



Together for the 1 in 6: UK Findings from My Neuro Survey

Acknowledgments

For the first time ever, we have worked across the UK to provide unparalleled insights 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 of our membership voluntary sector organisations, professional groups 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 Neurology 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 are very grateful to the family of Bert Kinghorn for their kind support.

Thank you to each and every person for your support. None of this would be possible without you.

Forewords

Foreword from

Tanith Muller, Chair, The Neurological Alliance of Scotland

David Galloway, Chair, The Northern Ireland Neurological Charities Alliance

Ana Palazon, Chair, Wales Neurological Alliance

Georgina Carr, Chief Executive, The Neurological Alliance (England)

Living with a neurological condition can be a daily battle. That battle shouldn't be made harder by a system that can mean you are turned away for mental health support, experience waits of more than a year for a few precious minutes with a specialist or that you don't get the information you need when diagnosed.

Yet, so many of the more than 8,500 people who shared their experiences with us as part of 'My Neuro Survey' reported serious shortcomings in their care.

Finding out you have a neurological condition is scary and confusing. Receiving the right information and support can make a real difference. 2 in 10 reported not being given an explanation of their diagnosis. Almost 40% of adults were not given any information at all. As one respondent told us, they were shocked to learn of their neurological diagnosis, but received no written information and had to wait five months before next speaking to a specialist.

Accessing the right support for your mental health and wellbeing is absolutely critical when you live with a neurological condition – **yet many people with a neurological condition are unable to access the mental wellbeing support they need. Over two thirds (67%) of all respondents said their mental wellbeing**

needs are being met to a small extent or most often, not at all.

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.** One person with Parkinson's told us they felt they had lost the ability to walk due to interruption to their physiotherapy.

There are ambitions to turn things around of course - we have achieved a great deal together in the last two years despite the impacts of the pandemic. The ABI community have successfully campaigned for and secured a new UK wide strategy for Acquired Brain Injury (ABI) and other neurological conditions. The UK Government has also committed to £375 million investment into research on neurodegenerative conditions, such as dementia, Motor Neurone Disease (MND), Parkinson's-related dementia, and Multiple System Atrophy (MSA).

Research into the causes, treatment and potential cures for many neurological conditions is also progressing fast. There has been a great deal of progress in our treatment of many neurological conditions, delivering better outcomes and better quality of life for many. With such exciting promise for the future too, we absolutely must build a health and care system that is fit for success in research.

We lack, however, a clear vision, a clear plan, with investment, for a radical transformation of services for people with neurological conditions and the support our professionals need to deliver them. That requires leadership from Government across the UK.

Thank you.

Foreword from

Professor Tom Warner, President of the ABN

Dr Catherine Mummery, Chair of the ABN Services Committee

The principal goal for the Association of British Neurologists (ABN) is to ensure the best possible care for people with neurological conditions is provided equally across the UK. In recent years our work in partnership with the Neurological Alliance has been a critical part of working to deliver this. We welcome this most recent patient survey which is very important for gauging the state of this provision, and highlights key areas for urgent attention, many of which have been heightened by the effect of the COVID-19 pandemic.

Neurological diseases are common, though under-recognised and poorly understood. Optimal care for these complex, often long-term conditions, requires well designed, integrated, responsive, multidisciplinary care. While much care is excellent, there is patchy provision so that in some areas, unfortunately, the reality is that care is fragmented and pathways hard to navigate, with insufficient workforce leading to long waits, variability in practice and difficulty accessing best care.

The pandemic has brought into focus the vulnerability of patients with neurological conditions and pushed already stretched community and hospital services to breaking point. As a result, the mental and physical health of many have deteriorated. This report highlights failures in picking up and

treating mental health problems in people with neurological conditions, which needs to be addressed and treated with better and more available psychological and psychiatric support. A key source of mental stress is uncertainty and the report also shows a need for better explanation of the diagnosis and information for our patients.

