was open to adults and children with a neurological condition, or with a suspected neurological condition across the UK and the Republic of Ireland, and anyone caring for someone with a neurological condition.

It was delivered in collaboration with Neurological Alliances across the UK and Republic of Ireland – Wales Neurological Alliance, Neurological Alliance of Scotland, Northern Ireland Neurological Charities Alliance (niNCA) and the Neurological Alliance of Ireland.

There were a couple of important firsts for the 2024 survey including opening it up to people in the Republic of Ireland and delivering a version of the survey specifically for carers.

The Neurological Alliance (England) engaged survey company Revealing Reality to undertake the survey. The Neurological Alliance and Revealing Reality worked in partnership, together with people affected by neurological conditions, neurological alliances, patient groups and healthcare professionals to develop and test the methodology and survey questions.

Responses were collected online and via paper survey between 22 July and 16 November 2024. The survey was promoted:

- By neurological alliances and associated member organisations through social media, email and other communications.
- By 50 clinics providing services for people affected by neurological conditions through unique weblinks.

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 or Welsh) or through a paper-based questionnaire returned to Revealing Reality.

Details about the methodology and data are available in the accompanying technical report and further reporting on the UK wide data set is available at www.neural.org.uk/act-now-for-the-1-in-6

About this report

This report is based on the findings of My Neuro Survey for adults living in England.

As well as reviewing available data from the survey for England, we have engaged more than 150 people affected by neurological conditions and our member organisations to develop the key themes for the report.

Experiences shared through the survey are central to each theme with relevant findings and free text comments presented alongside policy context to provide a snapshot of what is working well and what needs to improve for the neurological community.

- The realties of daily life
- Navigating the system
- Getting the right support
- Financial strain and difficult decisions

Alongside responses from adults and carers, we also received hundreds of responses from children and young people across the UK and their parents and carers. Due to response numbers, we will be reporting on the experiences of children and young people in a separate UK-wide publication to be published in the coming months.

The following conditions were the most reported:

- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) (17%, n=1041)
- Multiple Sclerosis (MS) (12%, n=757)
- Migraine (9%, n=579)
- Fibromyalgia (9%, n=571)
- Functional Neurological Disorder (FND) (9%, n=533)
- Dystonia (9%, n=532)
- Epilepsy (8%, n=485)

Carers' experiences

819 carers based in England responded about their experiences.

24% (n=200) were aged between 55 and 64, and a further 24% (n=198) were aged between 65 and 74. 78% (n=638) were female, 21% (n=175) male. 14% (n=114) reported supporting more than one person.

53% (n=433) were caring for their spouse/partner. 34% (n=276) were caring for their child, and 9% (n=77) were caring for their parent/guardian.

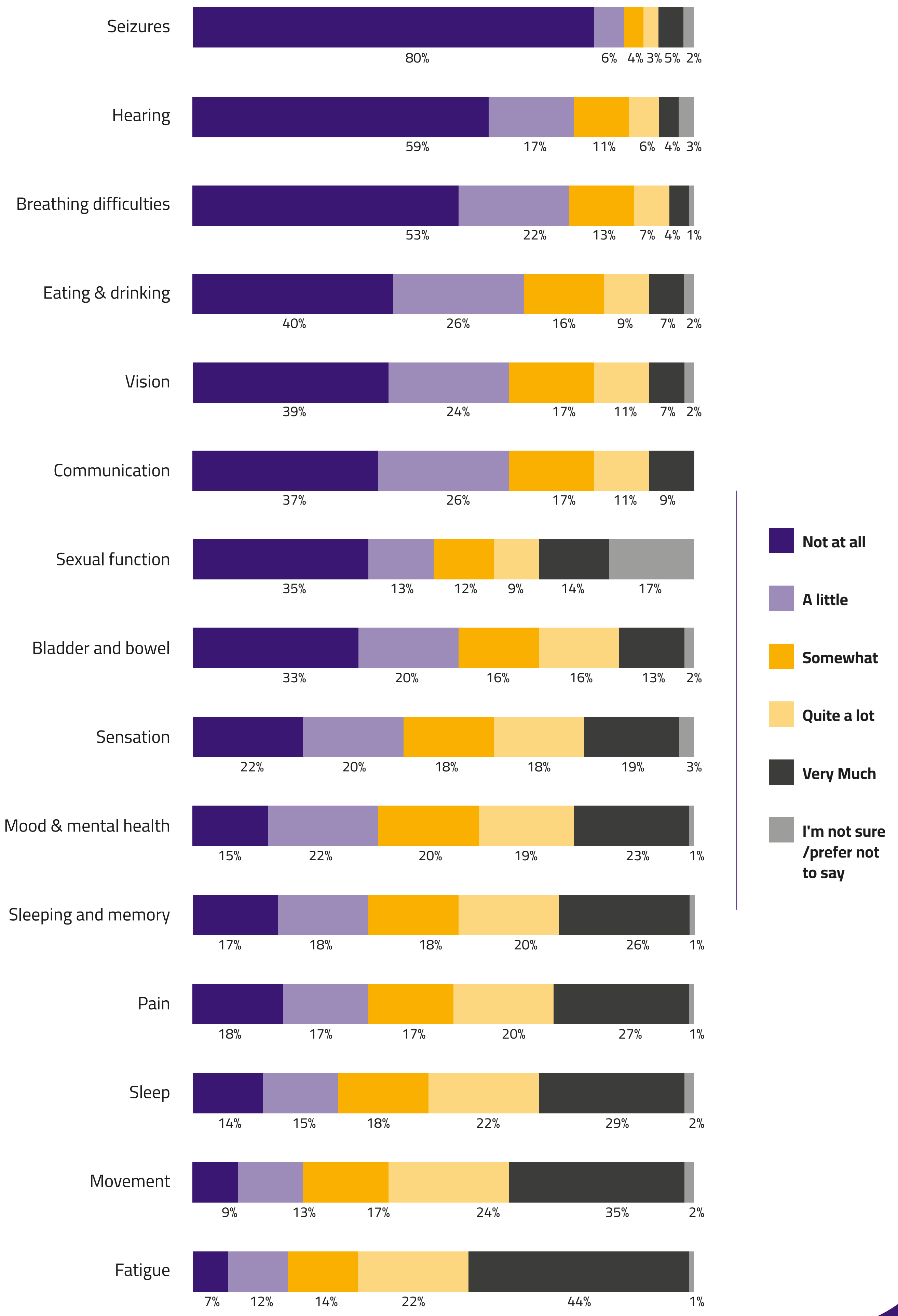
The realities of daily life

Living with a neurological condition can affect every part of life - from how people move and think, to how they feel, connect with others, and navigate everyday tasks. People who took part in My Neuro Survey told us clearly: the impact is constant, wide-ranging, and often invisible to those around them.

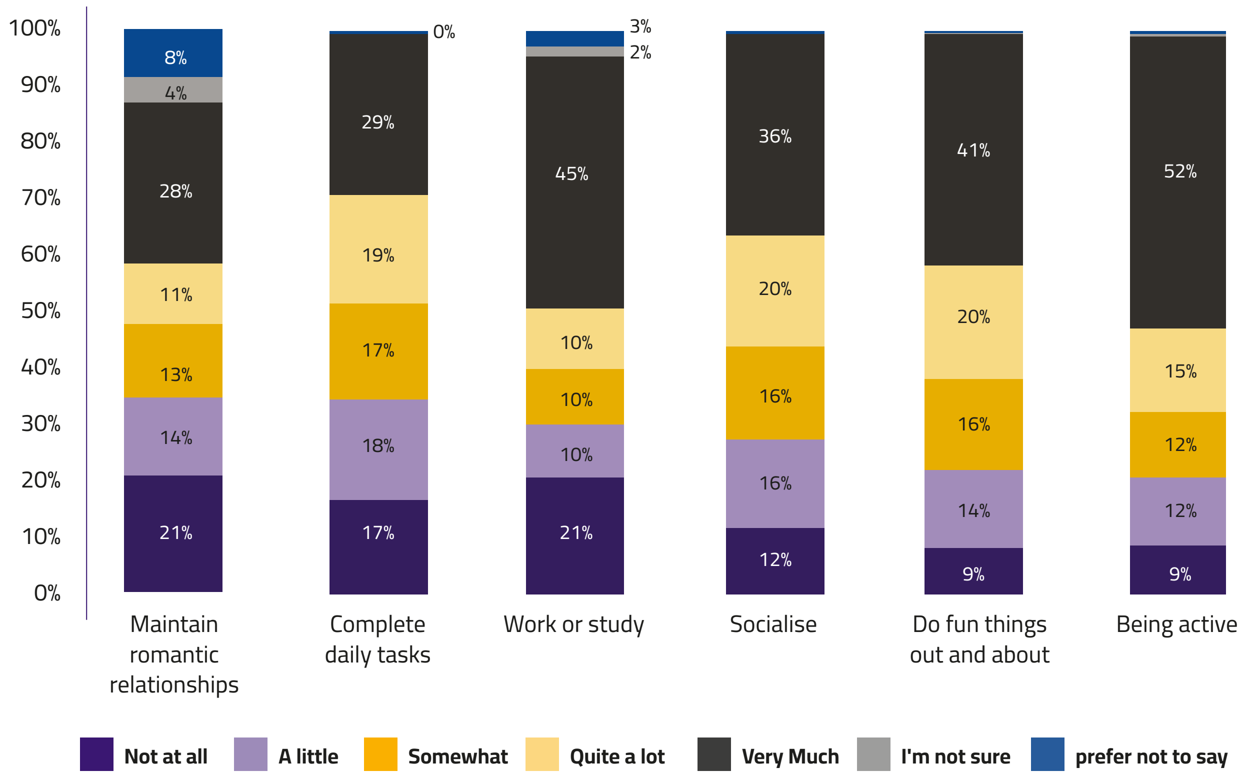
When asked about how their neurological condition impacted their health, people most commonly reported being affected by fatigue, problems with movement, pain, sleep disturbance, memory issues, and changes in mood and mental health. These experiences often overlapped and reinforced one another, making daily life more difficult to manage.

