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ALLIANCE

Neuro Voices:

Wales findings from My Neuro Survey

March 2026

Contents

Introduction

Wales Neurological Alliance (WNA) has once again collaborated with the Neurological Alliances of Scotland, England, and Northern Ireland, alongside the Republic of Ireland for the first time, to gather evidence from people living with neurological conditions across the UK.

More than 10,000 experiences were captured through the My Neuro Survey across the UK. In Wales, our survey captured the experiences of 484 adults and 30 children and young people living with a neurological condition, with 89 carers of adults also sharing insights into their day-to-day experiences. We are indebted to everyone who shared their experience with us.

We are pleased to present our findings from the 2024 My Neuro Survey in Wales. Our first My Neuro Survey Wales Report (June 2022) captured a snapshot of the experiences of the 100,000 people living with a neurological condition in Wales. Ahead of the Senedd elections in 2026, we bring together the voices of people living with neurological conditions across the nation.

This report highlights major themes that emerged from the Wales survey, including

- people's experience of health and care services
- the mental health crisis
- the day-to-day experience of carers for people with neurological conditions
- the impacts on daily life for people living with neurological conditions, and their support networks, including unpaid carers.

For example, **44% of adults surveyed who live with a neurological condition do not feel supported by the health system.**

My Neuro Survey provides essential insights into whether people living with neurological conditions in each UK nation are getting the treatment and support they need and deserve.

We hope that this report will go some way in closing the gaps in the Welsh Government's understanding of the demand for and impact of services for people with neurological conditions. People living with neurological conditions in Wales continue to report substantial barriers to accessing the treatment, services, and support that they need from health and social care services.

Policy Context

This report gathers the voices of people in Wales, between July and November 2024, living with at least one diagnosed or suspected neurological condition.

Two years earlier, in November 2022, the Welsh Government published its Quality Statement for Neurological Conditions, which "describes what good quality services for neurological conditions should look like":[i]

“Our aim is to ensure that people of all ages living with or affected by a neurological condition have timely and equitable access to high quality services to enable them to live their best lives.”[ii] Quality Statement for Neurological Conditions, Welsh Government

The Quality Statement was developed in the wake of the Neurological Conditions Delivery Plan (NCDP) and aims to ensure that people of all ages living with or affected by a neurological condition have timely and equitable access to high-quality services. However, progress against this has stalled. Over a third of people in our survey said their healthcare has not improved over the last 12 months.

Importantly, not all neurological conditions are covered by neurology services. For example, Parkinson’s frequently falls under the care of older people. These disjointed working risks inequity in the provision of services across neurological conditions and prevents joined-up workforce planning and resource allocation.

”Neurological Conditions Implementation Group (NCIG) will provide national leadership and drive forward change to deliver better quality, higher value, more consistent and accessible services for people affected by neurological conditions. This should take into account workforce challenges.”[iii]Quality Statement for Neurological Conditions, Welsh Government

Ahead of the Senedd elections in May 2026, political parties in Wales are setting out their intentions for the changes they would like to make over the next four years if they form the next Welsh Government.

Now is the time for political parties in Wales to decide whether they see high standards for neurological services as aspirational or as an area of focus to meaningfully improve the lives of one in six people living with a neurological condition in Wales. By engaging with this report and acting on the insights of the experts by experience, the next Senedd term could bring real change to the lives of the 100,000 people in Wales living with a neurological condition, and to their support networks.

This report raises the voices of constituents right across Wales. Policy makers must listen to what’s working and what’s not, for people with neurological conditions and their unpaid carers.

We urgently need an implementation plan for the Quality Statement for Neurological Conditions, along with an accompanying neurology workforce strategy, to ensure people can access timely and equitable diagnosis and support.

In the broader policy context, the UK Government announced in November 2024 the launch of a new UK Neuro Forum. This four-nation approach, which resulted from the #BackThe1in6 campaign of the previous iteration of My Neuro Survey in 2022, is an important step forward.

Some essential policies, like access to benefits and welfare reform, are non-devolved and decided in Westminster. Since we gathered responses, the UK Government’s welfare reform proposals have been very upsetting for people living with long-term health conditions across the UK.

While we were calling for reform of benefits that were already not working well for people living with neurological conditions in our previous report, the proposed changes to welfare, including the Personal Independence Payment (PIP), have received national media coverage, especially in spring 2025.

We know from our work as charities working closely with our communities that many people were terrified about what the proposed changes could mean for them, especially during a challenging cost-of-living crisis. While these proposals have been halted and the Timm's Review is conducting its full review of PIP, changes to Universal Credit are still possible. Due to the time that this survey was live, fears addressing these specific proposals are not captured in our survey. Instead, any fears around access to benefits and welfare reform reflect the concerns of our community in the first few months of the new Westminster Government's time in office (July-November 2024).

What is a neurological condition?

Neurological conditions affect the brain, nerves, and spinal cord. There are over 600 known neurological conditions, and they are the leading cause of disability worldwide.[iv] They can affect many aspects of everyday life and affect everyone differently.

About neurological conditions in Wales

In Wales, around 100,000 people live with a neurological condition.[v] These range from extremely rare to more prevalent conditions, including dementia, Parkinson's, multiple sclerosis (MS), epilepsy, dystonia, spina bifida, and motor neurone disease.

Neurological conditions are complex and variable – even within a single condition, both disease progression and support needs following diagnosis can vary widely. The correct support enables people living with neurological conditions to be diagnosed promptly and to live independently for as long as possible, which is vital for their health, well-being, and dignity.

Neurological conditions are diverse in their underlying causes and risk factors, as well as in their associated health outcomes. They are the leading group cause globally of disability-adjusted life years (DALYs), 11.6% and the second leading cause of deaths in the world at 16.5%.[vi]

> ***"The number of people living with a neurological condition is set to increase over the coming years as more children survive beyond birth into adulthood and as the UK's population ages, so does the number of people living with age-related neurological conditions."***[vii] Quality Statement for Neurological Conditions, Welsh Government

About My Neuro Survey

My Neuro Survey began in England in 2014. This is the second My Neuro Survey Wales report – the first was published in 2022.

Led by the Neurological Alliance (England), which engaged with Revealing Reality, a survey company, this vital work was done in collaboration with Neurological Alliances across the UK – Wales Neurological Alliance, Neurological Alliance of Scotland, and Northern Ireland Neurological Charities Alliance, and, for the first time, with the Republic of Ireland (the Neurological Alliance of Ireland). The Neurological Alliance (England) worked collaboratively with all four other Neurological Alliances, alongside people living with neurological conditions, patient groups, and healthcare professionals.

The survey collected responses for four months in both paper and online formats between 22 July and 16 November 2024. In Wales, the survey was available in English and Cymraeg, and via the language telephone line.

In 2024, My Neuro Survey captured the voices of over 10,300 individuals across the UK, including adults, children, and unpaid carers, making it the largest patient experience survey of people affected by neurological conditions.

For the first time, the perspectives of unpaid carers supporting people with neurological conditions were captured in the My Neuro Survey. The term 'unpaid carer' is not widely used by those in this role. Many carry out caring responsibilities as part of their daily lives, supporting those in their close friendships or families.

Recommendations

To improve the lives of people living with neurological conditions in Wales, we call on the next Welsh Government to:

1. Develop a neurology workforce strategy to increase specialist staff both now and in the future
2. Develop an implementation plan for the Quality Statement for Neurological Conditions
3. Increase the budget for delivery of support for people with neurological conditions
4. Establish a national system for the collection, collation, and publication of outcome data for all neurological conditions
5. Ensure social care engagement in the integrated delivery of the Quality Statement
6. Ensure statutory provision for psychological support for people living with neurological conditions in all local health boards

Executive Summary

In Wales, My Neuro Survey captured the experiences of 484 adults living with a neurological condition, 30 children, and 89 carers of adults, who also shared insights into their day-to-day experiences.

Key Findings

Themes

Based on the responses we received through our adults and unpaid carers survey responses, this report explores the following themes:

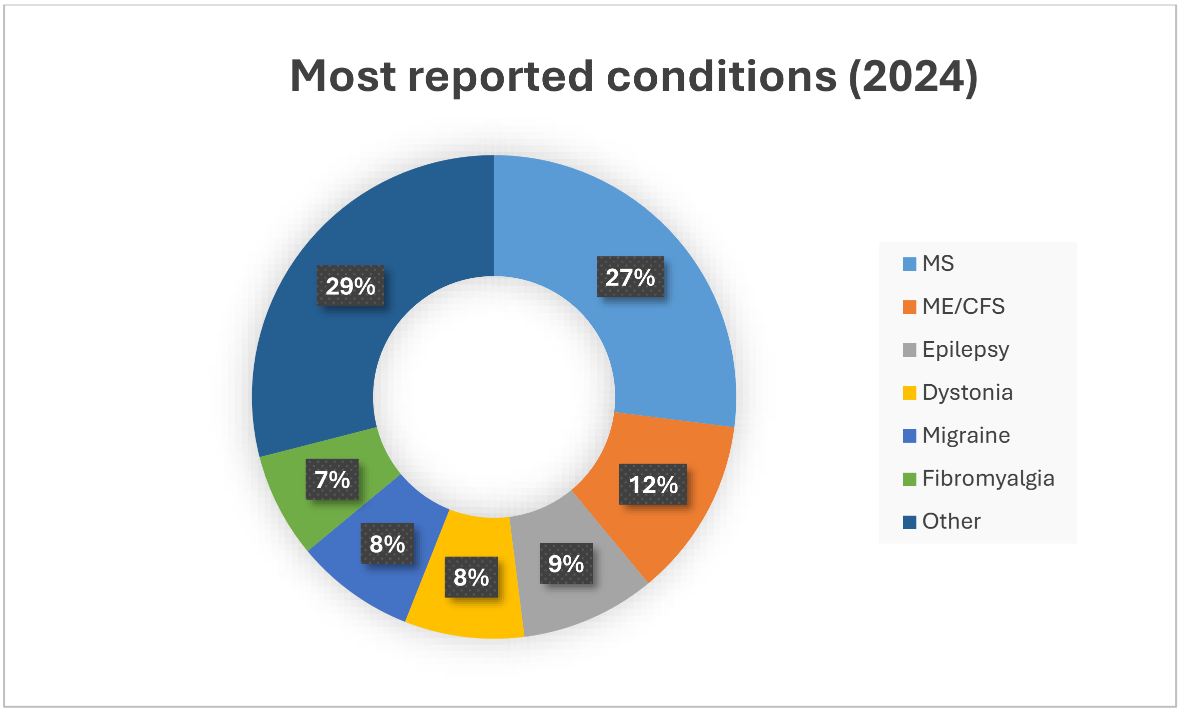
- Access to Healthcare
- Mental Health
- Impact on Daily Living
- Financial Burden

We have integrated the experiences of adults living with neurological conditions and carers in each thematic area.

Adult Survey

Of those who completed the adult questionnaire, 85% of responses recorded the lived experience of those living with a neurological condition; 15% recorded the experience of unpaid carers, friends, or family members of someone with a neurological condition.

The most reported conditions amongst adult respondents were multiple sclerosis, ME/CFS and epilepsy.



In the previous My Neuro Survey Wales report (2022), the most represented conditions were:

MS (23%); Dystonia (11%); Epilepsy (9%), Migraine (8%), and Parkinson's (8%).

As different neurological conditions are highlighted in the 2024 survey, compared to 2022, it's not possible to make direct comparisons between the two reports, as other conditions will entail different experiences.