In England, we have an opportunity for radical neurological service improvement following changes to commissioning and emergence of Integrated Care Systems (ICSs). Pilot work on models for neurology integrated care in ICSs are being developed by the NHSE Neurology Transformation programme, with ABN and Neurological Alliance collaboration. We have developed pathways for 'what good looks like' that map what care should involve for an individual.

In order to deliver the service we need, we must ensure our workforce is appropriately planned, and funded, across the different levels of care. The goal is to develop a multidisciplinary network of those with the right competencies to deliver the right care at the right place and the right time for the patient. Involving our patients in that design from the beginning will ensure the service works for them. To this end, we strongly support the proposal for a Neuro Taskforce or a Neuro Taskforce to help plan, influence and deliver a plan, influence and deliver a step change in the level of care for people with neurological conditions.

Foreword from

Dr Alasdair Parker, President of the British Paediatric Neurology Association

This ground-breaking survey has gained exceptional insight into challenges faced by families affected by neurological disorders. It is hard reading. The recurrent themes of delay in assessment / diagnosis and limited resources for therapy, run throughout the survey.

Voicing concerns is challenging for those affected by neurological disorders. The Alliances should be commended for calling and listening to these "expert" opinions.

Obtaining extra resources at a time when we are recovering from the pandemic is difficult. However, many of the messages are about integrating existing working patterns, starting processes earlier and avoiding unnecessary disability. This should merit appropriate scrutiny and action from governmental services.

Families caring for children and adult patients, have repeatedly voiced difficulties obtaining psychiatric and mental health support. This needs to be "hardwired" into all patient journeys.

The call for a UK Neuro Taskforce to bring together key UK stakeholders and existing service improvement initiatives, to develop and deliver plans to address gaps in care, is timely and essential.

About this report

This report is an overview of the experiences shared with us in 'My Neuro Survey'. We provide headlines here of the key themes shared on a UK wide level, as well as many direct experiences submitted via the survey.

Reports looking more closely at the policy context specific to each nation of the UK have been developed. **We urge you to read and act on the report for your nation.**

About neurological conditions in the UK

neurological condition. Neurological conditions can affect anyone at any time, no matter your age, circumstance or gender. They can impact all aspects of your life; how you think, feel, move, work and play.

There are more than 600 different types of neurological conditions, ranging from the very rare (affecting less than 1 in 2000 people), to more prevalent conditions you may be more familiar with, such as dementia, motor neurone disease (MND) or autism.

Conditions are broadly considered as: sudden onset conditions, for example acquired brain injury (ABI), stroke or spinal cord injury; intermittent and unpredictable conditions, for example epilepsy, or certain types of headache; progressive conditions, for example Parkinson's or multiple system atrophy (MSA); or stable neurological conditions, but with changing needs due to development or ageing, for example post-polio syndrome or cerebral palsy in adults.

For everyone with a neurological condition, the right support at the right time makes all the difference.

At least 1 in 6 of us across the UK live with a

Our call to action

We call on the UK Government, Scottish Government, Welsh Government and Northern Ireland Executive to prioritise services for people with neurological conditions and establish a 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:

- Assess the current neuroscience workforce and set out plans to ensure it is fit for the future.
- Share approaches to common problems, such as addressing longstanding barriers to accessing mental, emotional and cognitive support, driving down waiting lists for elective care, improving the quality and analysis of health and care data and supporting transition between paediatric and adult neuroscience services.
- Assess the level of investment in research into the causes, impacts and possible cures of neurological conditions and set out plans to level up investment in areas that do not receive a fair share currently.

Why is a taskforce needed?

There are currently a variety of initiatives that seek to address shortcomings in treatment, care and support for people affected by neurological conditions. These include the planned UK wide Acquired Brain Injury strategy, the Scottish Government's Framework for Action on Neurological Care and Support, a new quality statement and operational plan for neurological conditions in Wales, an ongoing Neurology Review in Northern Ireland, the NHS Scotland Centre for Sustainable Delivery Neurology workstream, the NHS England and NHS Improvement (NHSE/I) neuroscience transformation programme and the Getting It Right First Time (GIRFT) adult neurology, stroke and neurosurgery reports.