> **“I feel extreme fatigue… it affects my whole life – the ability to get jobs done for work and home, my mood with my family. I’m snappy and tired… it’s hard to accept feeling useless every 6 weeks."**

Which, if any, of the following ways does your neurological condition(s) impact your health?



We heard from people about how neurological conditions impact different parts of their lives, from completing daily tasks to maintaining romantic relationships. Almost 7 in 10 respondents reported that their neurological condition affected their ability to be active very much (52%, n=3208) or quite a lot (15%, n=901). More than half reported that their condition impacted their ability to socialise very much (36%, n=2214) or quite a lot (20%, n=1221) while almost 4 in 10 reported that their condition affected their ability to maintain romantic relationships very much (28%, n=1746) or quite a lot (11%, n=682).


How does your neurological condition(s) affect your ability to do the following?

The range of impacts neurological conditions often have on people's lives means that living with a neurological condition makes day-to-day life difficult for many. Almost 6 in 10 respondents reported regularly finding day-to-day life challenging (30%, n=1667) or finding every day challenging (27%, n=1536) with just 1 in 10 (12%, n=648) reporting that they feel confident and capable in their day-to-day life.

Carers, too, face significant pressure. Just 15% (n=121) of carers reported feeling confident and capable in their day-to-day life with more than 4 in 10 (43%, n=349) reporting sometimes finding day-to-day life challenging, a quarter (26%, n=209) regularly finding it challenging and almost 1 in 5 (17%, n=138) finding every day challenging.

I am feeling completely isolated in the care of my daughter with FND and autism. There is no one monitoring her symptoms or taking responsibility for her medically. I make daily medical decisions, I advocate for her, am the sole carer for her. This is very difficult and stressful. We do not feel supported by anyone.”

Like the people they affect, neurological conditions do not exist in isolation. An ageing population and improvements in diagnostics and life expectancy have led to an increase in the number of people living with multiple long-term conditions[4]. People affected by some neurological conditions are also at increased risk of other conditions including psychiatric conditions and frailty[5]. Living with multiple long-term conditions can reduce quality of life and lead to worse health outcomes, putting increased pressure on individuals and the health and care system.

Just over a quarter (27%, n=1700) respondents reported not having any other health condition aside from their neurological condition(s). 4 in 10 (41%, n=2570) reported also living with a physical health condition (e.g. arthritis, hypertension or heart disease); a third (33%, n=2031) reported also having a mental health condition; more than a fifth reported a sensory condition (e.g. myopia, retinal detachment, tinnitus etc.); 1 in 10 (8%, n=502) reported living with a cognitive condition and 2 in 10 (21%, n=1285) reported living with other health conditions.

> **Besides myasthenia I also have rheumatoid arthritis and melanoma. I feel I have full support in all my conditions – but that's not common."**

More than half of respondents to the carers' survey (56%, n=457) reported living with long-term conditions. The most commonly reported conditions were physical health conditions (43% n=352) followed by mental health conditions (19%, n=159), neurological conditions (8%, n=66) sensory conditions (8%, n=62), other conditions (8%, n=67) and cognitive conditions (3%, n=23).

Navigating the system

> **Seeing the doctor, physiotherapist and Occupational Therapist at the same appointment altogether is very beneficial as it feels a more holistic approach to my condiition! They are excellent!!"**

> **I seem to have slipped between the cracks and have not seen a neurologist for over 5 years and when requesting an appointment it has now been rescheduled 5 times and is not booked for nearly another year".**

Ensuring people can access the right treatment, care and support at the right time is fundamental to quality of life and clinical outcomes as well as reducing potential unnecessary interventions, emergency admissions and the overall cost of care [6 7]. Together with our member organisations, we've been highlighting the need to ensure timely access to services and support, no matter who you are or where you live, since the Alliance was established 30 years ago, in 1994. But in 2024 we over heard yet again about the challenges people face when trying to navigate the system and access the care they need to meet their needs.

Below we explore what these challenges mean for many people affected by neurological conditions. It is also important to highlight some of the issues within the health system that underpin their experiences.

Hundreds of thousands of people are waiting for neurology and neurosurgery appointments in England

According to the most recent waiting times data[8], in March 2025 there were 226,120 people waiting for an adult neurology appointment in England. This is an increase of almost 25% compared with March 2022 when we reported on wating lists alongside findings from My Neuro Survey in 2021/22.

The NHS has a target of 18 weeks from referral to seeing a specialist. In March 2025 more than 45% of people waiting for a neurology appointment had waited more than the 18-week target, the third highest across all specialties. As of March 2025, the average time someone waited for a neurology appointment was 16.3 weeks. This is the third longest average wait time of any speciality and represents a 30% increase in how long people are waiting for a neurology appointment compared to March 2022.

March 2025 saw 58,423 people waiting for a neurosurgery appointment in England, an increase of more than 4,000 people from March 2022.

How long people wait varies across the country

It isn't just the number of people waiting, but how long people are waiting, that matters.

Where you live can mean the difference between weeks and months of waiting – there is significant variation in average wait time and the amount of people seen within the 18-week NHS target between different Integrated Care Boards (ICBs).

According to the most recent waiting times data from March 2025, NHS Bedfordshire, Luton and Milton Keynes ICB reported the longest average wait time of 22.1 weeks and the highest number of people waiting for more than 18 weeks at 57%.

NHS Leicester, Leicestershire and Rutland ICB reported the shortest average wait time of 9.9 weeks and the lowest number of people waiting more than 18 weeks at 33%.

There are critical shortages across the neuroscience workforce

A key drive of long waits for treatment and care is both shortages of the neuro health and care workforce, as well as unequal distribution of specialist healthcare professionals across the country.

Despite efforts of consecutive governments to reduce the number of people waiting for care and how long it takes to access vital services, too many people are still unable to access the services and support they need when they need them. This must change.

In July 2025 the government is set to publish a 10-Year Plan for the NHS. The plan and subsequent work to deliver it must be the first step towards addressing the challenges highlighted in this report. Together with our members and people affected by neurological conditions, the Alliance developed three key tests to ensure the plan transforms services for the one in six people living with neurological conditions in England[9]. To do this the plan must:

- Deliver responsive and compassionate care closer to home for people with neurological conditions now and in the future. This includes ensuring the plan supports the growth, retention and sustainability of a neuro health workforce fit for the future.
- Exploit the promise of data, digital and tech for people affected by neurological conditions.
- Reduce the risk of onset, and prevent progression of, neurological conditions, and harm caused by them.

Underpinning these tests are a series of clear, evidence-based actions that formed the basis of our response to the 10-Year Plan consultation [10].

Recommendation

Ensure the NHS 10 year plan is supported by a specific implementation plan for services for people affected by neurological conditions.

Accessing services

Access to the right treatment, care and support at the right time can be the difference between living well and being unable to work, socialise or manage daily life. The right care, treatment and support at the right time should be the norm for everyone with a neurological condition - regardless of who they are or where they live - but too often, it's not.