Access to Healthcare

- Over half of adults surveyed have been living with a neurological condition for over 5 years. 53% of respondents were diagnosed within the past 10 years, while 37% were diagnosed more than 10 years ago.
- Only 2 in 5 adults (40%) affected by neurological conditions and their carers felt that the healthcare services they accessed met their needs, pointing out a gap in care and service delivery.
- Just 35% of adults agreed that they feel supported by the health system in Wales, leaving almost half (44%) feeling unsupported.
- Over 1 in 3 adults report having at least one other mental or physical health condition (a 'comorbidity')
- 26% disagree with the statement 'I feel involved in decisions about my treatment, care, and support plan' (agree 53%)
- 23% disagree that 'I can schedule appointments without conflicts with other commitments' (agree 57%)
- 23% disagree with the statement 'I understand my condition(s) and treatment options available' (agree 59%)

Mental Health

- Over a third of adults reported having a mental health (36%) comorbidity.
- 32% disagree with 'I have someone to talk to about my mental health and well-being' (agree 46%)

Impact on Daily Living

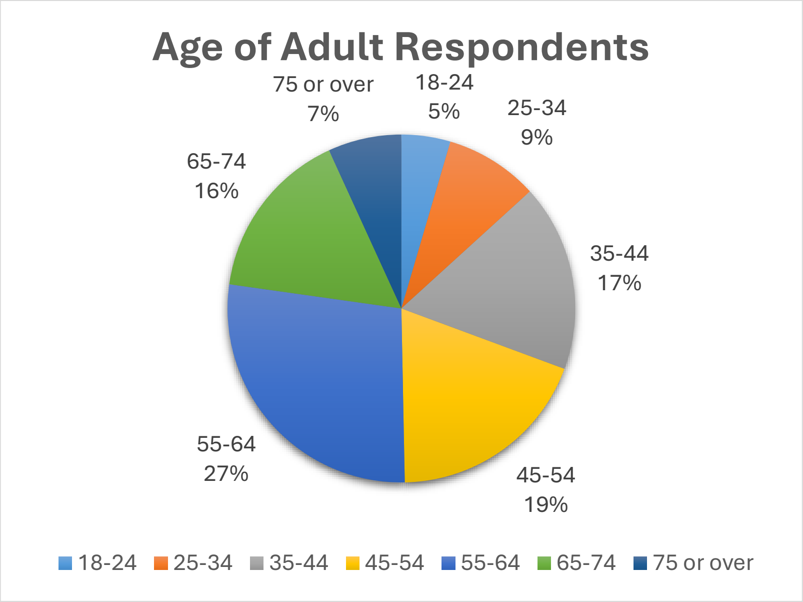
- 21% disagree that 'My housing is suitable for my needs' (agree 63%)
- 17% disagree that 'I have reliable transportation or assistance to attend appointments' (agree 69%)

Financial Burden

- 40% of adults cannot afford the additional costs associated with treatment for their health conditions.
- Almost half of adults with neurological conditions have had to give up work.
- Over a quarter felt they had been discriminated against at work because of attitudes towards their condition, with 13% strongly agreeing and 14% agreeing.

Demographics of Survey Respondent Adults living with Neurological Conditions

80% of the people who filled out our survey were between 35 and 74 years old. 69% were living with one condition, 16% with two, and 1% with six or more conditions.



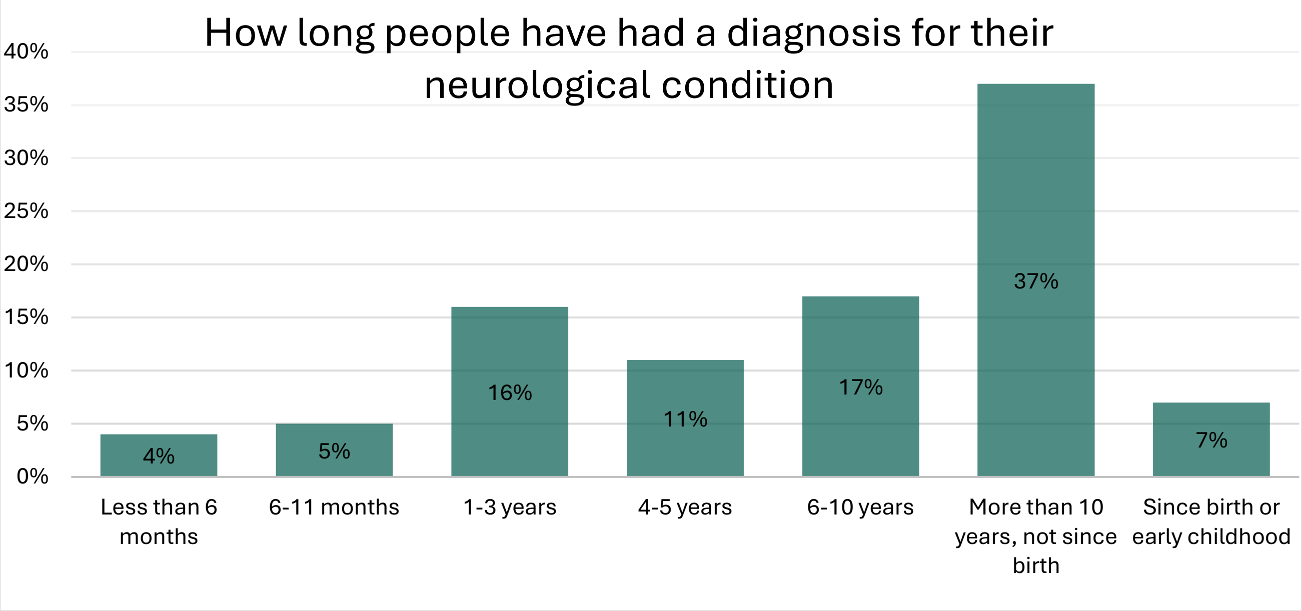
Nearly three-quarters of respondents (71%) were female (27% were male, 1% were other). Some neurological conditions are more prevalent in women. Women are almost three times more likely to be living with MS than men, and MS was the most reported condition, at 27%.

Other conditions, such as motor neuron disease (MND) and Parkinson's, affect women and men equally, despite public perceptions that these affect men more than women, which is sometimes a result of high-profile media coverage of public figures living with these conditions.

97% of people described themselves as White (White/British/Scottish/Welsh/Irish). This is higher than the 2021 ethnicity census data for Wales, which showed that 94% of the population identified as White.[viii]

Over half of the respondents have been living with a neurological condition for over 5 years.

20% of adults reported living alone, while 64% live with a spouse or significant other, and 13% live with a parent or other relative. Just 23% of adults said that their neurological condition did not impact their ability to maintain romantic relationships and intimacy (12% said it impacted them quite a lot, and 30% very much). When asked about their ability to maintain family relationships (e.g., having children, spending time with family, and fulfilling family responsibilities) 23% said they were affected very much, 18% quite a lot, and just 23% said 'not at all'.


How long people have had a diagnosis for their neurological condition

Carers' Survey

"Neurological conditions can have a devastating impact on people's lives and those around them."[ix]Quality Statement for Neurological Conditions, Welsh Government

We received 89 responses from carers of adults with neurological conditions in Wales. The most prevalent conditions of the people who are supported are Epilepsy (20%), Autism (16%), MS (11%) and Progressive Supranuclear Palsy (11%).

The majority of carers find day-to-day life challenging. While 80% of carers reported they could meet the day-to-day needs of the person they care for, and 15% reported they were unable to do so.

Overall, 57% of carers reported having a long-term health condition (36% did not). 34% said they have a mental health condition, such as General Anxiety Disorder, depression, and anxiety. 41% reported living with a long-term physical condition, such as arthritis, hypertension, high blood pressure, and heart disease. 6% of carers told us that they also live with a neurological condition.

"My mental health can vary because of the enormity of the caring task and what the future holds. If I think about the situation, it can seem very daunting to me." Carer

While 66% of carers told us they can meet the health and well-being needs of the person they care for, worryingly, 30% told us they were not. Carers have described how neurological conditions have the most significant impact on the person they care for, affecting movement, sleep, fatigue, thinking, and memory. It is unsurprising, then, that 78% of carers told us that they provide physical care (such as helping with daily activities like bathing and dressing), which is increasingly challenging for those carers living with their own physical and mental health conditions. 94% of carers also provide emotional care (for example, companionship and reassurance), and 65% provide financial care (such as help with bills).

"This has also impacted my own mental health in such a negative way that I often struggle to find motivation in any form of recovery for my wife." Carer, whose wife has a neurological condition

The majority of carers (58%) told us they feel unsupported in their caring role, with 19% reporting they do feel supported and a further 19% feeling neutral. When we asked whether carers in the last 12 months had received information and advice on accessing support, 13% said they had, and that it had met their needs. However, 29% had accessed it, but it had not met their needs, while 38% had not been able to access it. 15% of carers said this was not relevant to them.

Only a fifth of carers receive sufficient financial support, with the most significant impact on educational or career stagnation. After work commitments, access to healthcare professionals has the most significant impact on the provision of care.

There are also serious issues around people's access to Carer's Assessments, as highlighted by Carers Wales' 'State of Caring in Wales' Report in November 2025.[x] This reports that of those surveyed by Carers Wales, the vast majority of carers (75%) have not had a Carer's Needs Assessment in the last 12 months. Of those people who have had access to an Assessment, they have often not received any support as a result of the assessment being completed – with 12% still waiting to hear the outcome of their assessment and 55% stating they were only given advice as a result of the assessment, rather than any support.

In our My Neuro Survey, we asked carers how involved they were in decision-making for the person they cared for. Almost half (49%) said they are fully involved in all decision-making. 33% said they are involved in most decisions, but the person they care for makes the final choice. 13% said they are involved in some decision, but others are made by the person they care for or other professionals. Just 5% told us they are not involved in any decisions about the person they care for.

Only 21% of carers surveyed receive sufficient financial support. Carers Trust Wales has highlighted that the cost-of-living crisis is perhaps more profoundly impacting unpaid carers than the wider public, as the costs associated with caring roles are also increasing.[xi] These include types of specialist equipment, some of which requires higher energy use to power them, and high heating costs in homes. There are also further costs associated with being unable to access public transport that meets the accessibility needs of the people they care for. In open survey responses, some raised issues around Blue Badge applications being denied, sometimes repeatedly.

Of those who needed to access community transport, almost half (49%) have been unable to do so in the past 12 months. 36% have had a positive experience accessing this service, with 8% telling us it did not meet their needs. Of those who had used community transport services, 82% had their needs met; 18% did not.

33% of carers told us that in the last year, they have not been able to access transport support for themselves or the person they care for. Of those who have, 7% found it met their needs, and 8% found that it did not.

When asked what affects their experiences of providing care, carers told us that they were 'very much' affected in the following areas:

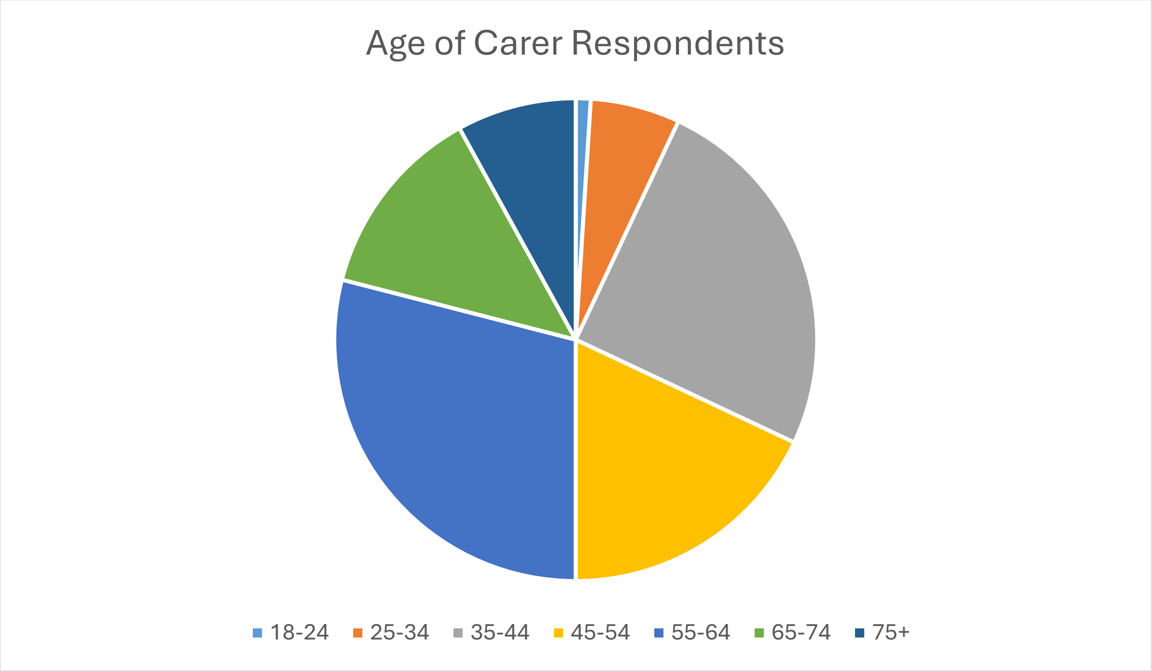
- Working full or part-time (31%)
- Lack of access to healthcare professionals for the person they care for (25%)
- Other caring responsibilities (such as for children or parents) (16%)
- Lack of knowledge or training in caring for specific condition(s) (15%)
- Limited mobility or physical abilities (12%)
- Their own health conditions (12%)
- Financial constraints (11%)
- Lack of access to reliable transport (10%)
- Educational commitments (3%)

In conclusion, the majority of carers find day-to-day life challenging. Carers are sacrificing their own physical and mental health, as well as their own earning potential or education, to care for someone else. The most significant challenges for carers are access to mental health support and respite care.