At present there is insufficient coordination of such initiatives, little leadership or prioritisation at the highest levels of Government to support their implementation and very limited opportunities to share learning across systems. Responses to My Neuro Survey highlighted many common challenges in improving access to treatment, care and support for the 1 in 6 people in the UK who live with a neurological condition.

The Taskforce would provide a framework to support greater collaboration and sharing of best practice in the approaches taken to tackle these common problems. It would build on similar policy approaches in health and care, such as the recent Rare Disease Framework and associated implementation plans.

Fundamentally, and most importantly, it would help to show that governments across the UK are listening to people affected by neurological conditions.

About the survey

- Data was collected between 25 October 2021 – 6 February 2022. The survey was promoted: by members of the Neurological Alliances' 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; a ballot box was used to collect paper responses – this was not widely used due to infection control restrictions in clinic; and via paid advertising on social media.
- People could respond to the survey via the website, via a language telephone line (if they preferred 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 our survey company, IQVIA.

About respondents

“ Thank you for caring

Adult affected by a neurological condition, Northern Ireland

- 8,510 people affected by neurological conditions across the UK took the time to fill out My Neuro Survey. 7,881 people filled out the adult survey, 629 filled out the children and young people's survey.
- Of those who filled out the adult questionnaire, 93% (n=7,258) lived with a neurological condition. For the children and young people's questionnaire, 87% (n=545) were the parent of a child or young person living with a neurological condition.
- In the adult survey, the most reported conditions were multiple sclerosis (n=1,245), epilepsy (n=1,006) and migraine (n=851). In the children and young people's questionnaire, the most reported responses were epilepsy (n=179), hydrocephalus (n=119) and Tourette syndrome (n=118). 44% (n=273) of respondents to the children and young people's survey lived with a condition other than the neurological conditions reported. 59% (n=4,509) of adults said the same.



The impact of living with a neurological condition

- For adults, 8 out of 10 (80% n=6,263) said that their neurological condition impacted their quality of life to a great or moderate extent. In 2018/19, 81% (n=8,260) of respondents said this, suggesting no improvement (or deterioration, given the pandemic). 7 out of 10 (70% n=453) children and young people said the same.
- 76% (n=468) of children and young people said that their neurological condition affected their day-to-day activities to a great or moderate extent, and 78% (n=6,132) of adults said this.
- 57% (n=4,483) of respondents to the adult questionnaire said their condition caused them pain to a great or moderate extent. 48% (n=264) of children and young people reported the same.
- As in 2018/19, those who identify as female, and those living in more deprived areas were more likely to report greater experience of pain, greater impacts on quality of life and greater impacts on day-to-day activities.

“ The problem is that if you break your leg or your arm other people can see it. But when something goes on in your brain and you look fairly ‘normal’, people think you’re making it up. Being unbelieved is devastating, just adding to our stress and making our symptoms worse.

Adult affected by a neurological condition, England

Experience and information at diagnosis

- In adults, more than a third (n=2,717, 36%) reported waiting more than a year between first experiencing symptoms and getting a diagnosis. 1 in 5 waited (n=1,501, 20%) more than 12 months between first seeing a GP and seeing a neurologist.
- 3 out of 10 (n=161) children and young people reported waits of more than 12 months between first experiencing symptoms and getting a diagnosis. 28% (n=147) reported waiting more than seven months between first seeing a GP and seeing a paediatrician. More than a third (36%, n=164) reported waiting more than 7 months between first seeing a paediatrician and seeing a neurologist.
- Over a quarter of adults (26%, n=1,194) reported receiving written information produced by the NHS, whereas just over a third of children and young people (34%, n=171) reported being signposted to information from a specific charity or patient group website. However, a third of children and young people (33%, n=165) reported receiving no information, and 38% (n=1,758) of adults said the same.
- A fifth of children and young people (20%, n=89) and a fifth of adults (20%, n=886) reported that they were not given an explanation at diagnosis.
- For adults, 68% of respondents (n=3,064) said their confirmed diagnosis was handled sensitively. However, nearly a third (31%, n=1,389) said it wasn't, with 402 people reporting that their diagnosis was not handled sensitively at all. In children and young people the picture is worse. 23% (n=105) said their diagnosis was handled poorly.