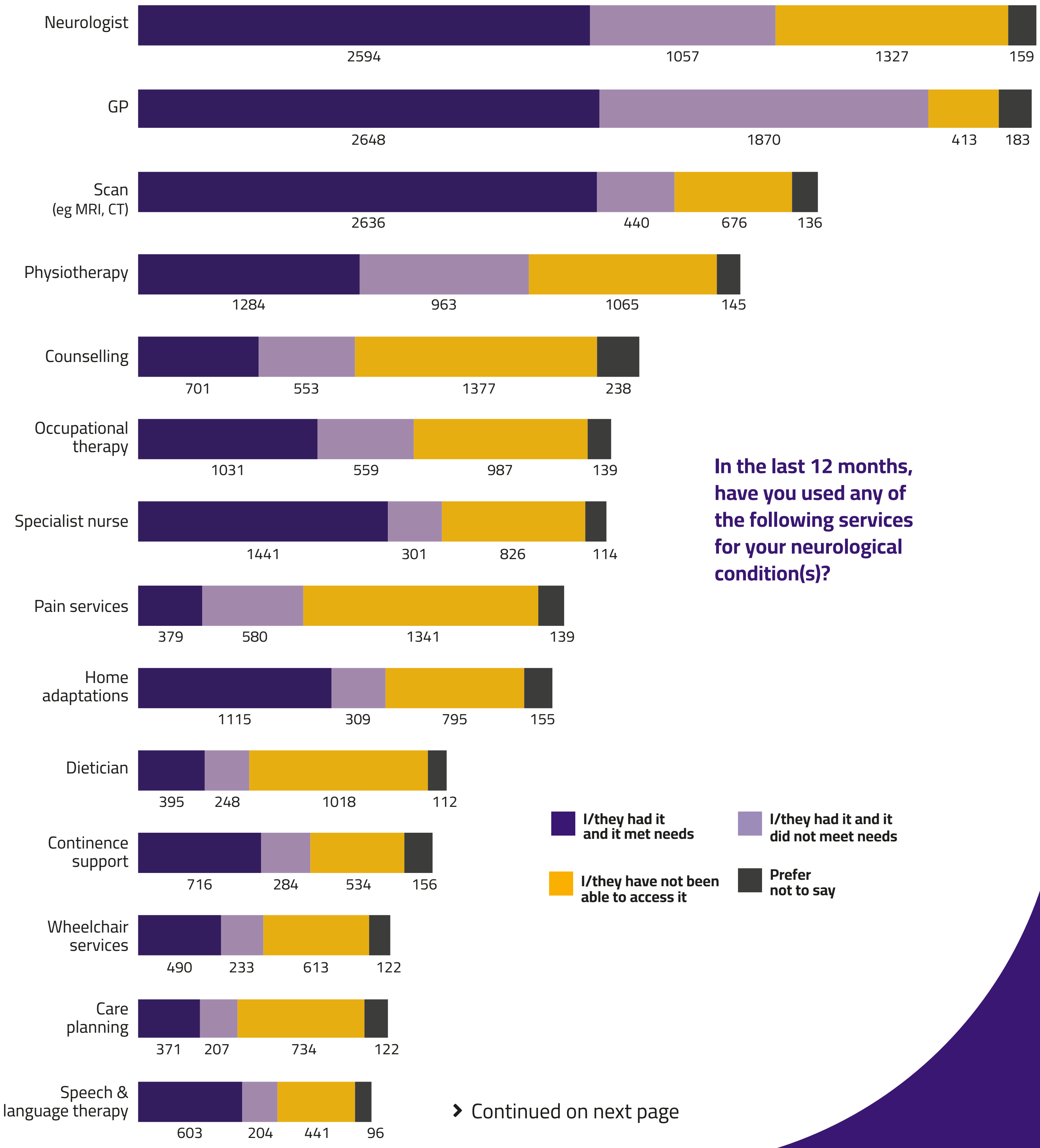
People often require multiple services and professionals to effectively diagnose and manage their neurological condition. This could include MRI and CT scans to diagnose a condition, physiotherapy or home adaptations to support symptom management and annual reviews with a neurologist or specialist nurse.

Despite the importance of these vital services, too often people reported being unable to access services they felt were relevant to them in the last 12 months. People most reported being unable to access specialist mental health support despite needing this, with 7 in 10 (69%, n=715) reporting being unable to access neuropsychiatry in the last year and more than 6 in 10 (62%, n=781) reporting the same for neuropsychology.

Neurorehabilitation services were also identified as one of the services that people reported experiencing difficulties with accessing, despite feeling they would benefit from this. More than 6 in 10 (64%, n=544) respondents reported being unable to access inpatient neurorehabilitation in the last year, over half (55%, n=687) reported being unable to access outpatient neurorehabilitation.

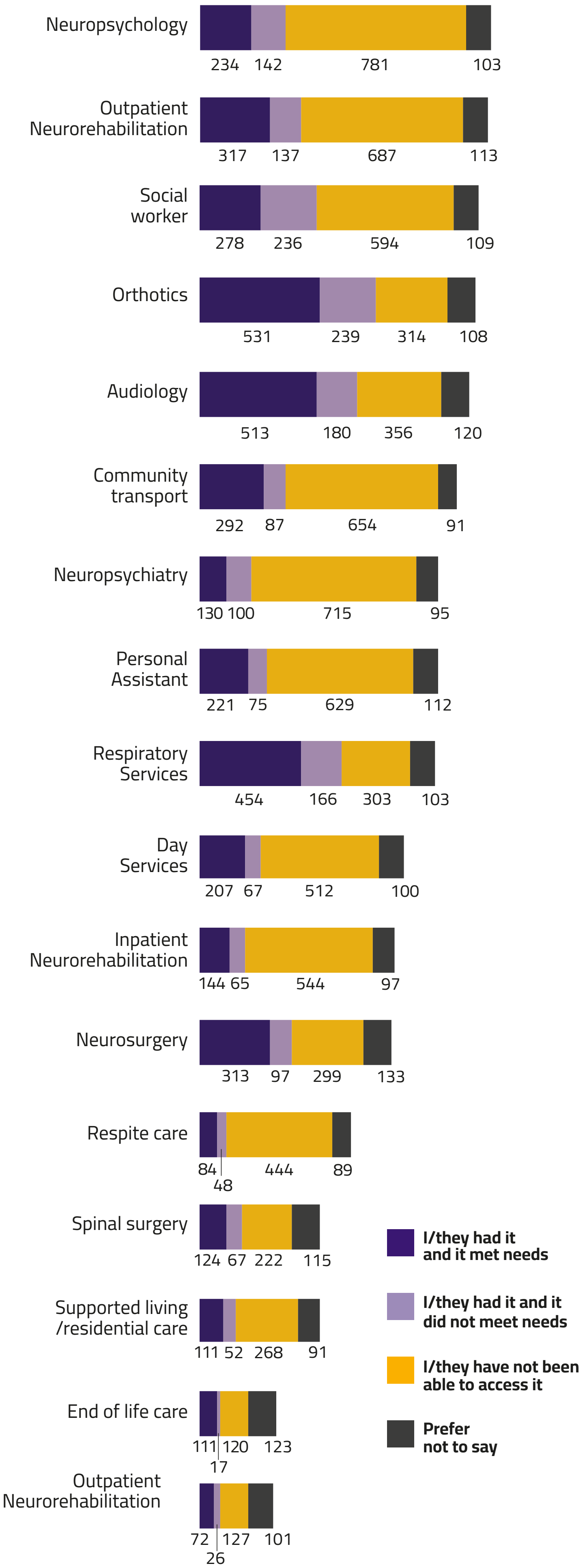
> **I had to fight for support from day one. Took me 7 years to access neuro rehab and I had to travel to London despite there being neuro rehab units in my locality."**

Similar challenges around access were reported in relation to pain services with over half of respondents reporting being unable to access these despite feeling they would benefit (55%, n=1341). 4 in 10 (42%, n=222) reported being unable to access spinal surgery despite needing this. 4 in 10 (42%, n=613) also reported being unable to access wheelchair services despite needing this. Access challenges were also reported for some more commonly used services. More than a quarter (26%, n=1327) of respondents reported being unable to access a neurologist in the last year despite needing to and almost a third (31%, n= 826) reported being unable to access a specialist nurse.



In the last 12 months, have you used any of the following services for your neurological condition(s)?

› Continued on next page



We also asked about whether people had participated, or would be interested in being involved, in research about the neurological condition. Just over a quarter of respondents (27%, n=1531) reported that they participated in research for their neurological condition. More than 7 in 10 (71%, n=3997) said that they would be interested in being involved in research studies about their condition. These findings indicate that there is currently significant unmet demand for participation in research studies and efforts should be made to increase opportunities for people to be involved in neurological research.

> **Having been born with Spina Bifida in 1967, I feel that it was, and has always been since, a matter of patch him up & send him on his way! And since then there has been very scant research into any improvements."**

> **The medical establishment could support ME/CFS patients better by funding physiological research to find a cure, so that patients can go back to work and to having a life again."**

Meeting needs

We also asked people who had been able to access specific services whether they met their needs. More than a third (37%, n=1869) of respondents who had been able to access GP services in the last year reported that it did not meet their needs. Of those who reported being able to access physiotherapy services, almost 3 in 10 (28%, n=963) reported that it did not meet their needs, as did a quarter of those who had accessed pain services in the last year (24%, n=580).