Please note that 85% of carers told us that the person they care for did not complete their own survey; therefore, carer data will differ from the responses from people living with neurological conditions themselves.

Demographics of Carers who responded to the survey

76% of carers surveyed are female, with 24% male. 98% are White. Half of the carers we surveyed were over 55, while the vast majority were below the UK average retirement age.



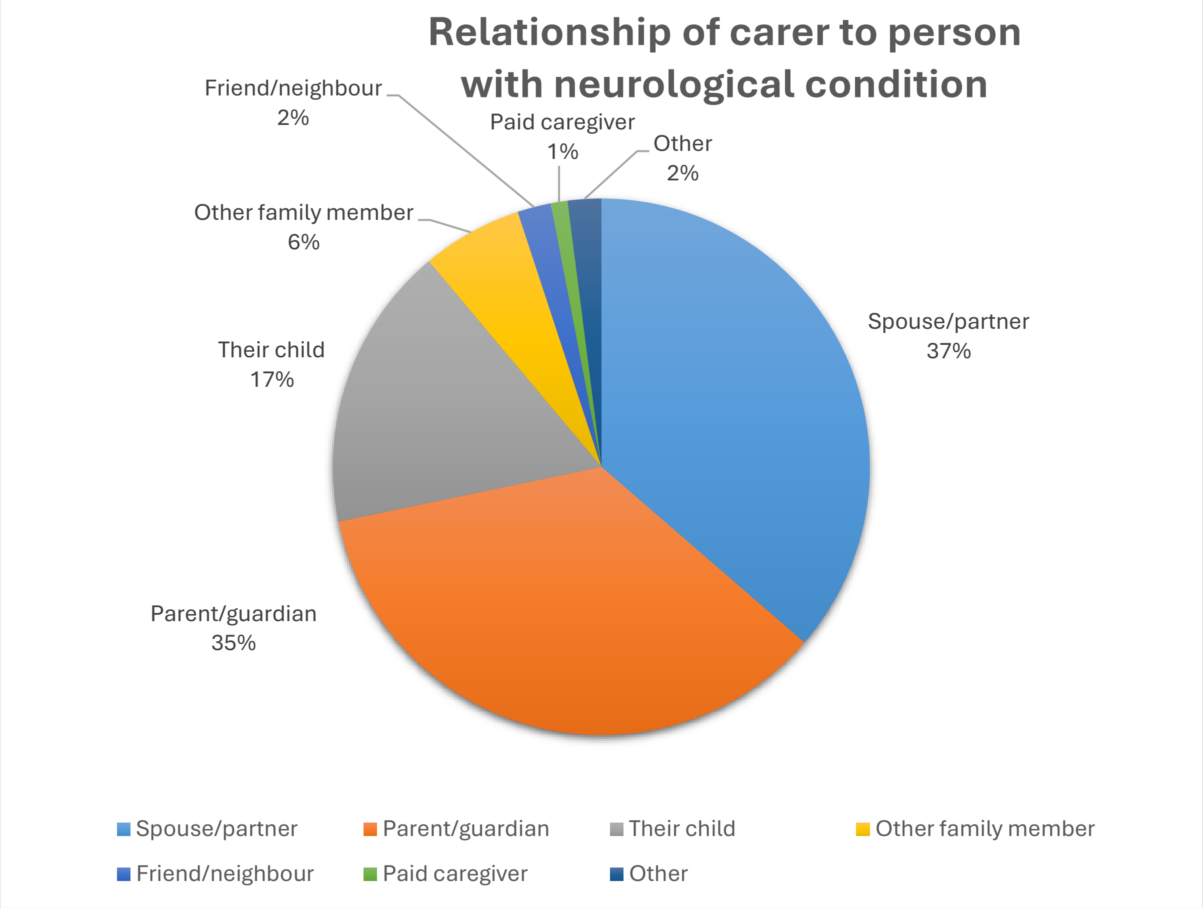
Weekly Hours of Caring Provided

Almost half of carers (45%) care for more than 50 hours per week (which is more than 7 hours a day). A small proportion of carers (5%) care for up to 1 hour a day (9 hours a week); 18% care for about 1-2 hours a day; 16% care for 3-5 hours a day; and 13% care for 5-7 hours a day. Therefore, **58% of carers are offering more than 35 hours of care a week, the equivalent of a full-time job**. 17% of carers also told us that they care for more than one person. It's not surprising that **carers are reporting their earnings, careers, and studies so heavily impacted by their caring role**.

Length of Time as Carer

The two main groups of carers had cared for 1-5 years (44%) or over 10 years (33%). Only 7% had been providing care for less than a year.

The majority of carers surveyed (67%) are the primary carer for the person, with a quarter of carers sharing the leading role with someone else. Just 8% of respondents told us that they help but are not the primary carer.



Children's survey

Due to the very small sample size (30 responses), we will not detail children's experiences in this report. Instead, we will report on the experiences of children and young people under 18 in a UK-wide briefing, in collaboration with the Neurological Alliances in Northern Ireland, Scotland, and England.

Healthcare for People with Neurological Conditions

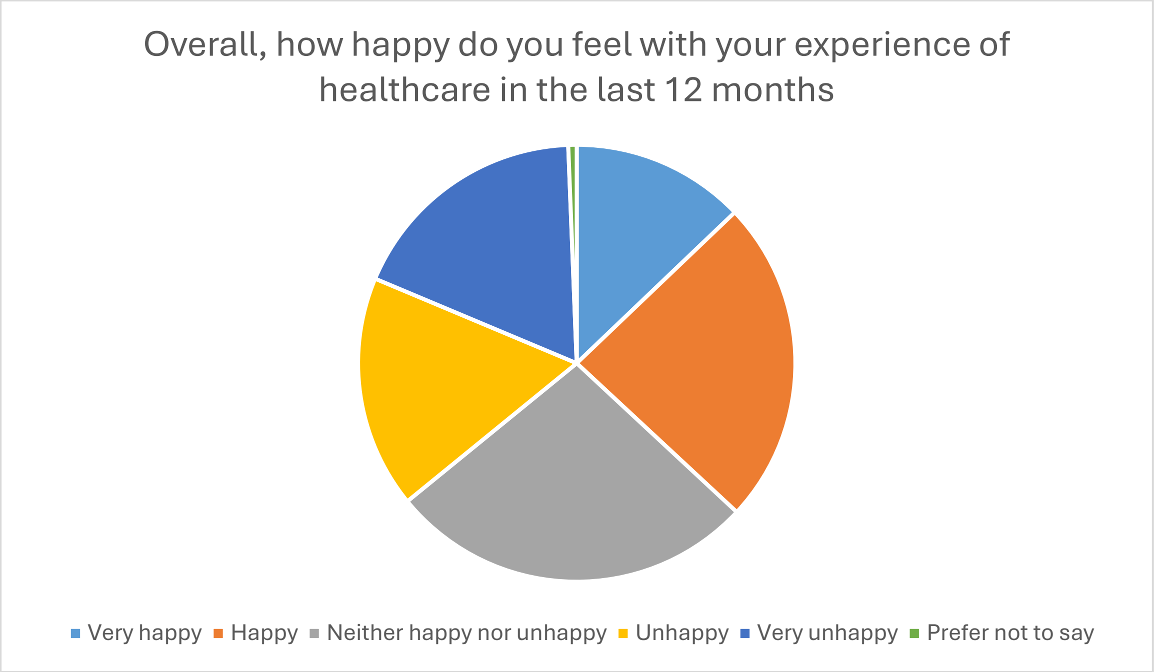
"A major health service resource challenge results in a lack of accessible services and contact points. Poor communication between the hospital's neurological department and GPs to the extent that GPs were unaware of my condition until I informed them myself – indeed, my condition didn't even appear on my GP profile until 6 months after my diagnosis, and only because I personally had to report it. My confidence in the health service is so low that I am now taking steps to invest in private healthcare through my business, for myself and my staff." Respondent living with a neurological condition.

Welsh Government's Quality Statement for Neurological Conditions states[xii]:

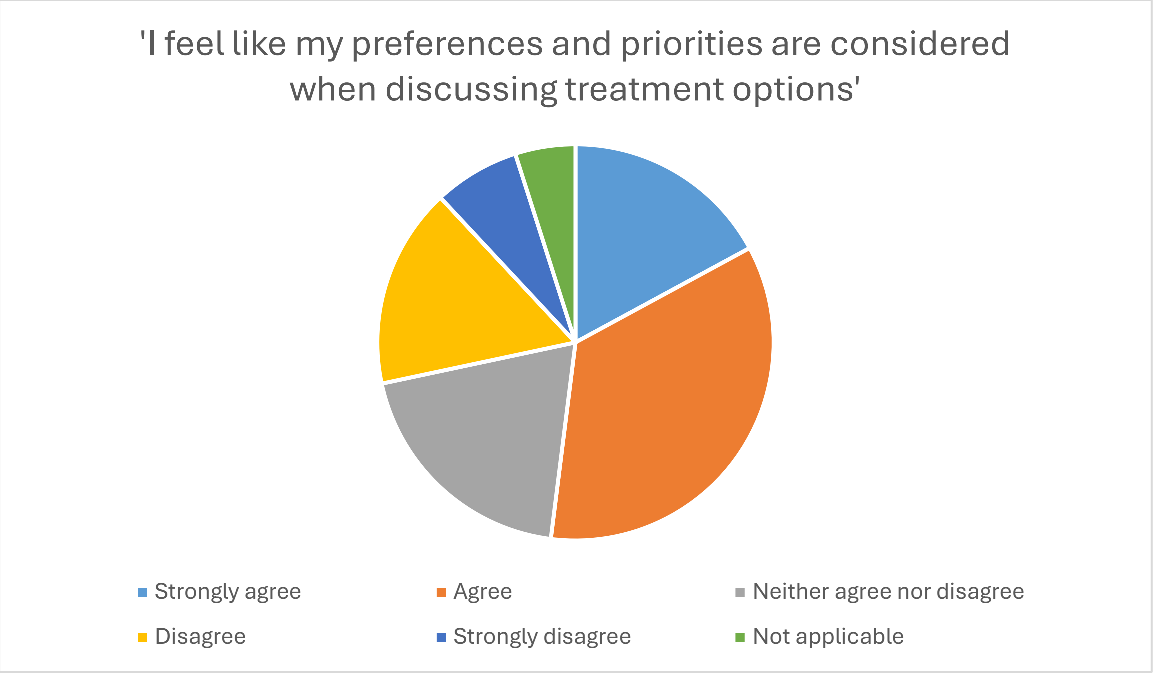
"***All neurological conditions follow a different disease course, with onset from before birth, through to older age. There are, however, some commonalities and neurological conditions can manifest by***:

- ***sudden onset, may improve over time or stay the same***
- ***progressive, will deteriorate over time***
- ***relapse and remit, may come and go***
- ***stable with changing needs"***

In our survey, we asked how happy people with neurological conditions were with their healthcare experience in the last 12 months. 37% of people were 'very happy' 'happy', and 37% were 'very unhappy' or 'unhappy'.



Over half of respondents said their preferences and priorities are considered when discussing treatment options:



The survey highlighted that:

- Only 2 in 5 adults (40%) affected by neurological conditions and their carers felt that the healthcare services they accessed met their needs, pointing out a gap in care and service delivery.
- Over a third of adults reported either a mental health (36%) or physical health (41%) comorbidity. Around a quarter of respondents reported having 'no other condition'.
- Many people also face inconsistent access to essential services such as neuropsychiatry, respite care, counselling, and personal assistance.
- Over a third (36%) of respondents disagree that medical and healthcare services or government-provided personal and support services are meeting their needs. Just 19% were satisfied with this provision.

Notably, 66% of respondents reported being happy with the format of their appointments, including whether they were face-to-face or by phone. 15% were unhappy with the format available to them. More than half of respondents said they were able to schedule appointments without conflicting with other appointments, though 1 in 10 could not.

While 42% of people stated that their care from medical and healthcare services met their needs, 40% said that it did not. Of those who didn't, 22% disagreed and 18% strongly disagreed.