“**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-old's tics are becoming more complex and frequent.**

Parent of a child with a neurological condition, England

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

Adult living with a neurological condition, England

Access to treatment and support

- 6% of adults (n=501) said that they had never seen a neurological specialist, and over a quarter (26%, n=1,964) said they last had an appointment more than a year ago – 19% (n=1,451) said more than 18 months ago.
- 7% (n=46) of children and young people had never seen a neurological specialist, and 14% (n=85) said they last saw a specialist more than a year ago.
- 44% (n=3,429) said they'd had an appointment with a specialist nurse, with 15% (n=1,178) of these saying this was more than a year ago. 35% (n=2,728) said they haven't had an appointment but they would like this. For children and young people, 4 in 10 (n=250) said they had had an appointment with a specialist nurse. However, around the same number of people (39%, n=244) reported they hadn't had an appointment but would like this.
- For children and young people, 33% (n=193) reported that it was difficult to travel to their appointments. 42% (n=3,123) of adults said the same. Female adults were more likely than male adults to report this.
- Nearly 4 in 10 (39%, n=233) of children and young people and adults (40%, n=2,880) disagreed that it was easy to contact their specialist.
- More broadly, respondents indicated that they weren't always being offered the services they believed could help them to live independently and minimise symptoms. Again, 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 proportion of respondents who would find

specific support helpful but have not been offered was highest in:

- Adults – end of life care (74%, n=140), dietetics (70%, n=1,616) and palliative care (65%, n=115)
- Children and young people – outpatient rehabilitation (55%, n=66), dietetics (46%, n=92) and inpatient rehabilitation (39%, n=27).

“ **A specialist nurse would have been fantastic, someone to talk to about how I'm feeling. I should feel grateful my life was saved but my husband and I have had no support, to help us understand what I'm going through.**

Adult with a neurological condition, England

“ **My neurologist was excellent as were the specialist nurses but appointments were difficult due to travel issues. Having to get a 25 minute boat journey then 30 to 40 minute car journey makes the journey impossible at times.**

Adult with a neurological condition, Scotland

- 7 out of 10 (72%, n=442) of children and young people (mostly represented by a parent or guardian) said they felt involved in decisions about healthcare to some or a great extent. Worryingly, 28% (n=169) said they didn't feel involved. 29% of adults (n=2,176) said the same.
- Thinking about their neurological condition, a quarter of adults (n=1,964) said they'd had an emergency admission in the past two years.
- Nearly half of children and young people (48%, n=307) reported an emergency admission in the past two years.
- 45% of adults (n=1,742) said they didn't get the support they needed after their hospital visit. 37% (n=168) of children and young people said this.
- Respondents indicated significant delays to care in the past 12 months, likely due to the impacts of COVID-19. The greatest proportion of delays were reported in:
 - Adults – a routine appointment with your neurologist (55%, n=2,491), a mental health appointment (44%, n=985) and a routine appointment with a specialist nurse (43%, n=107).
 - Children and young people – a routine appointment with your specialist for your neurological disorder (60%, n=305), a mental health appointment (60%, n=179) and physiotherapy (54%, n=154)

“ Care after discharge from hospital was non-existent. It took months for the local hospital, who do not have a paediatric neurologist, to take over care after child was discharged from nearest PICU. Community services and social care do not want to know. Apparently my child is too disabled for mainstream services but not disabled enough to receive any help or support.