> **GP Ignorance and an attitude of not being interested or even bothering to consider aspects of having had polio is frustrating."**

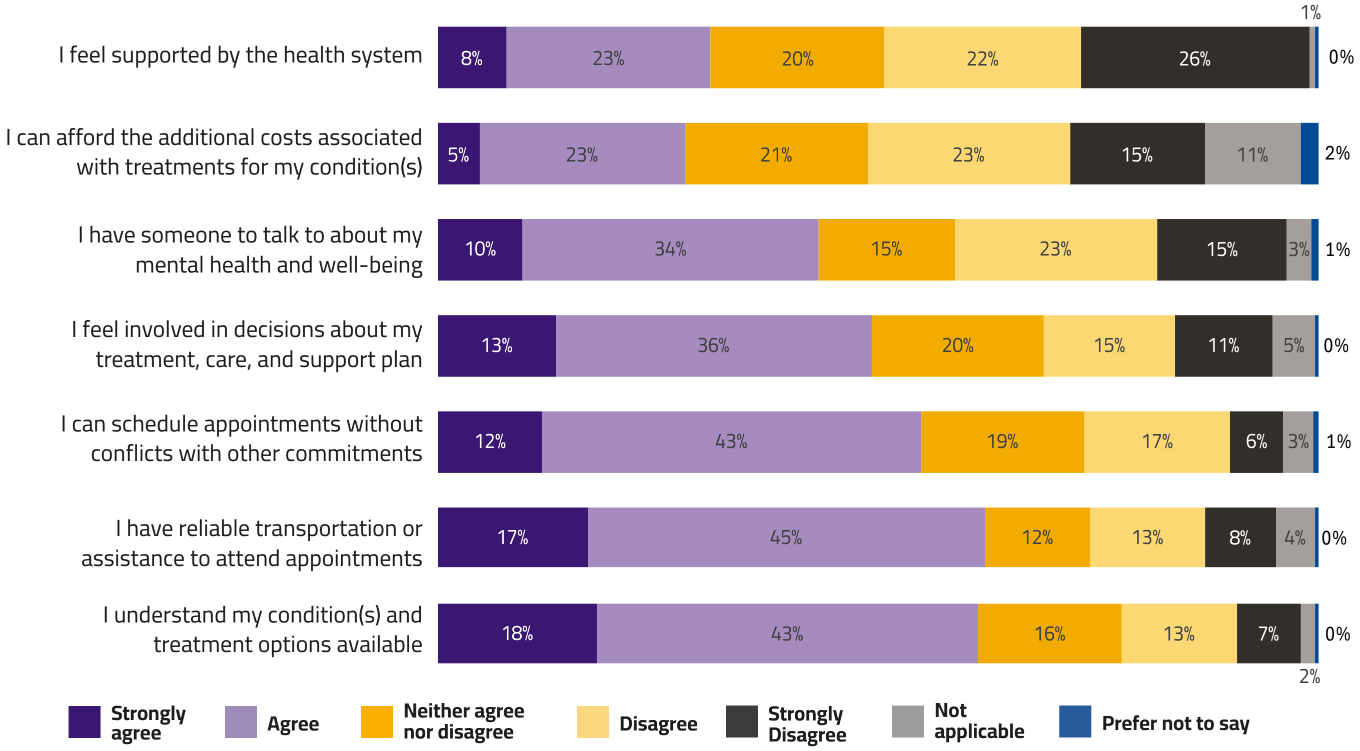
Being unable to access vital services, or services not meeting people's needs, can have a significant impact on clinical outcomes and on people's experience of the health system. When asked whether they agreed with the statement "I feel supported by the health system" almost half of respondents (48%, n=2705) either disagreed (22%, n=1249) or most often, strongly disagreed (26%, n=1456).

Across the UK sample, female respondents were significantly more likely to report not feeling supported by the health system compared to males, with 54% of females either disagreeing (24%, n=1339) or strongly disagreeing (29%, n=1603) compared to male respondents of whom 32% either disagreed (15%, n=327) or strongly disagreed (17%, n=367).

There was also significant variation between age bands across the UK sample, with respondents aged between 35 and 44 most likely to report not feeling supported by the health system (59%, n=629) and those aged 75 or over least likely to report not feeling supported (32%, n=236).

> **I cannot access a Parkinson's nurse or other services to support me in My young onset Parkinson's journey because I am told that my symptoms are not yet bad enough."**

Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)?



We provided a range of statements for people to agree or disagree with, according to their experiences. Respondents were most likely to agree or strongly agree that they understood their condition and available treatment options (61%, n=3442) and that they have reliable transport or assistance to attend appointments (62%, n=3488).
48% (n=7205) disagreed that they felt supported by the health system.

We also asked to what extent people felt the care they received from medical and healthcare services met their needs. Just one in three respondents (34%, n=2082) either agreed (27%, n=1660) or strongly agreed (7%, n=422) that medical and healthcare services met their needs. Again, across the UK sample, female respondents were less likely to agree with this statement compared with males with 31% (n=1792) of females either agreeing or strongly agreeing compared to 46% of males (n=1200). In relation to variation between age groups, respondents aged 35 to 44 were least likely to agree or strongly agree (28%, n=313) while those aged 75 or over were most likely to agree or strongly agree (44%, n=434).

> **I feel as a woman I am completely dismissed most of the time because I have hormones. E.g I went to the GP with constant 24/7 severe dizziness that was sudden onset... one day I was completely fine and then the next my life has been turned upside down and been awful since due to that and the worsening of migraine and daily headache... the GP would only offer me the contraceptive pill ... Nothing else... I had to fight SO hard to get a neurology referral."**

> **I've been waiting on a formal diagnosis for over 18 months and never feel listened to. I think because I am a relatively young female, the older male doctors dismiss me and try to palm me off with a mental health diagnosis when I have clear worsening physical symptoms and have already been assessed and discharged by mental health services. I feel I am being failed by male pride and ego."**

Overall experience

Challenges with accessing vital services and support, not feeling supported by the health system and needs not being met by medical and healthcare services are likely to impact people's overall experience with the health system. When asked overall how happy they felt with their experience with healthcare services in the last twelve months, only a third of respondents (33%, n=2061) reported feeling happy (25%, n=1551) or very happy (8%, n=510). Respondents were most likely to report feeling neither happy nor unhappy (29%, n=1765) but almost 4 in 10 reported feeling unhappy (20%, n=1212) or very unhappy (18%, n=1094) with their recent experience of healthcare.

Across the UK sample, respondents aged 64 to 74 were most likely to report feeling happy with their overall experience of healthcare services, with 40% reporting feeling happy (12%, n=196) or very happy (28%, n=467) compared to respondents aged 18-24 and 35-44 with just over a quarter (27%) of each group reporting feeling happy or very happy with their overall experience of healthcare.

We also asked whether people thought their care from medical and healthcare services had improved over the last 12 months. Across adult respondents, just 2 in 10 (22%, n=1348) reported that they agreed (18%, n=1124) or strongly agreed (4%, n=224) that their medical and healthcare had improved in the last year while 4 in 10 (39%, n=2394) either disagreed (23%, n=1414) or strongly disagreed (16%, n=980).

Getting the right support

Timely access to the right health and care professionals is the cornerstone of good care. Through our member organisations and our community, we hear regularly about the positive impact healthcare professionals have on people's lives, but we also know that not being able to see or contact the right specialist at the right time can cause significant challenges.

01

There are critical shortages across the neuroscience workforce.

The UK ranks amongst the bottom for the number of neurologists per 100,000 people when compared to European countries with a similar GDP. The UK has around four times fewer neurologists than France and Germany[11]. Acute workforce shortages exist across the multidiscplinary team required to deliver effective and responsive care for people affected by neurological conditions, including neuropsychiatrists[12], neuropsychologists, neurorehabilitation consultants[13] and specialist nursing. [14] [15]

02

Some areas are particularly badly affected by workforce shortages.

A third of neurologists in the UK are based in London and the South East.[16] Some specialist neuroscience services such as neuropsychiatry and neurophysiotherapy are simply not available in certain parts of the country, leaving people without access or having to travel long distances to receive vital care and support.

03

Good quality data about the current state of the neuro workforce does not exist or is not routinely available.

For many key roles such as specialist nurses and Allied Health Professionals – including neuro physiotherapists, neuro occupational therapists and speech and language therapists – good quality workforce data to support mapping and planning either does not exist or is not available publicly.

Many of the experiences shared with us through My Neuro Survey, good and bad, are directly linked to the workforce. Addressing the workforce challenges outlined above is critical to improving experience and outcomes for people affected by neurological conditions.