44% of adults surveyed do not feel supported by the health system in Wales. Of these, 21% strongly feel unsupported, and 23% feel unsupported. Just over a third (35%) told us they did feel supported (with 11% agreeing strongly and 24% agreeing).

> ***"[People living with a neurological condition] need rapid access to diagnosis and ongoing support from a wide range of health, social care and third sector services to live their best lives."***[xiii] Quality Statement for Neurological Conditions, Welsh Government

People told us that mental health support would have been particularly valuable during diagnosis and in the early years of living with their neurological condition.

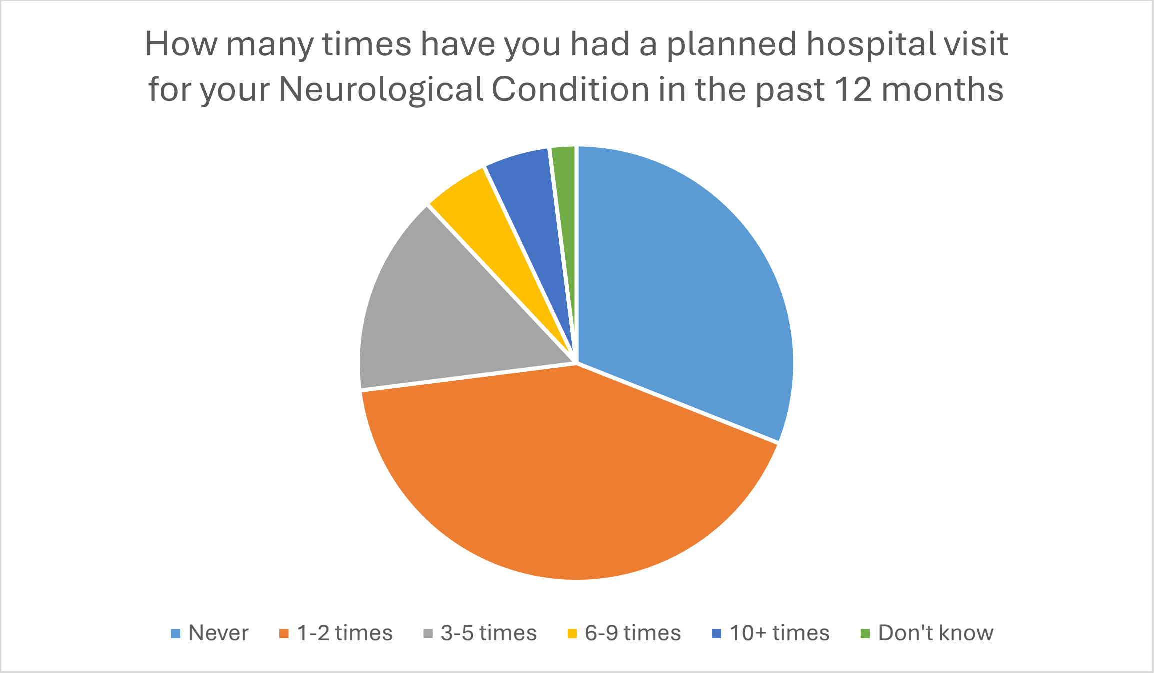
Awareness Raising

The Welsh Government's Quality Statement for Neurological Conditions highlights the need for greater awareness of neurological conditions.[xiv] Our survey respondents highlighted this as something they wanted for both health care professionals and the wider public.

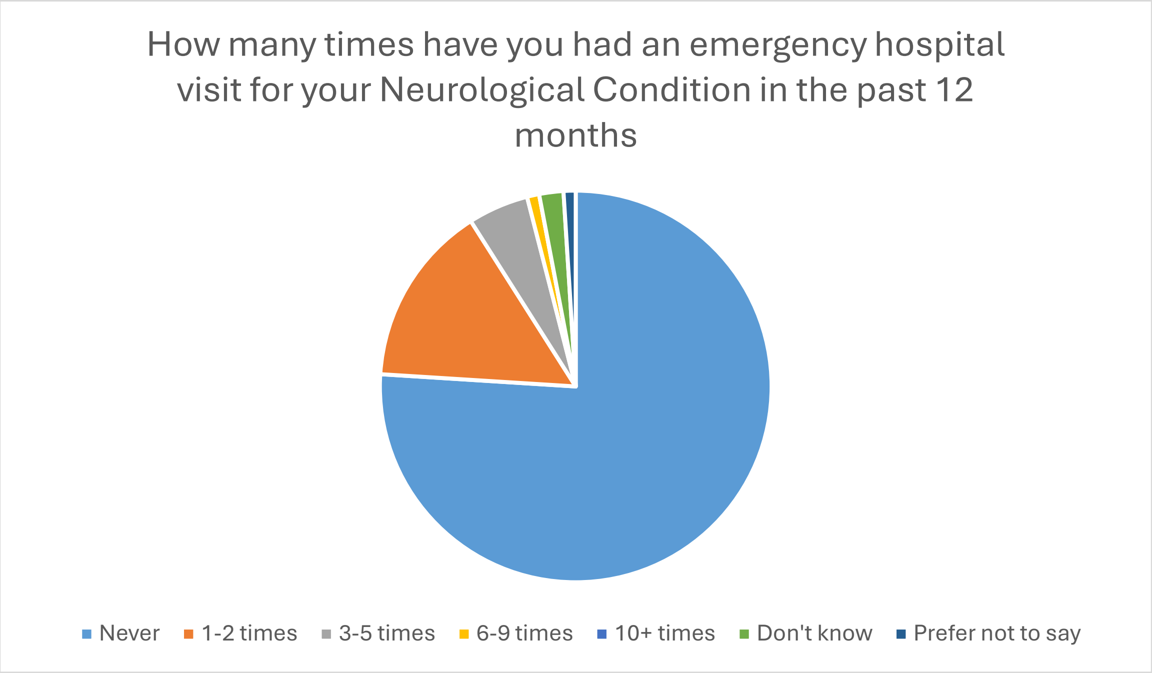
Access to Healthcare

34% of participants said they could get follow-up appointments when needed, while 41% said they could not. Over half said they know who to contact if they need support for their neurological condition(s) between appointments, though 34% said they did not know who to contact.

We asked participants about their planned and emergency hospital visits in the previous year.



How many times have you had a planned hospital visit for your Neurological Condition in the past 12 months



We asked whether people had enough time during appointments to discuss all of their concerns. While over half (53%) said that they did, worryingly 33% disagreed.

> ***"I need more time with a neurologist. I've ploughed my way through a physically uncomfortable life, resorting to yoga, Pilates and moderate alcohol to remain functional. I have always worked, have paid my way, have only ever received 6 weeks' benefit, and have even given recitals in aid of the Dystonia Society. I want a firm diagnosis. That surely is my right. Don't go on punishing me because I've coped. I'm a pensioner now. I don't ask for anything beyond the state pension I've earned. Favour me with a diagnosis."*** Adult living with Dystonia

Consistency of care is essential – when we asked whether people had a consistent healthcare professional, so they do not have to explain their condition(s) repeatedly to different people, respondents were almost as likely to say they did have consistency (42%) as those who did not (41%).

> ***"I feel totally let down by the medical professions who have gaslit me, abused me, eventually diagnosed me after nearly 3 decades, and then left me to rot with no meaningful help apart from offering psychological treatments for a physical illness! If I had the energy I would like to do a PhD on invisible illnesses and how the way you are treated makes you lose faith in society."***
> Person living with ME/CFS

Access to Consultant Neurologists

Given the Quality Statement's focus on 'timely and equitable access to services'[xv], we are concerned that this goal is not being met, including in relation to access to neurologists for people living with neurological conditions in Wales.

In the past 12 months, 56% had accessed their neurologist and had their needs met, while 16% had not. Worryingly, 25% told us they had been unable to access their neurologist when they needed to.

Of those who had accessed their neurologist, 77% had their needs met; 23% did not.

Access to Specialist Nurses

Many of our open responses to the survey have highlighted that good access to condition specific and/or neurological conditions specialist nurses can be hugely beneficial to how people are able to live well with neurological conditions. However, it must be stressed that many people with specific neurological conditions are unable to access specialist nurses, as they are not available through local health boards for many neurological conditions.

Of those we surveyed who have needed to access their specialist nurse in the last year, 59% have had their needs met. 10% have accessed their nurse and have not had their needs met. However, 27% have not been able to access their specialist nurse. Of those who had accessed their specialist nurse, 86% had their needs met; 14% did not.

General Practice (GP services)

We asked whether participants had accessed GP services in the past twelve months. At 47%, almost half told us they had accessed GP services and that it had met their needs. Worryingly, nearly a third (30%) had accessed it and found it didn't meet their needs. 8% were also unable to access their GPs. Of those who had used GP services, 61% had their needs met, and 39% did not.

Some survey respondents highlighted how helpful they found interventions from their GPs — for example, someone living with FND told us that their GP was ***"very supportive"*** and helped them learn about their condition. However, after the doctor retired, the patient was referred to professionals who lacked knowledge of their neurological condition. Another person with FND told us how the GP ***"tried hard"*** but was limited by the lack of a pathway for FND in Wales: ***"My GP is great, but he is frustrated with the lack of specialist support in Wales."*** Once again, we are deeply concerned about the disparate nature of whether treatment and services are available for people living with certain neurological conditions in Wales. While some conditions have clear pathways and records of good service delivery, for other conditions, there is a complete lack of pathway and a dearth of services, making the lives of people living with such conditions incredibly difficult.

Another person told us how helpful their GP was when they were experiencing symptoms over the Christmas period. The GP saw them quickly in the new year, made a fast referral, resulting in ***"a very quick and efficient turn around of results."***

However, many others have not been so lucky, and many responses reported a lack of interest or knowledge of the neurological conditions. While some people reported supportive GPs, who lacked specific knowledge of their condition: ***"my GP doesn't know anything about my condition. He is, however happy to listen to me and discuss treatments."***, others describe medical gaslighting: ***"GP don't believe my illness & had very unhelpful comments",*** which is very upsetting and unacceptable.

Survey respondents also described the difficulty of getting a GP appointment, which adds to the daily stress of living with a long term, neurological condition, and can put an additional burden on unpaid carers. One carer described ***"Always getting fobbed off by professionals."***

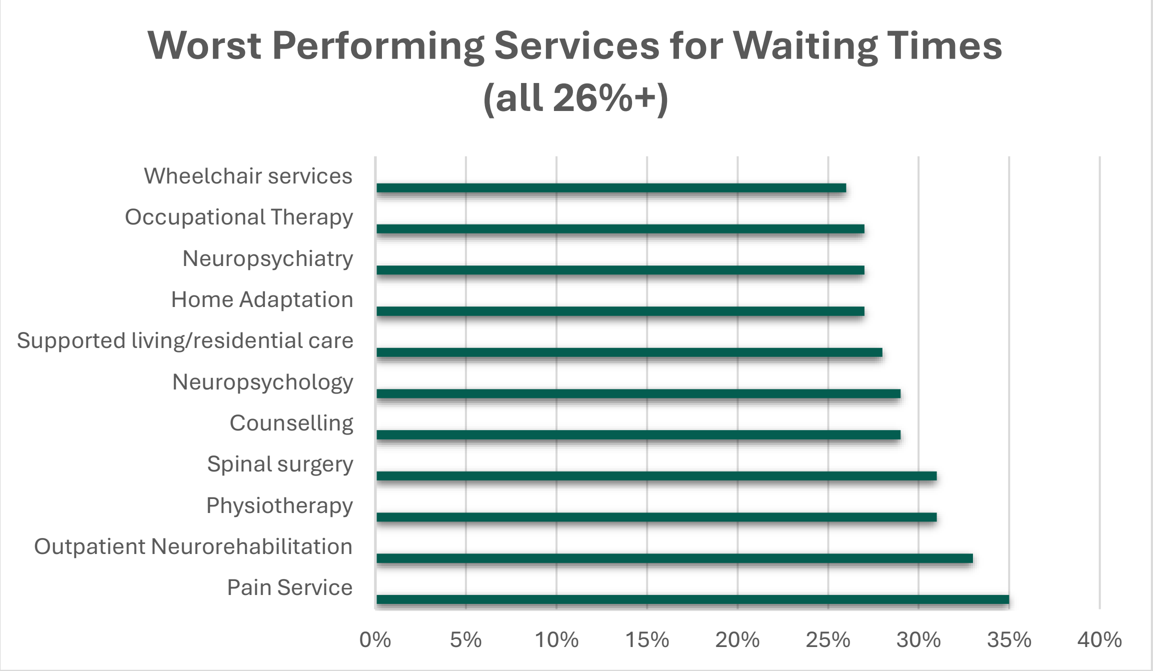
Perceptions of Improvement of Services

We asked participants whether they thought services had improved in the last twelve months.