Parent/Guardian of a child or young person affected by a neurological condition, England

“ The lack of physiotherapy services through the pandemic has cost me the ability to walk.

Adult with a neurological condition, England

Coordination of care

“ 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 or young person with a neurological condition, England

“ I think that there has been a lot of pressure on the NHS over the last 20 months or so due to covid 19. This has impacted on all the services provided by the NHS however it has been a double blow for Neurology services as they were struggling before the COVID-19 pandemic started and are now in extreme difficulty

Adult with a neurological condition, Scotland

- 39% (n=235) of children and young people said they disagreed that information about their care and condition was effectively passed between their health and care professionals. 38% (n=2,804) of adults said this.
- 7 out of 10 (73%, n=412) of children and young people said they had been offered a care and support plan. 79% (n=5,696) of adults said the same.
- 29% (n=89) of children and young people said they were not as involved in developing their care and support plan as they would have liked. 35% (n=1,240) of adults said the same.

How did we describe a care and support plan?

Following extensive consultation of available literature and with people affected by neurological conditions, healthcare professionals and patient groups, we defined a care and support plan as “a care and support plan should outline what treatment is offered to you, who to contact for further information about your treatment, care, or support, what to do if your symptoms change and who to contact in an emergency. It could be on paper or online.”



Mental health and wellbeing

- Nearly 7 out of 10 adults (67%, 3,953) said that their mental wellbeing needs are being met to a small extent or not at all. More than a third of children and young people (35%, n=179) said their mental health needs weren't being met at all.
- 52% (n= 296) of children and young people said they hadn't been asked about their mental wellbeing by a healthcare professional in the last three years. 6 out of 10 (60%, n=4,373) of adults said this.
- More than half of children and young people (56%, n=317) and more than a third of adults (34%, n=2,641) said their neurological condition made their mental wellbeing much worse. The pandemic has made this worse too – 44% (n=3,033) of adults said their mental health had worsened during the pandemic. 63% (n=349) of children and young people said the same
- In 2022, 36% (n=2,646) of adult respondents told us they would like to be signposted or referred to support for their mental wellbeing by a healthcare professional but haven't. 36% (n=211) of children and young people said this.
- More than 6 in 10 adults (61%, n= 2,194) said they would like counselling but haven't been offered. 6 in 10 (62%, n=1,318) also said they would find neuropsychology or neuropsychiatry helpful but haven't been offered this.
- When people can access mental health support they often say it has a positive impact – 61% of adults (n=848) who received support said it made them feel better/more positive.

“ **Every time I have attended the clinic I have been dealt with in an extremely lovely manner. I have mostly seen Dr [anonymous], and she has been fantastic. Whereas she has not specifically asked me about my mental health, she has always asked me how I am and I feel she truly cares. I prefer this approach rather than asking me outright about my mental health.**

Adult with a neurological condition, England

“ **I feel sad sometimes and I don't like it.**

Child or young person with a neurological condition, Scotland

Remote consultations

- Remote consultations seemingly have their place, but are not appropriate for everyone. 7 out of 10 children and young people (73%, n=455) said they would prefer appointments in person. 4 out of 10 adults (43% n=3,317) said the same. A fifth of adults (22%, n=1,427) agreed that remote consultations are ineffective.
- Adult males were more likely than females, non-binary and those who preferred not to disclose their gender to report that they would prefer a face-to-face appointment.
- Children and young people living with Functional Neurological Disorder (FND) and at least one other neurological condition were most likely to say they would prefer to speak to their doctor in person (79%, n=26). Adults living with dementia and at least one other neurological condition were most likely to say this (62%, n=21).
- 45% (n=2,816) of adults said they found remote consultations helpful, but 21% (n=1,346) said they disagreed that remote consultations were helpful. 49% (n=279) of children and young people said they found their remote consultations helpful, 19% (n=110) disagreed that remote consultations were helpful.
- Crucially, 14% of adults (n=926) said they disagreed they felt confident in using technology for remote consultations. Those living in more deprived areas, compared to less deprived areas, were more likely to say this.
- A fifth of both adults (21%, n=1,299) and children and young people (20%, n=112) disagreed that their healthcare professional called when they expected them to.