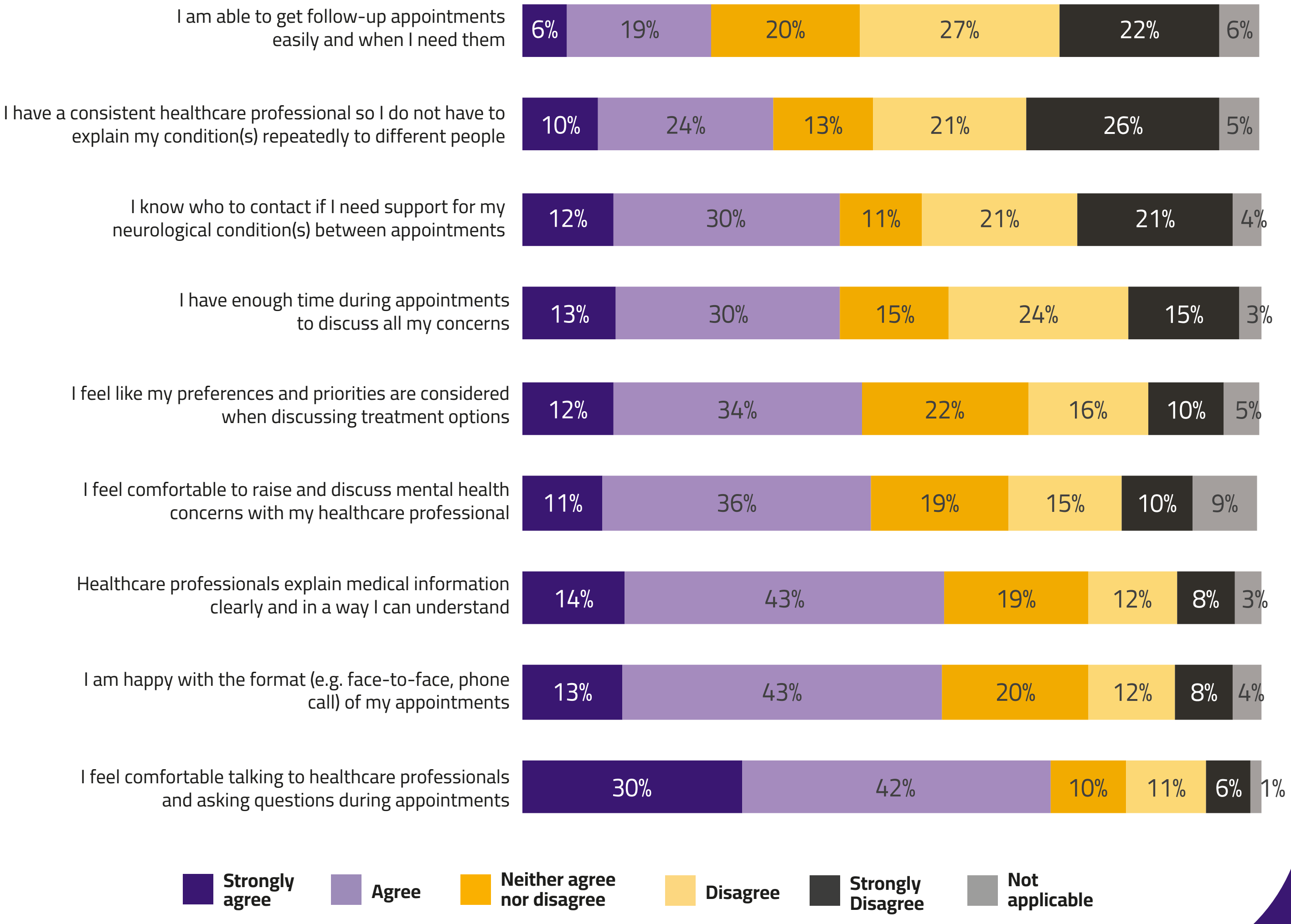
There is an opportunity to start this vital work now. The Government is developing a refreshed long-term workforce plan for the NHS [17] which is expected to be published in Summer 2025. The Government must listen to the experiences of people affected by neurological conditions and work with the sector – including professional bodies and patient groups – to ensure the plan addresses the critical challenges facing the neuroscience workforce.

Recommendation

Tackle critical workforce shortages in neuroscience and associated specialties in the forthcoming workforce plan.

Support between appointments

One of the key messages that we heard from our community is that too often, people don't know who to contact for support between appointments. There are many reasons why people need to seek advice or support between appointments including the onset of new symptoms or worsening of existing symptoms, questions about medications including side effects or simply seeking advice related to their neurological condition.



More than 4 in 10 (42%, n=2355) reported that they either disagreed (21%, n=1165) or strongly disagreed (21%, n=1190) that they know who to contact for support for their neurological conditions between appointments.

> **I haven't heard from my neurologist for over 2 years and feel like I'm forgotten and I don't know who to contact if I need help in the meantime. My GP's knowledge of myasthenia is practically non-existent".**

Being unable to access support between appointments is of particular concern given ongoing challenges around waiting lists for NHS neurology and neurosurgery services in England highlighted earlier in this report. Waiting is not static: without the timely access to appropriate support health can deteriorate, leading to worse outcomes, poorer experiences and reduced quality of life.

Free text comments also highlighted limited knowledge of neurological conditions amongst GPs. Challenges with accessing specialist support between appointments can add additional pressure on already stretched GP services and these services are often unable to meet the specific needs of people affected by neurological conditions.

> **I find the GPs hesitant to discuss/ deal with anything that they believe if MS-related and say to discuss with neurologist, which is not possible when you have an appointment once a year."**

Specialist nurses

For those with access to them, specialist nurses can provide excellent support both during and between appointments. However, these roles do not exist for many neurological conditions and for those conditions with specialist nurses, not everyone has access to them.

Of those who reported specialist nurse services were relevant to them more than half (54%, n=1441) reported that they were able to access this service and it met their needs, one in ten (11%, n=301) reported they were able to access and it did not meet their needs and three in ten (31%, n=826) reported that they had not been able to access specialist nurse services.

> **I don't have an epilepsy nurse so I have no one to contact between appointments when I have concerns or questions about what is and isn't safe".**

> **My specialist nurse is very open to me contacting her if I need anything which provides a comfort net around me so I do not research online and overwhelm myself".**

Booking follow-ups

We also heard about challenges with getting follow-up appointments when they were needed. Half of respondents (49%, n=2725) either disagreed (27%, n=1519) or strongly disagreed (22%, n=1206) that they were able to get follow-up appointment easily and when they need them.

People regularly highlighted issues with administration and poor communication being a barrier to accessing appointments, with the burden often put on the individual and causing them additional stress during what is often an already challenging time.

> **I have to chase the booking office to have my next appointment with the MS nurse or neurologist - this never used to happen previously until the person left and the service got worse. I hardly ever receive a copy of the letter sent to my doctor after an appointment or to get my results. I only know they have received it becauseI can see it on the NHS app, then I have to contact the neurology team for a copy. Once I receive the support from either the neurologist or MS nurse its always very helpful but the NHS 'process' and administration is stressful and poor."**

Experiences with professionals

Responses also spotlighted challenges around being able to see the same healthcare professional. Nearly half of respondents (47%,n=2623) either disagreed (21%, n=1,166) or, most often, strongly disagreed (26%, n=1,457) that they have a consistent healthcare professional so they do not have to explain their conditions repeatedly to different people.

> **The specialist nurses are wonderful but I never see the same one again which doesn't help with continuity in care."**

It is important to highlight the examples of fantastic care provided by healthcare professionals and the difference this has made to people's lives. Many respondents provided examples of care they had experienced in the free text comments. Some aspects of good care were reflected in the survey data:

- Nearly three quarters of respondents (72%, n=3992) either agreed (42%, n=2336) or strongly agreed (30%, n=1656) that they felt comfortable talking to healthcare professionals and asking questions during appointments.
- Almost 6 in 10 (57%, n=3502) respondents reported that healthcare professionals explained medical information clearly and in a way they can understand.

> **My neurologist has been lovely since I first met him and still to this day. My occupational therapists were both great and really did there best to help me. My physiotherapist did lots to help me get walking again. My psychotherapist has helped me quite a lot and still does everything he can to help me."**

Support from charities

A number of questions referenced the role of charities in providing information and support. 14% (n=825) of adult respondents reported that the received support from professionals funded by charities or non-profit organisations. Almost a quarter (23%, n=1,289) of adults reported that they had been offered or directed to information about their condition by charities or patient organisations in the last 12 months.

Dozens of free text comments referenced the critical role of charities in supporting people affected by neurological conditions. This includes providing practical services and support where the health system has been unable to do so as well as providing vital information and peer support.

Below is a snapshot of comments highlighting the importance of charities and patient groups in supporting people during the neurological journey, many more organisations were referenced but there simply isn't the space to include them all by name.

I cannot speak too highly about the British Polio Fellowship, without whose advice and physical help (in 2003/4) I would be in a much worse place."

Different Strokes Charity are excellent".

I find it very hard to ask for help but the support and understanding I have had from my neuro-oncology nurse specialist has been invaluable. I also benefited greatly from an 8 week counselling session from The Brain Tumour Charity which was much quicker to access than NHS counselling services."

The support from the MSA Trust and, our local Hospice, has been excellent. Without their support we would have felt totally abandoned after diagnosis".

I was referred to the charity GAIN when I was in hospital as a good source of information and found their website helpful. Through them I found various social media groups, especially on Facebook, which have been very useful."

MS nurse invaluable MS Society and MS Trust brilliant."

Mental health

Neurological conditions have a significant impact on people's mental health. Living with a long-term condition often negatively impacts people's mental health [18], but there is also a unique, complex and often poorly understood interplay between neurological conditions and psychiatric, cognitive and emotional impacts.

Despite their impact, too often people with neurological conditions are unable to access appropriate mental health support.

Listening to our community and our members, we hear about people being refused access to mental health services as a direct result of their neurological diagnosis. Mental health services should be available based on need and should not exclude anyone because of a physical health diagnosis, including a neurodevelopmental or neurological condition. NHS England have clarified this on their website [19] and have previously provided guidance on this directly to NHS services [20]. However, with mental health services often stretched to breaking point or for some, simply not available, the reality is often very different.

Given the complex interplay between mental health and neurological conditions, some people require support from specialist neuropsychiatrists and neuropsychologists. We referenced the critical shortages across the neuroscience workforce earlier in this report. They are most acute amongst the specialist mental health workforce.

- **Neuropsychiatrists:** data from the Royal College of Psychiatrists 2023 census [21] indicates there are just 22 full time and 34 part time neuropsychiatry consultants working in England.
- **Neuropsychologists:** unpublished workforce data from the British Psychological Society, Division of Neuropsychology showed that in 2019 there were 525 neuropsychologists working in the NHS across the UK. The number working in different areas of the country ranged from 0.5 to 0.06 per 100,000 people.