Service	**Agree** *(agree/ strongly agree)*	**Disagree** *(disagree/ strongly disagree)*	**Neither Agree nor Disagree**
Mental Health Services (counselling, psychiatric care, support groups	**8%** *6% agree* *2% strongly agree*	**27%** *12% disagree* *15% strongly disagree*	**15%**
Personal & Support Services (assistance with daily activities, in-home support, personal care)	**11%** *8% agree* *3% strongly agree*	**22%** *12% disagree* *10% strongly disagree*	**19%**
Medical & Health Care (visits to doctors, hospital care, medication management)	**27%** *21% agree* *6% strongly agree*	**37%** *18% disagree* *17% strongly disagree*	**33%**

Waiting for Services

"Patients have timely and co-ordinated access to all services."[xvi]Quality Statement for Neurological Conditions, Welsh Government



73% of patients surveyed are comfortable talking to healthcare professionals and asking questions during appointments. 66% are happy with the appointment format, and 62% are satisfied with the clarity of the information provided. But 41% find that it is not easy to get follow-up appointments when needed.

Condition-specific information isn't routinely given to patients, with 22% not receiving any info over the past 12 months.

Symptoms

"I have felt sometimes abandoned, and left to flounder on my own, partly due to being over 65, I don't feel confident to express the symptoms I am experiencing with any of my healthcare professionals, after years of experiencing raised eyebrows and being thought of as a bit of a neurotic nurse." Adult living with a neurological condition

People with neurological conditions told us:

Fatigue was the most commonly reported impact (84% reported that fatigue somewhat (14%), quite a lot (25%) and very much impact on daily life (45%)); followed by **movement** (82% reported that somewhat (19%), quite a lot (23%) and very much (40%)); and **poor sleep** (71% reported that somewhat (18%), quite a lot (22%) and very much (31%)).

Symptoms that were reported by people living with neurological conditions impacting them 'quite a lot' and 'very much' were:

- Fatigue (70%)
- Movement (63%)
- Sleep (e.g. difficulty falling asleep, excessive daytime sleepiness) (53%)
- Thinking and memory (e.g. difficulty concentrating, confusion, memory problems, difficulty planning) (49%)
- Pain (46%)
- Sensation (numbness, tingling, pain, hypersensitivity, etc) (43%)
- Mood and mental health issues (43%)
- Bladder and bowel symptoms (33%)
- Sexual function difficulties (27%)
- Communications (e.g. difficulty speaking clearly, slurred speech) (22%)
- Vision (21%)
- Challenges eating and drinking (14%)
- Hearing (12%)
- Breathing difficulties (10%)
- Seizures (8%)

While 32% of respondents told us they have no additional condition, 32% reported that they live with a mental health condition, 37% said they live with a physical condition, 19% live with a sensory condition, 6% with a cognitive condition. 18% reported living with another condition (2% preferred not to say).

With a high proportion of people living with neurological conditions significantly affected by pain, it's worrying that just 16% of respondents have had their needs met when accessing pain services. In comparison, a further 20% have accessed the service and not had their needs met. 57% told us they've been unable to access this service, despite needing to.

Of those who had used pain services, 45% had their needs met, 55% did not have their needs met.

15% of respondents to the survey reported being unable to access physiotherapy when they needed it in the past year. 26% told us they had their needs met when accessing physiotherapy, though 19% of those who accessed the service did not. In isolation, of those who had accessed physiotherapy, 58% had their needs met. 75% of people accessing wheelchair services had their needs met.

Carers told us that the person they care for 'quite a lot' or 'very much' experiences the following symptoms:

- Movement (62%)
- Sleep (e.g. difficulty falling asleep, excessive daytime sleepiness) (60%)
- Fatigue (58%)
- Thinking and memory (e.g. difficulty concentrating, confusion, memory problems, difficulty planning) (55%)
- Mood and mental health issues (54%)
- Bladder and bowel symptoms (49%)
- Pain (43%)
- Communications (e.g. difficulty speaking clearly, slurred speech) (43%)
- Sensation (numbness, tingling, pain, hypersensitivity, etc) (34%)
- Challenges eating and drinking (30%)
- Vision (25%)
- Breathing difficulties (19%)
- Sexual function difficulties (19%)
- Seizures (17%)
- Hearing (5%)

Many people living with neurological conditions have told us that they experience bladder and bowel symptoms and need assistance using the toilet. Of those who have needed continence support, 48% have accessed this service and found it met their needs. 11% found that it didn't meet their needs. Concerningly, 28% have been unable to access this support. Of those who had used continence support services, 81% had their needs met, and 19% did not.

Crisis in Mental Health Support

"Develop and embed evidence-based, comprehensive and integrated neuro-rehabilitation services for all conditions, including psychological support and opportunities for self-referral for those living or affected by a neurological condition."[xvii] Quality Statement for Neurological Conditions, Welsh Government

In our 2022 report, we highlighted the crisis in mental health support for people living with neurological conditions, when 43% told us that their mental health had worsened during the Covid-19 pandemic.[xviii]

When surveyed in 2024, people living with neurological conditions raised really concerning issues about mental health provisions in Wales. Half of the respondents said they felt comfortable raising and discussing mental health concerns with their medical professional. Unfortunately, 22% said they did not feel comfortable doing so.

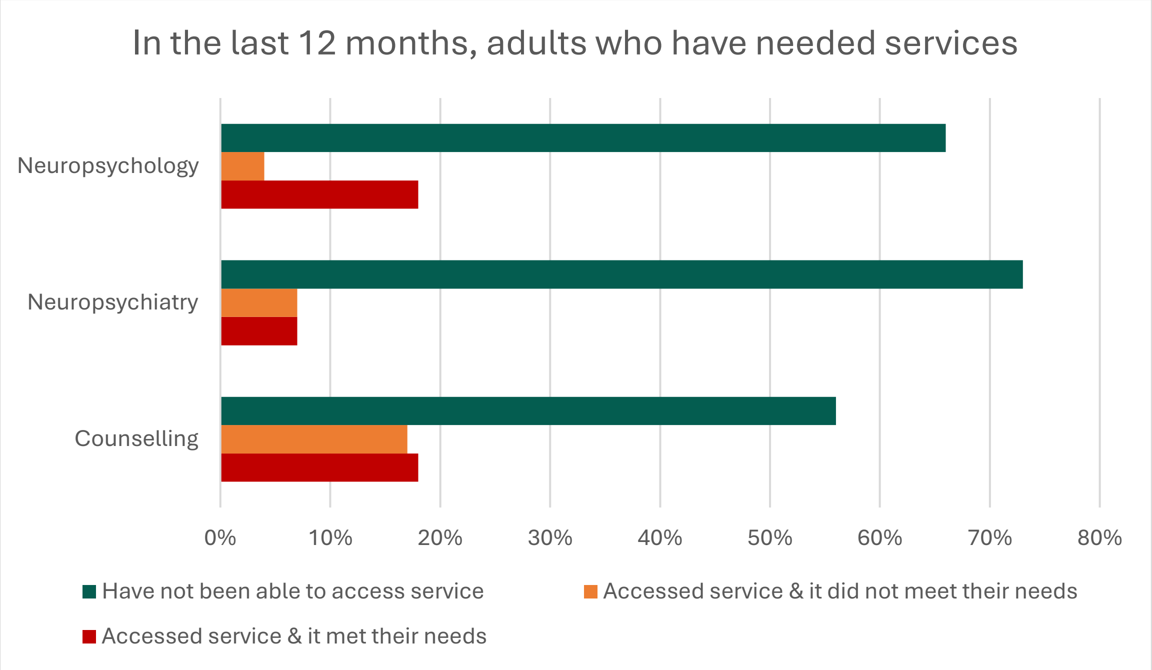
Almost 1 in 3 respondents (32%) told us that they have no one to talk to about their mental health (46% of people did report having someone).

For those who accessed counselling, 52% found that it met their needs. 43% reported that they were still waiting to access counselling. Some commented that it would have been, or had been, essential to access counselling around the time of diagnosis.

> ***"I've begged for mental health support when my medical anxiety has become uncontrollable, extreme panic attacks when [the GP] said 'what do you want me to do?' I was referred on to mental health services and after 2 telephone assessments, they came to the conclusion that all I could do was attend courses for people with chronic illness, as it's always going to affect my mental health. They then discharged me back to the GP, where I've got no support at all."***
> Respondent living with a neurological condition

We asked whether people felt there had been improvements in mental health services in the last twelve months, including counselling, psychiatric care, and support groups. Of the 52% of respondents who felt this applied to them, 27% disagreed, 15% were neutral, and just 8% felt services had improved.

Of those who did need the following services in the last twelve months, high percentages of people had not been able to access services in neuropsychology (66%), neuropsychiatry (73%), and counselling (56%).



Of those who managed to access services, 81% found neuropsychology services met their needs. Neuropsychiatry was found to meet needs as much as it didn't (50% meeting/not meeting needs).

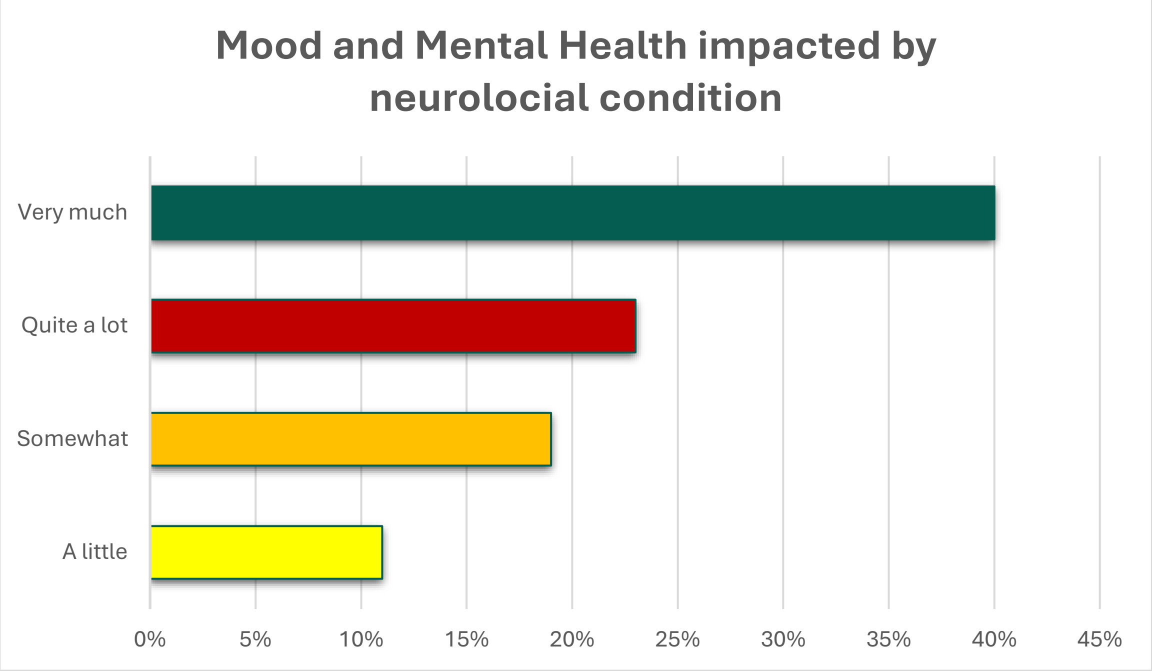
In open answers, people told us that their condition-specific needs were not met:

> ***"They do not provide enough support for the anxiety side of my condition, and the counselling I was offered was not appropriate for my condition."***
> Respondent living with a neurological condition