“ **Don't like doing remote appointments as they seem impersonal, often rushed and also the Dr might not have full access to your notes or other medical history which is relevant. Also communication can be interrupted by lack of WI-FI and connections lost. I found the letters after such consultations aren't always an accurate account of the appointment as the health professional has not heard what you are saying, not been interested or misinterpreted what you have said.** ”

Adult with a neurological condition, England

“ **All of my appointments have been successful via phone/ video conference. I don't feel as connected to them as I do in person, I like seeing the doctors, although my mum does all the explaining about my seizures and medications.** ”

Child or young person with a neurological condition, England

Access to care

- 73% of children and young people (n=326) said they hadn't been assessed by their local council to see if they were eligible for funded care or support. 78% (n=4,038) of adults said the same.
- 45% of adults (n=3,551) said they received unpaid help with day-to-day living from friends and family, 57% (n=356) of children and young people said this.
- Just 23% (n=695) of adults and 15% (n=48) of children and young people said their social care meets their needs. 26% (n=657) of adults said their social care had deteriorated in the last three years. A fifth (n=57) of children and young people said this.
- 45% (n=215) of children and young people (mostly represented by their parents or guardian), said they didn't feel involved in making choices about social care. More than half of adults (53%, n=2,800) said this.

“ I feel that I have been treated disgracefully by my local authority and social workers.

Adult affected by a neurological condition, Wales

“ Social care will be needed very soon when my savings acquired from benefits and help from my parents and frugal living are below the levels required. Will that be covered perhaps for 20 years ? My 82 year-old widowed mother will not be able to help.

Adult affected by a neurological condition, England

Access to financial support

- 29% (n=1,990) of adults disagreed they had enough money (in their household) to manage well. A fifth (20%, n=1,259) said they disagreed that their household had enough money to get by. 38% (n=2,142) said they had enough money but were dependent on their savings. 1 out of 10 (11%, n=606) said they didn't have enough money to meet their basic needs.
- Adults or those who care for them were most likely to be in receipt of Personal Independence Payments (PIP)/Disability Living Allowance (DLA) (43%, n=3,308), a Blue Badge (43%, n=3,217) or Employment and Support Allowance (ESA) (20%, n=1,416).
- Children and young people, or those who care for them, were most likely to be in receipt of Child Benefit (70%, n=415), PIP/ DLA (54%, n=327), or a Blue Badge (35%, n=212).

“ I am doing everything in my power to stay mobile and to keep walking but I find that the current system favours placing MD patients in wheelchairs at the earliest convenience. As an example, I need a car with high tech adaptations yet, because I can walk, I have been unable to secure higher rate PIP and therefore I am not entitled to a Motability vehicle. Trying to sort this out has been a nightmare and in December 2021 I had to leave my job as an architect because of an inability to be able to access work. As an adult with muscular dystrophy, I feel that I have been completely and utterly abandoned by the public systems in this country.

Adult living with muscular dystrophy, England

Education

- 6 out of 10 (60%, n=372) children and young people said they were in mainstream school. 13% (n=81) said they were in a specialist school.
- More than 4 in 10 (43%, n=255) said they had been assessed for and offered an education and health care plan. Half (50% n=298) said they have not been assessed.
- 7 out of 10 (71%, n=406) of children and young people said their attendance at school has been affected due to their neurological condition. Yet, a fifth (19%, n=101) disagreed that their school has made useful changes to help them attend.
- 59% (n=336) said that other children or young people are friendly. 11% (n=64) disagreed with this. 75% (n=431) said that staff (adults and teachers) were friendly, while 5% (n=31) disagreed with this.
- 16% (n=89) of children and young people disagreed that staff (adults and teachers) at school listen to them.