Action to address critical shortages in the specialist mental health workforce, remove barriers preventing people from accessing appropriate mental health services, and to fully integrate mental health care across care pathways for people affected by neurological conditions could transform the lives of thousands.

There are solutions, but we need Government and the health system to deliver them. Existing commissioning guidance, including from the British Psychological Society [22], sets out what good integrated care looks like and how they benefit people and the health system.

Through the National Neuroscience Advisory Group (NNAG) specialist clinicians, patient groups and people who use services have developed a cross-cutting optimal clinical pathway for mental health [23].

In our response to the NHS 10-Year Plan for the NHS consultation process, the Alliance has made evidence-based recommendations to ensure equitable access to specialist multidisciplinary teams and mental health services and support, including removing barriers and ensuring people can access the right mental health support at the right time, whoever they are or wherever they live[24].

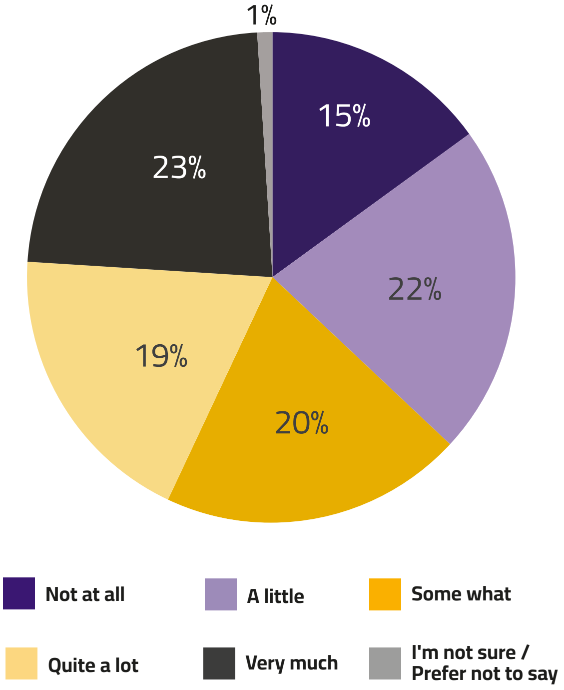
Recommendation

Implement NHS guidance that seeks to ensure no-one is turned away from mental health services due to their neurological diagnosis.

> **Counselling is not available on the NHS in my area, other than CBT therapy for PTSD."**

More than 8 in 10 people 84%, (n=5187) reported that their neurological conditions affected their mood and mental health with almost a quarter 23%, (n=1407))reporting the highest level of impact. A third of respondents reported having a mental health condition in addition to their neurological condition.

Which, if any, of the following ways does your neurological condition(s) impact your health? Mood and mental health issues



Despite the prevalence and impact of neurological conditions, too often people reported being unable to access support for their mental health. Of the respondents who reported it as relevant to them, in the last year:

- Almost half (48%, n=1377) were unable to access counselling services .
- 7 in 10 (69%, n=715) were unable to access neuropsychiatry services.
- 6 in 10 (62%, n=781) were unable to access neuropsychology services.

When people were able to access services, the majority reported that they were able to meet their needs. Of those who were able to access mental health services, we heard whether specific services met their needs:

- Counselling: 56% (n=701) reported that the service met their needs, 46% (n=553) reported that it did not.
- Neuropsychiatry: 57% (n=130) reported that the service met their needs, 43% (n=100) reported that it did not.
- Neuropsychology: 62% (n=234) reported that the service met their needs, 38% (n=142) reported that it did not.

When asked whether their care from mental health services met their needs, just 1 in 10 adult respondents (11%, n=681) either agreed (9%, n=573) or strongly agreed (2%, n=108).

Around a third (31%, n=1927) either disagreed (16%, n=980) or strongly disagreed (15%, n=947) while 21% (n=1280) reported neither agreeing nor disagreeing, with a further 36% (n=2222) reporting the statement was not applicable to them.

There was also an opportunity for people to share whether they felt the care they received from mental health services had improved in the last year. 4 in 10 respondents (41%, n=2559) reported that this question was not applicable to them. Fewer than 1 in 10 (8%, n=485) either agreed (7%, n=406) or strongly agreed (1%, n=79) that care from mental health services had improved in the last year while 3 in 10 (29%, n=1765) either disagreed (15%, n=915) or strongly disagreed (14%, n=850).

Caring and mental health

We heard from carers about whether they had accessed support for their mental health and wellbeing. Of the respondents who reported it as relevant to them, in the last year almost 7 in 10 (66%, n=406) reported that they had been unable to access mental health and wellbeing support.

> **There is no specialist counselling/ mental health for carers who have children with neurological conditions that I have been able to access and general counselling through a GP/ NHS has huge waiting list and I do not believe will meet my ongoing needs to deal with grief, guilt, anxiety and dealing with hardship day to day."**

Financial strain & difficult decisions

Living with a neurological condition costs more. This includes additional costs accessible transport, specialist equipment such as medication, help with household activities and spending more on everyday essentials such as heating. Living with a neurological condition can cost, on average, an additional £200 a week [25]. The Latest research from Scope [26] puts the additional costs of living with a disability in 2024, or Disability Price Tag, at £1,010 per month.

Alongside these extra costs, living with a neurological condition or caring for someone with a neurological condition can prevent some people from working, make it harder to get a job or stay in work.

This is why financial support to help with the additional costs of living with a neurological condition is vital. However, we've heard yet again about significant shortfalls in support for disabled people to get and stay in employment (where this is possible) as well as barriers to accessing financial support through the welfare system.

As part of their mission to increase economic growth, the government has recently proposed significant changes to employment support and to the health and disability benefits system [27].

Improving support for disabled people and those with long-term health conditions who can work to get and stay in employment is of course welcome. However, there are significant concerns about the potential impact of proposed changes to the health and disability benefits system on people affected by neurological conditions and those who care for them.

The government is planning to cut £5 billion from health and disability support through their proposed changes. This includes tightening the eligibility criteria for Personal Independence Payments (PIP) – a non-means tested benefit intended to support with the additional costs of living with a disability.[28]

Figures from the Department of Work and Pensions (DWP) show that almost half a million people with neurological conditions receive Personal Independence Payments [29].

> **"If the PIP green paper is imposed on us...my wife and I are done for as we will be unable to pay our basic costs. I have worked in full time employment since I was 16 years old until medically retired. The government has abandoned my wife and I."**

The changes would make it much harder for people, including tens of thousands with neurological conditions, to qualify for PIP, seeing them lose thousands of pounds of vital support every year. The proposals would also see many people losing support linked to PIP, such as Carers' Allowance, as well as cuts to the 'health element' of Universal Credit.

> **"We are very worried about changes to PIP as my husband's condition is getting worse and he worries a lot about this which causes him more distress which he doesn't need. I am worried about my overall future especially on the financial side as I have had to give up full time work to help my husband. The government do not do enough for people like me."**

According to the government's own impact assessment, these changes are set to push a quarter of a million people, including 50,000 children, into poverty [30].

Together with hundreds of charities, patient groups, and disabled people's organisations, we are calling on the government to rethink and reverse the planned cuts. We fully endorse calls from the Disability Benefits Consortium (DBC) for Parliamentarians to act to protect vital support for disabled people, including people affected by neurological conditions.

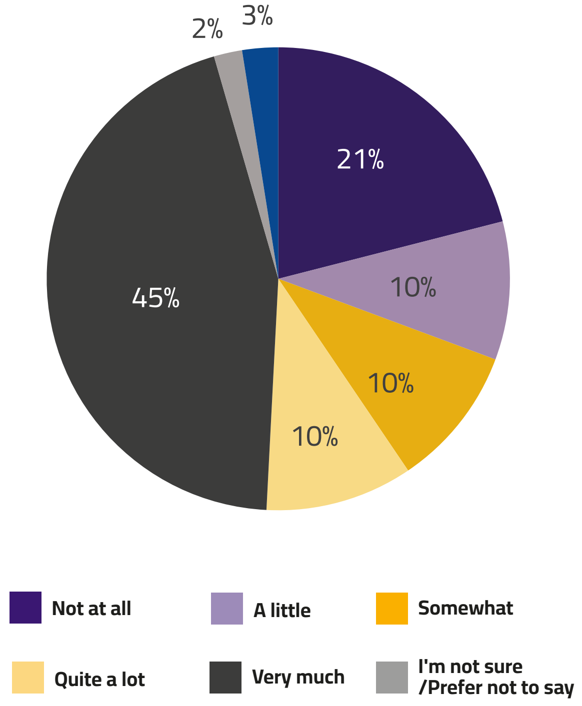
Recommendation

The government must rethink and reverse planned cuts to the health and disability benefits system and ensure any changes do not negatively impact people affected by neurological conditions.

Work and study

We heard from thousands of people that their neurological condition has a significant impact on their ability to work or study. Three quarters of respondents (75%, n=4606) reported that their condition affected their ability to work or study to some extent, including almost half (45%, n=2763) who reported the most significant impact.

How does your neurological condition(s) affect your ability to do the following? Work or study (e.g., unable to work or study due to my condition(s), had to give up my job or reduce working hours, had to stop studying or reduce study hours)



People often reported having to stop working as a direct result of their neurological condition, half of adult respondents (49%, n=2754) agreed or strongly agreed that this was the case.