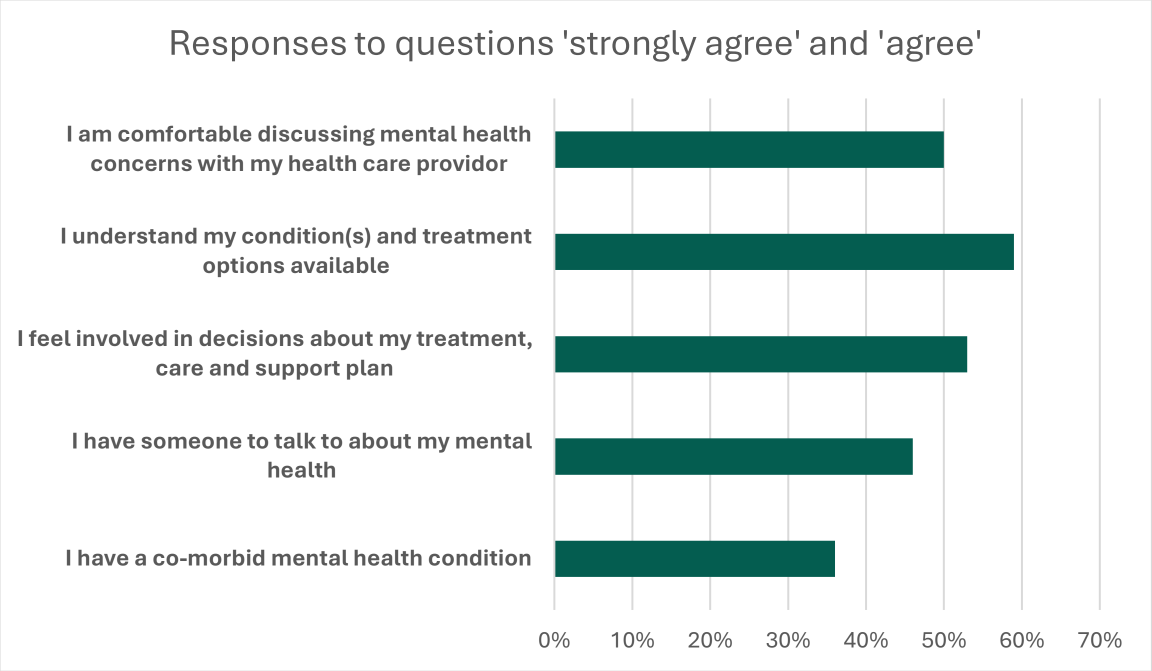
One respondent told us that they had waited years to receive support – ***"I get no support. After 5 years of waiting, I am receiving counselling, but it is only for a***

max of 12 sessions.", while another told us that the much-needed support was stopped suddenly: ***"Mental Health support was stopped with 4 days' notice. Have not been able to access other Mental Health support, although very much needed."***

It is not too dramatic to say that the mental health crisis is life and death for some people. The open answers of the survey from adults living with neurological conditions, and carers supporting them, brought to the surface the often daily mental health struggles of living with a condition or offering care to someone with a long-term health condition, or living without appropriate support. Some people spoke about suicidal ideation. Others highlighted how transformative condition-specific mental health support can be***: "Brain Tumour counselling has been a lifesaver for me."***



We asked additional questions about mental health and well-being for adults with neurological conditions:



Worryingly, 30% of people stated that care from mental health services did not meet their needs, with just 11% of people agreeing that it did.

Access to psychological support is crucial for people living with neurological conditions to manage their mental health and wellbeing, and is not routinely accessible across Wales.

Over 80% of people with a neurological condition in Wales reported that it impacts their mood and mental health, with almost a third of people having no one to talk to about their mental health.

- Few respondents identified improvements in mental health services, although Aneurin Bevan saw the highest numbers
- People reported largely not being able to access counselling services across Wales
- 83% report their neurological condition impacts mood and mental health
- Just over a third (36%) reported a mental health co-morbidity (depression, anxiety, generalised anxiety disorder, etc.)
- 57% reported low coping day to day with their neuro condition
- Almost 1 in 3 have no one to talk to about their mental health, but for those who have access to counselling, 52% report that it meets their needs
- Nearly half (43%) of those trying to access the service reported they were still waiting to access counselling services

We urge the next Welsh Government to ensure that statutory provision for psychological support after a neurological diagnosis is in place across all health boards in Wales.

Mental Health of Unpaid Carers

Unpaid carers are an essential yet often invisible backbone of our health and care system in Wales and are key to ensuring people living with neurological conditions live well.

The estimated economic value of unpaid carers' contribution to the Welsh economy is over £10 billion a year.[xix] And yet we know that carers are struggling to cope with the enormity of providing day-to-day, long-term care for their loved ones.

In the last twelve months, 43% of carers told us that they had been unable to access mental health and wellbeing support (such as counselling, therapy, or carer recreational activities). Of those who had been able to access it (21% of carers surveyed), it was just as likely to meet their needs as not. Almost a third of carers told us this wasn't relevant to them.

> ***"This has also impacted my own mental health in such a negative way that I often struggle to find motivation in any form of recovery for my wife."*** Carer of an adult with a neurological condition

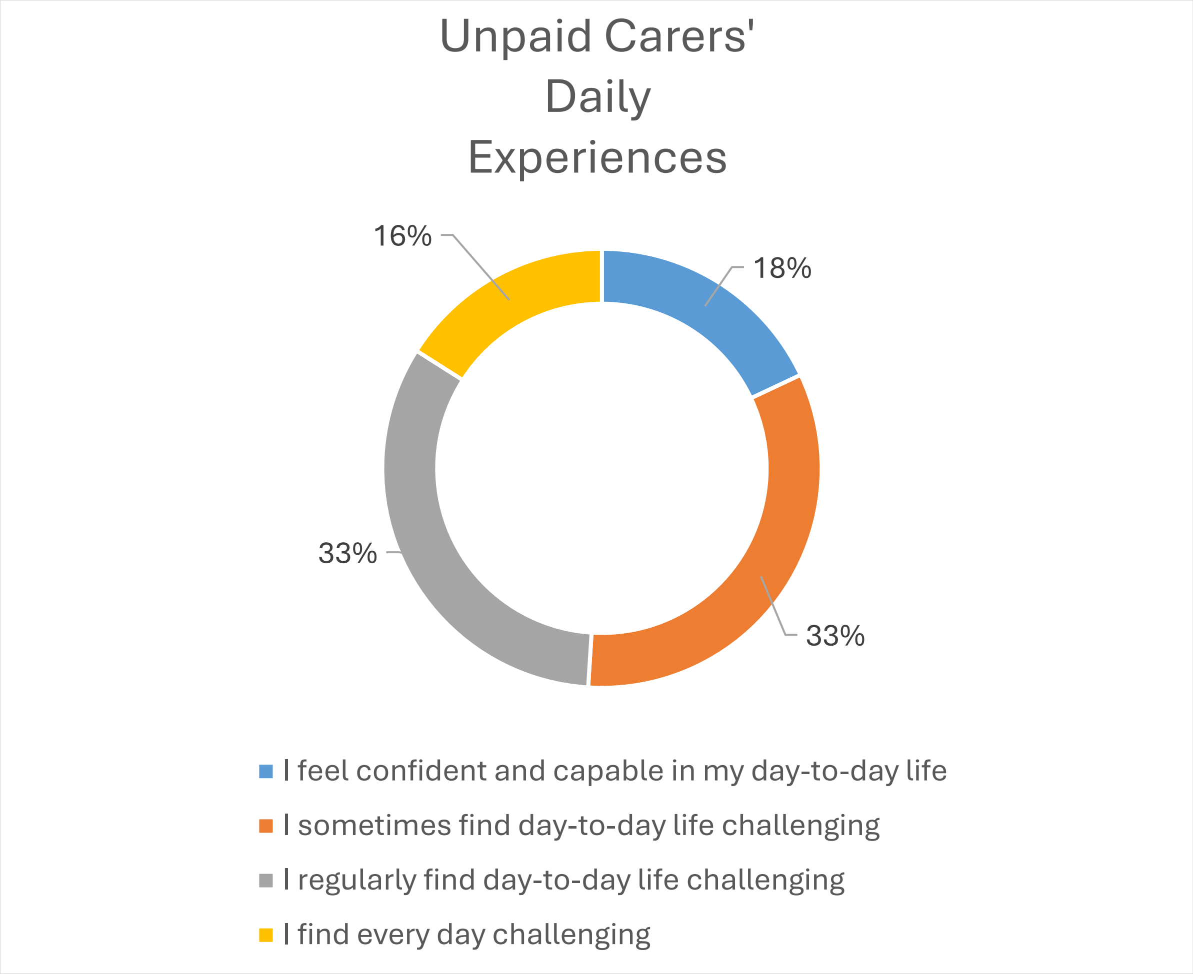
We asked carers whether they had access to respite care, where a temporary carer is provided by someone else to allow them a break from their caring responsibilities. Only 7% of carers had accessed respite care and found it met their needs, while 3% had accessed it but found it did not meet their needs. 40% of carers told us this was something they have not been able to access. 46% said that this is not relevant to them, indicating that while this service is vital to some carers, it is not needed for all, and it should be in place for those who need to access it, as part of a long-term strategy to support carers in their vital roles.

The majority of carers find day-to-day life challenging. While 80% told us that they can meet the day-to-day needs of the person they care for, only 18% feel confident and capable in their own day-to-day life.

When asked whether carers were able to meet their own day-to-day needs, a quarter said they were not (19% disagreed, 7% disagreed strongly). 55% told us they were able to meet their own day-to-day needs, and almost half (48%) said they were able to manage their own health and wellbeing. Again, 25% disagreed, and a further 11% strongly disagreed, reporting that they were not able to manage their own health and wellbeing.

> ***"Counselling but funding got pulled. Don't know how long I can go on caring for my husband at home. He has […] 2 carers 4 times a day."*** Carer of an adult with neurological condition, Guillain-Barré Syndrome

While some unpaid carers are supported by paid care work, we know this is often insecure and costly, and provisions can change at short notice, putting unpaid carers under increased pressure to cope in challenging circumstances.[xx]



34% of carers reported a long-term mental health condition (General Anxiety Disorder, depression, anxiety, etc), 41% reported a long-term physical condition (e.g. arthritis, hypertension, high blood pressure, heart disease).

> ***"My mental health can vary because of the enormity of the caring task and what the future holds – if I think about the situation, it can seem very daunting to me."*** Carer of an adult with a neurological condition

Welsh Government must prioritise more mental health support for unpaid carers, to support their day-to-day experiences, and provide regular access to respite care for those who need it.

Impact on Daily Living

Neurological conditions affect everyone differently. Many conditions are lifelong, with fluctuating symptoms, affecting the people living with the condition(s) and their support network — including unpaid caregivers — in every aspect of daily life.

Welsh Government's Quality Statement on Neurological Conditions states that:

> ***"Neurological conditions can affect the way people think, feel and interact with the world around them. They often have a huge impact on a person's quality of***

life and their ability to live independently and participate in family life and their community."[xxi]

The most commonly reported symptom of people with neurological conditions was fatigue. An often misunderstood and frequently overlooked aspect of chronic health conditions, fatigue is far more than just being tired. It can have a significant impact on people's home, work, and educational lives.

"Support all those living with a neurological condition to live their best lives, recognising the impact of their wider lived environment and need to participate in daily occupations."[xxii] Quality Statement for Neurological Conditions, Welsh Government

Over half of the adult respondents reported significant impacts on their ability to be active (68%) or to enjoy recreational activities (60%).

The ability to complete daily tasks was reported to 'very much' impact on people living with the following conditions:

- CBD (70%)
- Alzheimer's (63%)
- Muscular Dystrophy (62%)
- MS (61%)
- Dementia (57%)
- Long Covid (55%)
- Fibromyalgia (54%)
- ME/CFS (54%)

Over half of survey respondents reported a significant impact on their ability to be active, work, and enjoy recreational activities. The following percentages of people told us that their neurological condition affected their ability to do the following categories 'quite a lot' or 'very much':

- **42% maintaining romantic relationships and intimacy,** including sexual function
- **50% completing daily tasks**, like getting dressed, doing chores, taking showers, or other hygiene tasks
- **60% doing fun things out and about**, like enjoying hobbies and interests, travelling for holidays, or going places like the cinema
- **68% being active**, like doing exercise or sport

In open response answers, people highlighted worries about finances in light of welfare reform and benefit access, difficulties accessing Blue Badges, driving licenses, and home adaptations. For those who are in work, there are also worrying reports of the lack of support and discrimination in the workplace in relation to having a neurological condition.

We asked carers how independent the person they care for is in their daily activities without their assistance. 6% of carers told us that the person they care for is 'completely independent' (can move around independently, attend school or work with help). 16% said 'mostly independent' (can perform most tasks independently but needs some assistance with complex activities). 38% said 'somewhat independent' (described as requiring regular assistance with daily tasks but can perform basic activities independently), and 41% said 'not independent' (requiring assistance with most or all daily activities).