“ My school has also been horrible in helping me with my condition. I have been shouted at, told off and denied access to things I need to make my life easier. If they actually helped me my life would be so much easier but instead they treat me like I’m faking it. I wish schools had more training and there were more laws to make sure this didn’t happen.

Child or young person with a neurological condition

“ I am suffering from anxiety and depression. I can’t sleep and hardly go to school. I have asked for help but nothing is happening with CAMHS.

Child or young person with a neurological condition, Scotland



Employment

- Four out of 10 adults (42%, n=2,336) said they disagreed that they had been able to continue working since having a neurological condition. 58% (n=3,060) said they had stopped working due to the symptoms of their neurological condition.
- More than a quarter (28%, n=1,182) said they agreed they had left their job due to their employers' actions/inaction.
- Nearly a third of adults (32%, n=1,423) said they had been discriminated against at work due to attitudes towards their neurological condition.

“ **My employers (I was a community children’s nurse) were dreadful and eventually suspended me on medical grounds! It was the most stressful time for me and their treatment only aggravated my condition. I think this will be quite common for many people with this condition and employers should be made aware of the impact.** ”

Adult living with a neurological condition, Scotland

Conclusion

As is laid bare here, and in more depth in the specific national reports, significant gaps remain in access to the right treatment, care and support for far too many people with neurological conditions across the UK.

Despite being the hallmarks of good care, the right information at diagnosis, the right support for mental health and wellbeing and timely specialist support are too hard to access for many. In some cases, opportunities to slow or stop progression of a condition, to avoid harm to themselves or others and to maintain financial wellbeing are being missed – and with catastrophic consequences.

Multiple policy initiatives across the UK are attempting to address unwarranted variation in access to treatment, care and support – at present these are poorly coordinated. On a more fundamental level many people with neurological conditions are not aware of these efforts nor their potential impact. Indeed, many healthcare professionals, having committed so much during the pandemic are in a similar position. Now more than ever, people with neurological conditions and those delivering services need to be seen. Starting with high level commitment and coordination of initiatives to improve care. Inaction now will result in far greater numbers leaving our neuroscience workforce and people with neurological conditions facing even more battles for the support they need and deserve.

Our call to action

We call on the UK Government, Scottish Government, Welsh Government and Northern Ireland Executive to prioritise services for people with neurological conditions and establish a 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:

- Assess the current neuroscience workforce and set out plans to ensure it is fit for the future.
- Share approaches to common problems, such as addressing longstanding barriers to accessing mental, emotional and cognitive support, driving down waiting lists for elective care, improving the quality and analysis of health and care data and supporting transition between paediatric and adult neuroscience services.
- Assess the level of investment in research into the causes, impacts and possible cures of neurological conditions and set out plans to level up investment in areas that do not receive a fair share currently.

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.

www.neural.org.uk

Email: info@neural.org.uk

Registered by the Charity Commission for England and Wales (registration number 1039034) and a company limited by guarantee registered in England (registration number 2939840).

Northern Ireland Neurological Charities Alliance (NINCA)

NINCA was established in 2006 to represent and provide a voice on behalf of people living with a neurological condition in Northern Ireland.
NINCA

Email: info@ninca.org.uk
Twitter: [@NINCA_NI](https://twitter.com/NINCA_NI)

Wales Neurological Alliance

The Wales Neurological Alliance is a focused and purposeful forum of not-for-profit organisations and groups representing many thousands of people affected by neurological conditions in Wales.

www.walesneurologicalalliance.org.uk

Email: info@walesneurologicalalliance.org.uk

The Neurological Alliance of Scotland

We are an umbrella body of organisations that represent people with a neurological condition and those who support them. We work to improve the care and support that people receive.

www.scottishneurological.org.uk

Email: info@scottishneurological.org.uk

Registered with the Scottish Charity Register (084555)