Concerningly, more than a quarter of adults (28%, n=1593) reported that they faced discrimination at work due to their neurological condition.

> **"M.E. has been misunderstood and unsupported by my employer. I have had to resort to reducing my hours and taking the financial hit because I cannot cope with full time any longer. I am worried about the future and the impact on my husband and I financially. I put in an application to access to work in April. I still haven't heard back so resorted to a part time request. I feel discriminated against at work but my union have been unable to help. I am unable to advocate for myself without being accused of being too sensitive or facing capability."**

Financial support

Living with a neurological condition or caring for someone with a neurological condition puts additional pressures on people's finances.

> **"My concerns are not physically being able to care for my child as she gets alot older if she can't be more independent and financially how we would pay for help should it be needed."**

More than 6 in 10 (64%, n=3954) adult respondents reported that their neurological condition affected their ability to manage financially with 2 in 10 (20%, n=1246) reporting that it affected their ability to manage financially very much. More than a 6 in 10 carers (65%, n=533) also reported that financial constraints affected their experience of providing care with over a quarter (26%, n=210) reporting it affected them very much (13%, n=104) or quite a lot (13%, n=106). Financial support to help with the additional costs and employment challenges is vital for many.

Almost half of adult respondents (47%, n=2818) reported receiving financial support such as disability benefits or grants. Proposed changes to the health and disability benefits system are causing significant concerns to many, with the risk of losing out on thousands of pounds of vital support every year.

> **I constantly worry about the income I receive in benefits from the government. I gave up my self employed job due to my condition as I could no longer manage but I stress all the time that I will lose my benefits and be made to work and also the constant re assessments regarding PIP."**

PIP assessments were frequently referenced in free text responses as being unable to effectively capture the realities of living with a neurological condition. We also heard about the impact the assessment process can have on people's neurological conditions and mental health.

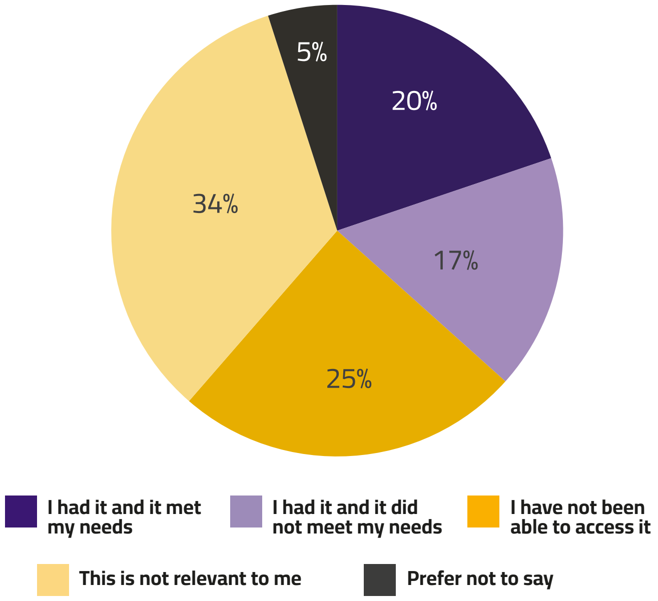
> **PIP is all about washing and dressing yourself and how far you can walk but the fatigue which stops you working full time is debilitating. Then you struggle to pay the bills, the government need to look at this, dropping your hours for no fault of your own, and then the stress of paying the bills, Multiple Sclerosis and stress can cause relapses, making symptoms worse. The system needs to change."**

Caring and finance

Carers also often require financial support to help offset the costs of caring and the impact caring responsibilities often have on their ability to stay in work. When asked whether they had been able to access financial support for their caring responsibilities, a quarter of carers (25%, n=206) reported being unable to access this. 2 in10 (20%, n=161) reported that they had been able to access financial support and it met their needs whilst 17% (n=140) reported that they had accessed but it did not meet their needs.

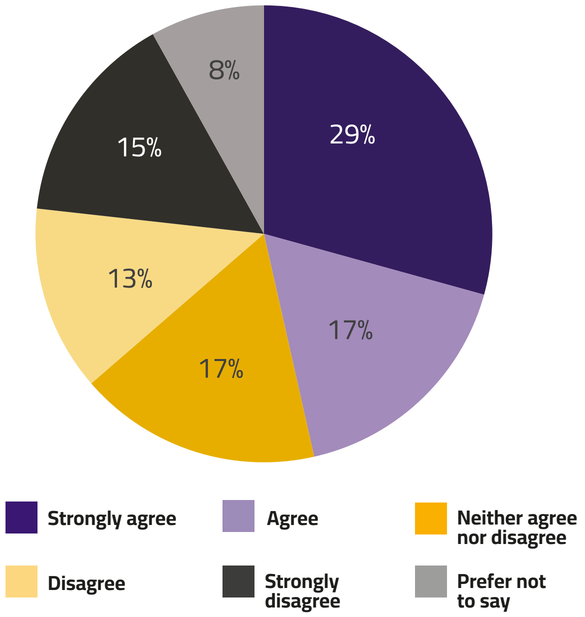
> **I am at the point of looking for more work and then coming off Carers' Allowance as the cap on earnings means we are struggling financially. Working more does worry me, as I am not sure how I can support my child if he has difficulties at school and I am called to help out/collect him/accept a reduction in his timetable.”**

In the past 12 months, have you used any of the following types of support for your caring responsibilities?



Often, carers reported that the financial support they receive is not sufficient – more than 4 in 10 carers (45%, n=362) reported that the financial support was not sufficient compared to just under a quarter (23%, n=183) who reported that it was.

I have had to reduce my hours or leave my job entirely due to caring responsibilities



Carers also reported that their caring responsibilities often impacted their ability to stay in work with almost half of carers (46%, n=381) reporting that they agreed (17%, n=140) or strongly agreed (29%, n=241) that they have had to reduce their work hours or leave their job entirely due to their caring responsibilities.

Going private

Challenges in accessing the right support close to home mean many people are turning to private healthcare instead, adding to the financial strain of living with a neurological condition. When asked whether they had accessed support from professionals funded by themselves or their family, more than 1,000 respondents (17%, n=1025) reported that they had.

For some, private healthcare services provide an opportunity to access additional services and support alongside positive experiences of care provided by the NHS.

> **I have had to use private dietician, counsellor, osteopath and acupuncture over the years I've had MS which creates a strain in our family finances. But I can not expect the NHS to find this. I am extremely grateful to the NHS for what it has provided me in treatment and support. I feel thoroughly supported."**

However, we also heard from people who felt they had no option but to access care privately, because of long waits and an inability to access vital services and support through the NHS, despite struggling to meet the additional costs.

> **I cannot afford to pay for any more private care. I feel so disillusioned and let down by the lack of care and support I've received. The biggest issue I want the government to know is how badly the length of waiting lists is letting down everyday people."**

It is concerning that so many people felt driven to access services privately that should be routinely available through the NHS, in line with the NHS Constitution, which outlines that the aim of the NHS is to provide a comprehensive health service to all, with access based on clinical need, not ability to pay. Over a third of adults expressed concerns about their ability to afford the additional costs associated with treatments for their condition.

> **My GP helped as much as they could, but the waiting list to see the neurologist was years long as it was cancelled and rescheduled. My migraines are chronic and I felt extremely anxious about losing my job because of how much they impacted my ability to work. My mental health was terrible at that point; I couldn't spent time with friends, family, do exercise, nothing to have a normal enjoyable live. I decided to pay for a private neurologist while on the waiting list as I felt so hopeless."**

Act now for the 1 in 6

At least one in six people in England live with a neurological condition - yet too many continue to face long waits, limited access, and fragmented care. The findings of My Neuro Survey 2024 make clear that, despite the dedication of healthcare professionals and signs of progress, the system is still falling short. People affected by neurological conditions are being let down by services that do not recognise their experiences or meet their needs.

This is not a new story. For over 30 years, we have campaigned alongside our members and community to improve care for people with neurological conditions. We know what good looks like: timely diagnosis, coordinated support, access to specialists, and care that treats the whole person - including their mental health. And we know the life-changing difference these things can make.

There are real opportunities to turn this situation around.

Ensure the NHS 10 year plan is supported by a specific implementation plan for services for people affected by neurological conditions.

Tackle critical workforce shortages in neuroscience and associated specialties in the forthcoming workforce plan.

Build a health system architecture that provides much needed clinical leadership and delivers transformation of services for people affected by neurological conditions. Draw from the extensive work undertaken within the NHS England national neuroscience transformation programme, National Neuro Advisory Group optimal clinical pathways of care and relevant Getting It Right First Time programmes.

Implement NHS guidance that seeks to ensure no-one is turned away from mental health services due to their neurological diagnosis.

Rethink and reverse planned cuts to the health and disability benefits system and ensure any changes do not negatively impact people affected by neurological conditions.

Unlock the potential of the UK Neuro Forum by providing dedicated, time-limited government funding to support its coordination and engagement activities.

We urge government, the NHS and all decision-makers to act on what this report clearly shows. Don't let this evidence go unanswered.