Carers' daily lives are also highly affected by their caring responsibilities, impacting their ability to work at all, continue studying, or accessing benefits. Household finances are worryingly low amongst people living with neurological conditions, despite the increased financial burden of living well with long-term health conditions.

Many carers also highlighted that they live with physical and mental health conditions themselves. When we asked carers how they feel most of the time about their own life, we found that:

- 16% of carers find every day challenging
- 33% regularly find day-to-day life challenging
- 33% sometimes find day-to-day life challenging
- Just 18% of carers feel confident and capable in their day-to-day life

Social care

While some people living with neurological conditions can live independently for many years, many have complex social care needs that can progress rapidly. Currently, the adult social care system is too slow, too inflexible, and too disjointed, meaning people with neurological conditions face an inequality in access to social care alongside long waits and care packages that do not fully meet their needs.

Unmet social care needs leave people facing unnecessary hospital admissions and premature physical and psychological deterioration. This also increases strain and burnout on the 310,000 unpaid carers in Wales.[xxiii]

While we are mindful of the strain on health and social care services, and the progress made against the delivery of a National Care Service[xxiv], we urge all parties to continue this work with haste and to ensure that social care engagement is included in the delivery of the Quality Statement for Neurological Conditions.

Service provision

> ***"The number of people living with a neurological condition is set to increase over the coming years as more children survive beyond birth into adulthood and as the UK's population ages, so does the number of people living with age-related neurological conditions."***[xxv] Quality Statement for Neurological Conditions, Welsh Government

Despite the clear need for multi-disciplinary care close to home, support and services remain unequal across Wales. NHS Executive research shows Wales needs eight more neurologists to meet the ABN recommendation of 1 per 65,000 of the population. Yet, almost half of the current neurologists in South Wales are due to retire in the next 10 years. There is just one specialist neurology nurse per 58,976 of the population, mainly in epilepsy, MS, and Parkinson's care. The neurology workforce is significantly lagging behind demand, and without immediate intervention, attrition will worsen.

My Neuro Survey underlines this. We found that 44% of adults do not feel supported by the health system, and that over one-third say the services provided do not meet their needs.

Home adaptations

"I have found the adaptations to my home by the [Occupational Therapist] most helpful to enable me to stay in my first floor flat." Respondent living with a neurological condition

Over a fifth (21%) of people living with neurological conditions told us that their homes are not suitable for their needs, while 63% said their house met their needs. Of those requiring home adaptation services, 34% told us they had been unable to access them in the past 12 months. Of those who have managed to access this service, 12% found it did not meet their needs, while 48% found it did. Of those who had used home adaptation services, 80% had their needs met.

In the last 12 months, 42% of carers had accessed support that met their needs for equipment and home adaptations for the person they care for. 8% had accessed this, but it hadn't met their needs, while 24% had not been able to access it. This was not relevant for 26% of carers.

Our council occupational therapists has carried out bathroom and accessibility survey but it takes 2 months before the technical team get involved and it could be possibly next year if all is approved." Carer of an adults with a neurological condition"

While over half of respondents haven't needed to access Occupational Therapy (OT) services, among those who did, just under half (48%) accessed services in the last 12 months and had their needs met. 12% accessed the service but found it did not meet their needs. A further 34% of those needing the service have not been able to access it. Of those who have had access to an Occupational Therapist in the past year, 81% had their needs met.

"Waiting lists for home adaptations and mental health support are about 2 years and the latter isn't tailored for disability/neuro illness. Had to move towns away from family to find level access accommodation. Wheelchair services have given me a better wheelchair but have had to come to fix it about 8 times since the start of the year. Motability have denied me a car as I am not worth the cost of adapting a vehicle. They told me if I wanted a car I had to have a child, or work 2+ days a week (but I can't get anywhere in my wheelchair and nobody will hire me)." Adult living with FND

Welsh Government's Housing Adaptations Standards of Service sets out expected timelines for installation of adaptations. We are concerned that this standard is not being consistently met, as we see in the above quote.

Support

People living with neurological conditions told us how they felt about their own lives most of the time, regarding day-to-day livng:

- 28% of people regularly find it challenging
- 28% find every day challenging
- A further 1/3 sometimes find day-to-day life challenging
- Just 10% of people feel confident and capable in their day-to-day life

Most people receive support from family and friends. Lack of awareness of external support is the most significant barrier to accessing it:

- 75% said they receive support from family and friends
- 42% receive support from professionals funded by the state, e.g. NHS or local authority
- 15% receive support from professionals funded by charities or Not-For-Profit organisations

While just 13% of those not accessing support stated that they don't need it, the following barriers were highlighted for others:

- 25% were unaware of available support
- 19% don't know how to access support
- 14% stated that they weren't eligible for support
- 14% have asked for support but haven't received any
- 11% are on a waiting list for support
- 8% can't afford support.

Adult respondents reported that the most significant barriers are in accessing neuropsychiatry, inpatient neurorehabilitation and personal assistance.

Neurorehabilitation Services

The Welsh Government's Quality Statement for Neurological Conditions sets out the standard for 'neurological rehabilitation services for all conditions.'[xxvi] And yet, satisfaction is lowest with neuropsychiatry, outpatient neurorehabilitation, personal assistant services and inpatient neurorehabilitation.

Not everyone needs access to neurorehabilitation – 59% told us they did not need this service in the past year. For those who do need this service, only 12% of respondents have had access to satisfactory outpatient neurorehabilitation, and 16% who have accessed it have not had their needs met. 59% have been able to access outpatient neurorehabilitation. Of those who had accessed outpatient neurorehabilitation, 57% did not have their needs met.

Of those needing the service, 68% have been unable to access inpatient neurorehabilitation. Just 15 people told us they had used this service in the last 12 months; 11 were satisfied and four were dissatisfied. Of those who have accessed inpatient neurorehabilitation, 73% had their needs met.

Welsh Government must ensure that neurorehabilitation services are available for people living with neurological conditions across Wales, and utilise the ongoing work of NHS Performance and Improvement in this area to bring about change and improved services.

Participations in Research

Broadly speaking, people are keen to participate in neurological research: 69% said they would be interested in taking part in research studies about their condition(s) to help others with neurological conditions, with only 31% having already participated.

Lack of information

When asked, 'In the last 12 months, have you been offered or directed to any information regarding your neurological condition by the following?', respondents highlighted the following sources:

- 39% own research (including the internet)
- 37% neurologist
- 25% charity/patient organisation
- 25% specialist nurse
- 20% GP
- 19% social media
- 14% peer support
- 15% NHS website
- 22% I have received no information

But the majority of adults (61%) surveyed valued the information provided about their condition, and almost a third had participated in research.

It was encouraging to see that 63% agreed that healthcare professionals explained medical information clearly, in a way people could understand. However, 10% disagreed and 6% strongly disagreed.

Financial Impact

> ***"I've had to self fund my wheelchair and home adaptations, we moved countries [from England to Wales] to be able to afford a bungalow."*** Adult living with several conditions, including Long Covid, migraines, and suspected stroke (2024 survey).

In 2022, our survey report[xxvii] highlighted significant financial impacts for people living with neurological conditions. These can take the form of loss of earnings for themselves and for carers. There are additional expenditures, such as the cost of buying equipment, mobility aids, and home adaptations, as well as increased household bills. Additionally, many face costs for help with personal care, cleaning, and childcare.

We also highlighted a Swansea University Medical School study that found that people living with neurological conditions and their families fund up to 75% of non-medical costs from their own pockets.[xxviii] These might include wheelchairs and home and car adaptations that are necessary.

Our 2024 survey highlighted that the ongoing cost of living crisis is deeply worrying for people living with neurological conditions. Heating costs are a particularly concerning area. People often need to heat their homes more than the average household to stay comfortable and avoid increased nerve pain. There are also more power costs associated with using assistive technology devices.

Many may also rely on their own personal vehicles, as public transport is not accessible, so increased fuel costs also have an impact. While the vast majority (69%) told us they have reliable transport or assistance to attend appointments, a worrying 19% told us they do not.

While medical professionals may tell people living with neurological conditions that they can improve their conditions through a healthy diet, the cost of healthy, nutritious food is also very high and out of reach for some.

Our 2024 survey asked whether respondents could afford the additional costs associated with treatments for their neurological conditions. While 27% agreed they could, 24% said they could not.

We found that the conditions that people lived with who were 'very much' struggling to manage their finances were:

- Alzheimer's (79%)
- Dementia (60
- CBD (51%)
- Autism (40%)
- ME/CFS (38%)
- Huntington's (37%)
- Fibromyalgia (37%)
- Cluster headache (33%)
- FND (32%)
- Chronic headache (32%)

Using data from My Neuro Survey across the UK, we looked at the impact of ‘doing fun things’ by financial status. We found that household income is only a partial contributor to the barrier to enjoyment. Of households that earn:

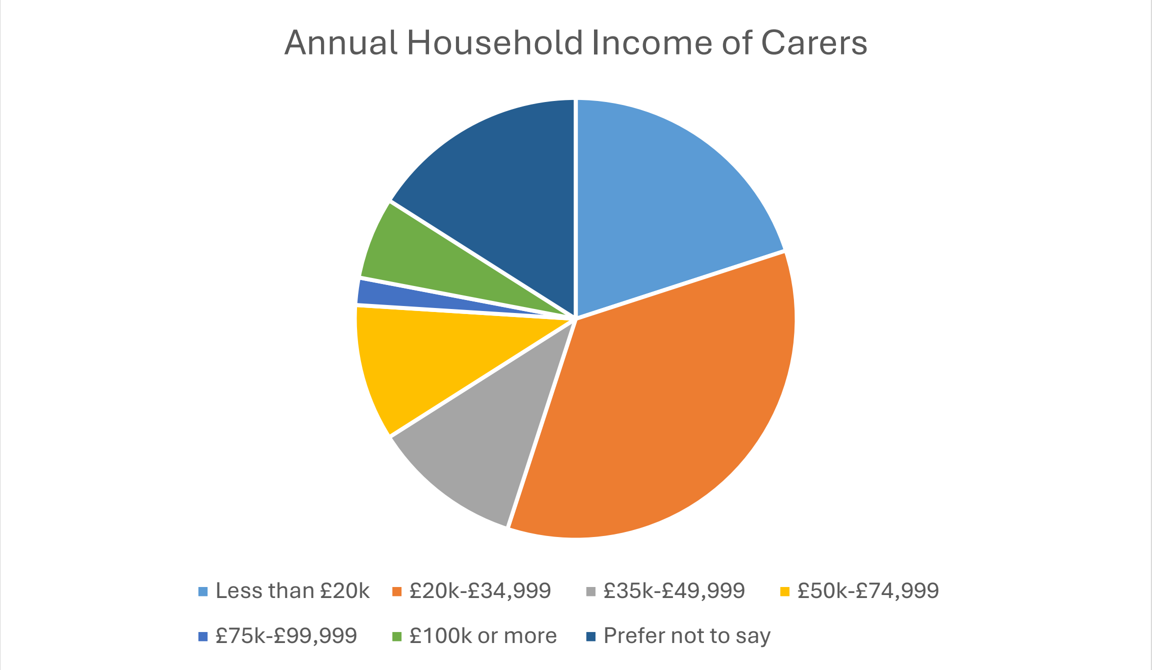
- less than £20,000 a year, **52%** cannot do fun things
- between £20,000-£39,999 a year, **29%** cannot do fun things
- between £50,000-£74,999 a year, **31%** cannot do fun things
- between £75,000-£99,999, **26%** cannot do fun things
- more than £100,000, **22%** cannot do fun things

Despite 45% of respondents holding university degrees or postgraduate qualifications, over half reported household incomes below £34,999, with 25% below £20,000.

This sits well below the UK minimum wage for adults over 21, which is around £25,400 for a 40-hour workweek. As just 20% of people told us that they live alone, the majority live in multiple-adult households, with 64% living with a spouse or significant other.

25% of carers told us they have a university degree, with a further 16% also holding a postgraduate degree, such as a Master's Degree or PhD.

Carers told us about their annual household income; the majority live in households with incomes below £35,000.



When we asked about the support people received, 15% said they received support from professionals funded by themselves or their family. In comparison, 8% highlighted that a barrier to accessing support was their inability to afford it.

Almost half the respondents have not received sufficient financial support, with nearly a quarter (23%) saying they don't understand the financial support they are entitled to, and 57% saying they are unable to advance in their careers.

Over half of carers have had to cut back on other expenses due to the costs of caring, while 46% have had to reduce work hours or leave their job entirely due to caring responsibilities. 57% of carers told us they were unable to advance in their careers. In comparison, 63% said they were unable to find time to pursue educational opportunities, such as courses and training, that they want to take alongside their caring responsibilities.

Welfare and Benefit Reform

> ***"Luckily I have a good support network at home, but the majority of stories I have listened to involve poverty and poor housing, endless court appeals for PIP and spiralling depression as a result of it all."*** Adult living with epilepsy

In our My Neuro Survey report in 2022[xxix], we raised concerns that the Personal Independence Payment (PIP) was not working for people living with neurological conditions and needed to be reformed by the UK Government. We also highlighted the cost-of-living crisis. This crisis is ongoing, and while news headlines of the proposed changes to PIP in spring 2025 came after our survey closed, we still found that people were worried about access to essential benefits in 2024.

> ***"I am fortunate having a great family and friendship support within my home setting. Government should realise PIP is a very important financial support and to take it away and offer an alternative such as a voucher scheme would push many into debt and in my opinion would cause great mental stress and pain."*** Adult living with a neurological condition

Our survey of adults living with a neurological condition found that:

- 54% receive financial support (disability benefits, grants)
- 25% are unaware of available support
- 19% don't know how to access support

> ***"The government PIP system has not met my needs. Assessments were carried out over phone and not face to face. Points were not awarded fairly. I have struggled financially and had extra expenses of staff and equipment and services on a small budget."*** Adult living with a neurological condition

Financial Impact on Carers

We asked carers whether they had used financial support in the last twelve months to support their caring responsibilities, for example, carer's allowance and PIP.

Of the carers who had accessed financial support in the last year, 17% told us it had met their needs, while 19% said that it had not. 16% said they had not been able to access it, while 41% said it wasn't relevant to them, and 7% preferred not to say.

> ***"Carers allowance [is] too little and the amount you can earn in an alternative job is too small."*** Carer of an adult with a neurological condition

In the past twelve months, 18% of carers have accessed information and advice on benefits that have met their needs. 16% have accessed this support, but it did not meet their needs, and a further 19% have not been able to access this type of support when they have wanted to. This has not been relevant for 43% of carers.

Work and Study

> ***"Government financial support has never been an option as I've never had enough seizures to meet their criteria, even though they have had enough effect to force me out of a job, and limited how many hours I can work per week without triggering seizures activity through fatigue or overexertion. I can't work more than 3 days a week or I'll have seizures, but there is no support unless I work more hours and make them happen daily."*** Adult living with epilepsy

59% of people told us that their neurological condition 'quite a lot' or 'very much' affected their ability to work or study (i.e. that they were unable to work due to the condition, had to give up their job/studies, or reduce working and/or study hours.

"The governments need to STOP the scrounger narrative and work with us in a co-production way to make sure their support serves our needs and empowers us instead of dehumanising us. They need to pour more resources into the NHS and support services, tackle poverty and other wider determinants to stop more people becoming sick / more sick. They also need to ensure all employers are clued up on social model of disability, and that all reasonable adjustments are met so as those of us well enough can stay in work. In Wales they need to change the healthcare system so as we can be referred out of area and ensure funding follows the patient." Respondent to Wales, living with ME/CFS.

The economic impact of neurological conditions is stark, with over half the adult respondents having had to give up work (52% have stopped working because of their neurological condition(s), with just 24% telling us this was not the case for them). While not applicable to 35% of respondents, 22% said they had to leave a job because of their employer's actions or inaction. Worryingly, 27% of respondents stated that they had been discriminated against at work due to attitudes towards their neurological condition.

"I have recently been forced to stop working due to my health. I have applied for financial support from the government (ESA and PIP) – my application for PIP was refused and I am currently appealing this decision and will be taking it to tribunal. To date, this process had taken over a year." Adult living with ME/CFS

Almost a third (29%) of respondents told us they have needed specific support to retain their employment. 15% of respondents told us they needed specific support to enter the workforce. 27% of respondents are educated to degree level, and 18% have a postgraduate qualification – this is a significant loss to the workforce

"Abandoned by my first MS team... discrimination at work... partner had to beg for treatment for me... what do you think life with MS is like...it's sh*t and no-one cares." Adult living with MS

Conclusion

Over 500 people affected by neurological conditions in Wales answered our calls to respond to My Neuro Survey. In this report we have raised their concerns about access to healthcare, the mental health crisis, the huge impacts on daily living and the financial burden of living with neurological conditions in Wales today.

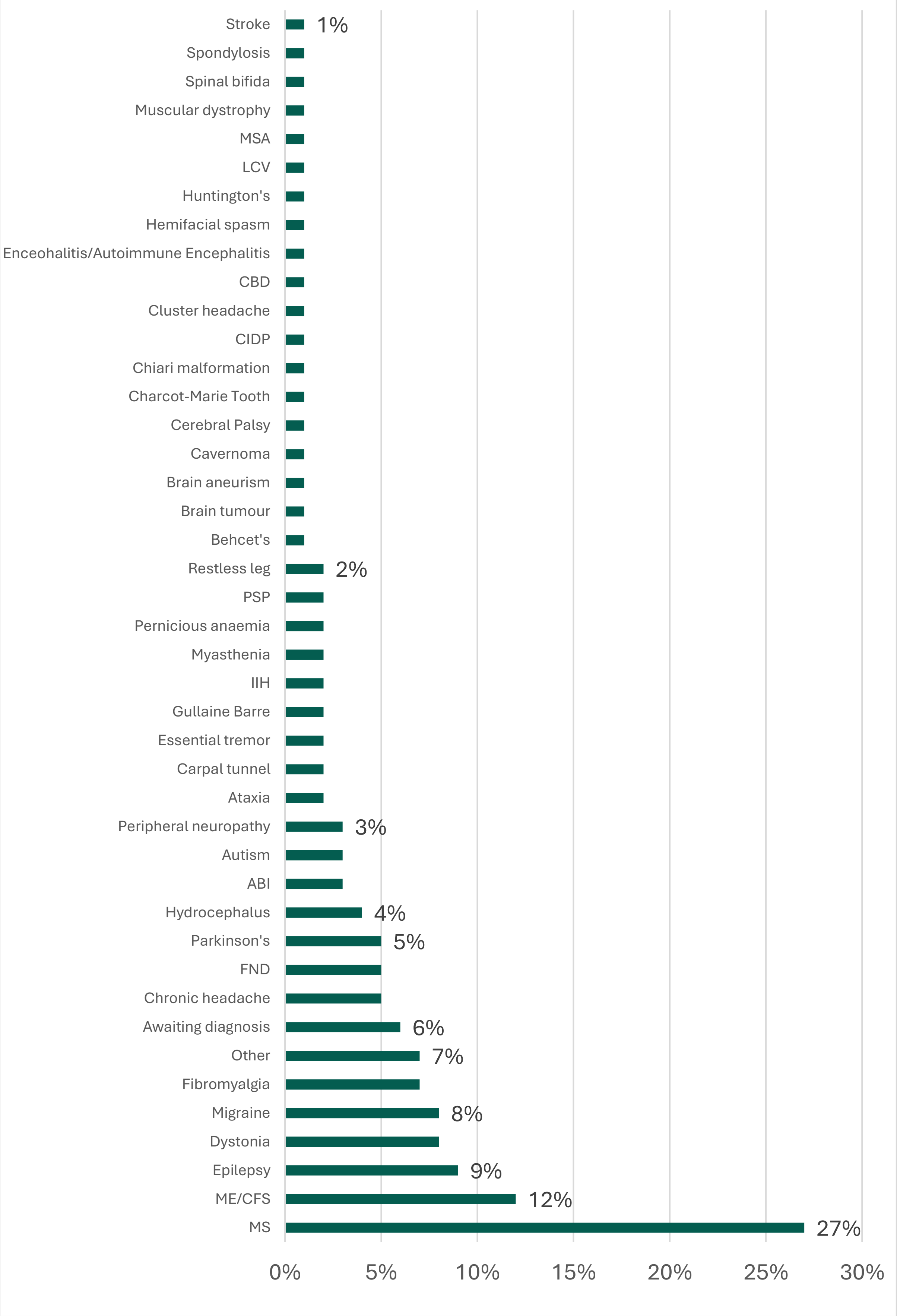
Wherever people live in Wales, they should be able to live well, with good access to quality service and support that are laid out in the Quality Statement for Neurological Conditions. Delivering to these standards would make a marked different to the lives of over 100,000 people in Wales, and their support networks.

We ask policymakers to honour their voices and commit to delivering meaningful change for a better future for everyone. The next Welsh Government must listen to the voices of the one in six who live with neurological conditions, and those of their friends and loved ones in unpaid carers roles, to ensure that across Wales, our communities can live with the dignity and respect they deserve.

Thank You

Across the UK, over 10,000 people's voices were captured in My Neuro Survey in 2024. In Wales, over 500 experiences were captured. We offer heartfelt thanks to everyone who completed this survey and to those who helped us reach so many people across Wales. The findings and recommendations in this report reflect your voices and your expertise. Without you, this report wouldn't have been possible.

Appendix


Stroke
1%
Spondylosis
Spinal bifida
Muscular dystrophy
MSA
LCV
Huntington's
Hemifacial spasm
Enceohalitis/Autoimmune Encephalitis
CBD
Cluster headache
CIDP
Chiari malformation
Charcot-Marie Tooth
Cerebral Palsy
Cavernoma
Brain aneurism
Brain tumour
Behcet's
Restless leg
2%
PSP
Pernicious anaemia
Myasthenia
IIH
Gullaine Barre
Essential tremor
Carpal tunnel
Ataxia
Peripheral neuropathy
3%
Autism
ABI
Hydrocephalus
4%
Parkinson's
5%
FND
Chronic headache
Awaiting diagnosis
6%
Other
7%
Fibromyalgia
Migraine
8%
Dystonia
Epilepsy
9%
ME/CFS
12%
MS
27%
0%
5%
10%
15%
20%
25%
30%

Adult Survey Participants reported living with the following neurological conditions:

Total %	Condition and number of participants reporting living with the condition
27%	Multiple Sclerosis (n=131)
12%	Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) (n=56)
9%	Epilepsy (n=42)
8%	Dystonia (n=39) Migraines (n=40)
7%	Fibromyalgia (n=36) Other (n=36)
6%	Awaiting diagnosis (n=31)
5%	Chronic Headache (n=23) Functional Neurological Disorder (FND) (n=26) Parkinson's Disease (n=23)
4%	Hydrocephalus (n=17)
3%	Acute Brain Injury (ABI) (n=15) Autism (n=14) Peripheral Neuropathy (n=16)
2%	Ataxia (n=8) Carpal Tunnel Syndrome (n=9) Essential Tremor (n=12) Guillain-Barré Syndrome (n=9) Idiopathic Intracranial Hypertension (IIH) (n=8) Myasthenia (n=8) Pernicious Anaemia (n=10) Progressive Supranuclear Palsy (PSP) (n=11) Restless Leg Syndrome (RLS) (n=9)
1%	Behçet's Disease (n=3) Brain Tumour (n=4) Cavernoma (n=6) Cerebral Palsy (n=6) Charcot-Marie-Tooth Disease (n=5) Chiari Malformation (n=5) Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) (n=6) Cluster Headache (n=3) Corticobasal Degeneration (CBD) (n=5) Encephalitis/Autoimmune Encephalitis (n=4) Hemifacial Spasm (n=3) Huntington's Disease (n=3) Long Covid Related Neurological Symptoms (n=6) Multiple System Atrophy (MSA) (n=6) Muscular dystrophy (n=5)

	Spina Bifida (n=7) Spondylosis (n=7) Stroke/Tia (n=6)
Below 1%	Alzheimer's Disease (n=1) Autoimmune Encephalitis (n=1) Brain Aneurism (n=2) Dementia (n=1) Lennox Gasteut Syndrome (n=1) Meningitis (n=1) Motor Neurone Disease (MND) (n=2) Narcolepsy (n=1) Neurofibromatosis (n=1) Poliomyelitis/Post-Polio Syndrome (n=1) Vasculitis (n=1)

About the Wales Neurological Alliance

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

We aim to improve services for people living with and affected by neurological conditions through:

- Engaging and working in partnership with people affected by neurological conditions
- Raising awareness of neurological conditions and their impact on individuals and communities
- Informing and influencing policymakers about the needs of people living with neurological conditions
- Supporting and promoting appropriate research

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WALES NEUROLOGICAL ALLIANCE

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