Acknowledgements

Abdusshakur Muhammad Auwal,
Saphia Baktout,
Andy Barrick,
Margaret Burn,
Ellie Byron,
Annalisa Casarin,
Nicky Cowsill,
KripenDhrona,
Maya Amber
Erin Field-Cross,
Linda Evers,
Shelley Elgin,
Catherine Elizabeth Field,
Anne Finlayson,
Victoria Goodwin,
Rebecca Haigh,
Simon Harris,
Alice Edith Howard,
Anna Hunter,
Vivienne Isebor,
Hester Lee,
Sarah-JayneMoore,
Dr Arani Nitkunan,
Rebecca Packwood,
Stephen John Portelly,
Professor Ros Quinlivan,
Rejhaai Robinson,
Mags Rogers,
Dr Sean Slaght,
Thomas Shillito,
Dr Jaspal Singh,
Carla Smyth,
Maisie Speight,
Paul Stevenson,
Alice Struthers,
Victoria Wareham,
Hilary Watson,
Steven Webster,
Brian Whitters,
River-James Whybrow.

References

1 Neurological Alliance (2019) Neuro Numbers, available at: https://www.neural.org.uk/wpcontent/uploads/2021/04/neuro-numbers-2019-1.pdf accessed 24 June 2025

2 Economist Impact (2024) The value of action: mitigating the impact of neurological disorders in the United Kingdom. https://assets.ctfassets.net/9crgcb5vlu43/3X482MJEP8rrLsLnlbqklK/2aa365d2899eb60f96d5d7a6a4c904e0/PDF_The_value_of_action__mitigating_the_impact_of_neurological_disorders_in_the_United_Kingdom Accessed 25 June 2025

3 Steinmetz, Jaimie D et al. (2024) Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. The Lancet Neurology, Volume 23, Issue 4, 344 - 381. https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(24)00038-3/fulltext Accessed 25 June 2025

4 Steinmetz, Jaimie D et al. (2021) Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021, The Lancet Neurology, Volume 23, Issue 4, 344 - 381 https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(24)00038-3/fulltext Accessed 25 June 2025

5 Roca F, Lang PO, Chassagne P (2019) Chronic neurological disorders and related comorbidities: Role of age-associated physiological changes. Handb Clin Neurol. 2019;167:105-122 (accessed online) https://pubmed.ncbi.nlm.nih.gov/31753128/#:~:text=They%20are%20also%20described%20as,;%20Pathologic%20aging;%20Vascular%20aging Accessed 25 June 2025

6 Reynolds S & Chhetri S (2024) Specialist referrals and diagnostic delays in motor neurone disease: Mapping patients' journey through hoops and hurdles in healthcare, Clinical Medicine Vol 24 (4) (accessed online) https://www.sciencedirect.com/science/article/pii/S1470211824054137 Accessed 25 June 2025

7 Lewis A, Taylor N, Carney P & Harding L (2021) What is the effect of delays in access to specialist epilepsy care on patient outcomes? A systematic review and meta-analysis, Epilepsy & Behaviour Vol 122 (accessed online) https://www.sciencedirect.com/science/article/abs/pii/S1525505021004534 Accessed 25 June 2025

8 Consultant-led Referral to Treatment Waiting Times Data 2024-25 https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/rtt-data-2024-25/#Mar25

9 Neurological Alliance (2025) Neurological Alliance sets out tests for NHS 10 Year Plan to transform services for the 1 in 6 https://www.neural.org.uk/news/neurological-alliance-sets-tests-for-nhs-10-year-plan-to-transform-services-for-the-1-in-6/ Accessed 25 June 2025

10 Neurological Alliance (2025) 10 Year Plan Consultation Response https://www.neural.org.uk/wp-content/uploads/2025/01/NA_Response_NHS_10_Year_Health_Plan_for_England_121224.pdf Accessed 25 June 2025

11 Nitkunan A, Lawrence J & Reily M (2020). Association of British Neurologists, Neurology Workforce Survey 2018-2019 www.theabn.org/resource/collection/219B4A48- 4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf Accessed 25 June 2025

12 Royal College of Psychiatrists (2023) Census 2023: Workforce figures for consultant psychiatrist posts, SAS psychiatrist posts and a survey of private and independent psychiatrists (accessed online) https://www.rcpsych.ac.uk/docs/default-source/improving-care/workforce/workforce-census-2023-final-020224.pdf?sfvrsn=853bcc23_5#:~:text=There%20were%201%2C516%20filled%20SAS,female%20and%2044.3%25%20male). Accessed 25 June 2025

13 Sivan M, et al. (2022) A Proposal for Expansion of the Medical Specialty of Rehabilitation Medicine. Rehabil Process Outcome. 2022 Nov 17;11 https://pmc.ncbi.nlm.nih.gov/articles/PMC9677288/ Accessed 25 June 2025

14 Roberts M, Chico D, Naik P. Multiple Sclerosis Trust, Multiple Sclerosis Specialist Nursing in the UK 2021:Results from the MS Trust Nurse Mapping Survey. https://mstrust.org.uk/sites/default/files/2024-01/ms-trust-specialist-nursing-uk-2021.pdf Accessed 25 June 2025 Accessed 25 June 2025

15 Parkinson’s UK, UK Parkinson's Audit: Transforming Care 2022 https://www.parkinsons.org.uk/professionals/uk-parkinsons-audit-transforming-care Accessed 25 June 2025

16 Nitkunan A, Lawrence J & Reily M (2020). Association of British Neurologists, Neurology Workforce Survey 2018-2019 https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf Accessed 25 June 2025

17 Department of Health and Social Care, NHS England (2024) Government to tackle NHS workforce crisis with refreshed plan https://www.gov.uk/government/news/government-to-tackle-nhs-workforce-crisis-with-refreshed-plan#:~:text=Through%20a%20refreshed%20workforce%20plan,to%20deliver%20world%2Dclass%20care. Accessed 25 June 2025

18 Naylor C, Parsonage M, McDaid D, Knapp M, Fossey M, Galea A. Long-Term Conditions and Mental Health: The Cost of Co-Morbidities. The King's Fund, 2012. https://www.kingsfund.org.uk/insight-and-analysis/reports/long-term-conditions-mental-health. Accessed 25 June 2025

19 NHS England (2024) Adult and older adult mental health https://www.england.nhs.uk/mental-health/adults/ Accessed 25 June 2025

20 Neurological Alliance (2024) Unpacking the 2024 England Rare Disease Action Plan https://www.neural.org.uk/blog/unpacking-the-2024-england-rare-disease-action-plan/ Accessed 25 June 2025

21 Royal College of Psychiatrists (2023) Census 2023: Workforce figures for consultant psychiatrist posts, SAS psychiatrist posts and a survey of private and independent psychiatrists (accessed online) https://www.rcpsych.ac.uk/improving-care/workforce/our-workforce-census Accessed 25 June 2025

22 British Psychological Society (2024) Guidelines for Commissioning NHS Neuropsychological Services https://www.bps.org.uk/guideline/guidelines-commissioning-nhs-neuropsychological-services Accessed 25 June 2025

23 National Neuro Advisory Group (2025) Optimum clinical pathways https://www.nnag.org.uk/optimum-clinical-pathways Accessed 25 June 2025

24 Neurological Alliance (2025) Neurological Alliance sets out tests for NHS 10 Year Plan to transform services for the 1 in 6 https://www.neural.org.uk/news/neurological-alliance-sets-tests-for-nhs-10-year-plan-to-transform-services-for-the-1-in-6/ Accessed 25 June 2025

25 Extra Costs Commission (2015) Driving down the extra costs disabled people face: final report https://assets-eu-01.kc-usercontent.com/73ea709e-f9f8-0168-3842-ebd7ad1e23ac/ca5ea908-a558-4aae-9e9d-d07990ee08c7/2015%20Extra%20Costs%20final%20report.pdf%23search%3Dextra%20costs%20commission.pdf Accessed 25 June 2025

26 Scope (2025) Disability Price Tag 2024: Living with the extra cost of disability https://www.scope.org.uk/campaigns/disability-price-tag

27 Department for Work and Pensions (2025) Transforming Support: The Health and Disability White Paper https://www.gov.uk/government/publications/transforming-support-the-health-and-disability-white-paper Accessed 25 June 2025

28 Department for Work and Pensions (2025) Transforming Support: The Health and Disability White Paper https://www.gov.uk/government/publications/transforming-support-the-health-and-disability-white-paper Accessed 25 June 2025

29 Department of Work and Pensions Stat Xplore (2025) PIP Cases with Entitlement from 2019 https://stat-xplore.dwp.gov.uk/webapi/jsf/dataCatalogueExplorer.xhtml Accessed 25 June 2025l

30 Department of Work and Pensions (2025) Spring Statement 2025 health and disability benefit reforms – Impacts https://www.gov.uk/government/consultations/pathways-to-work-reforming-benefits-and-support-to-get-britain-working-green-paper/spring-statement-2025-health-and-disability-benefit-reforms-impacts Accessed 25 June 2025

The Neurological Alliance

☎ 01923 882 590

✉ info@neural.org.uk

The Junction, Station Road, Watford, WD17 1EU

Socials

THE
NEUROLOGICAL
ALLIANCE