Today's Challenge, Tomorrow's Hope

An Observation of Neurology Patient Experience in Scotland

July 2025

neurological alliance of scotland

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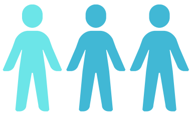
Foreword

We are pleased to present the findings from the second national survey for people impacted by neurological conditions in Scotland. Gathering experiences from people affected by a wide range of neurological conditions is one of the best ways to understand how these conditions impact not only those living with the condition, but also those who care for them.

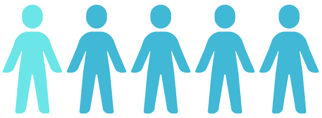
Our first Scotland Neurology policy report, “Together for the 1 in 6”, which was published in June 2022, shone a light on delays to treatment and care, the crisis in mental health support and the need for better information and support. It was the first time neurology patient experience data had been independently published in Scotland and is the benchmark for how services have changed since then.

We have chosen to title this report “Today’s Challenge, Tomorrow’s Hope” because it is important that we recognise the scale of the challenge we face today so that we can take action to improve things for tomorrow. Many people affected by neurological conditions, particularly those with conditions known as ‘multi system disorders’, still fall between the cracks and are having to cope while their needs go unmet.

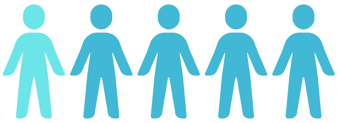
Our findings show that health and social care services are not meeting peoples' needs with over half of adult respondents (53%) saying they do not feel supported by the health system.



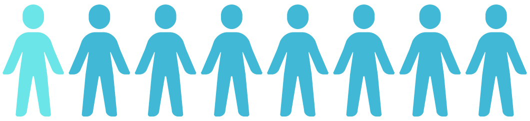
1 in 3 adults agree that medical and healthcare services meet their needs



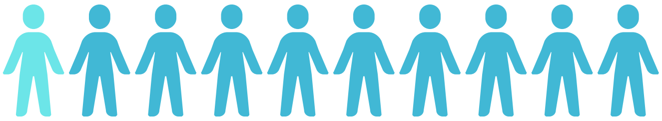
1 in 5 adults agree that social care services meet their needs



1 in 5 are ‘very unhappy’ with their experience of healthcare in the last 12 months



1 in 8 agreed that mental health services meet their needs



Only 1 in 10 agreed that their social care and mental health care had improved over the past 12 months

We received 1,013 responses to this survey following a four-month fieldwork period from July to November 2024. This includes 776 responses to the adult survey, 67 responses to the children and young person survey, and 170 responses to the carers' survey.

While we managed to reduce its length from the previous iteration, it was still a long survey, taking on average 20 minutes to complete. Considering this, we are impressed by the high proportion of respondents with energy-limiting conditions, for whom this would have been difficult and I'd like to thank each and every person who took the time to complete the survey.

Of the 67 responses to the children and young person survey, only 11 came from children themselves, the remaining responses were from carers on their behalf. This means that we do not have a robust sample to draw from, and so the insights in this report reflect the children's experience mainly through the perspective of their carer.

The decision to include a third survey for carers in this wave of engagement has enabled us to gather rich data on the impact of caring for someone with a neurological condition. The findings from this survey illustrate just how challenging it is to be a carer in Scotland, particularly when you care for someone with a long-term, chronic, unpredictable and, sometimes, life-threatening condition. Many carers are not coping well and the need to provide meaningful support to unpaid carers has never been as critical as it is now.

While there are many areas which require urgent attention, we have seen some improvements in the patient experience. These include more patient confidence in sharing concerns with healthcare professionals, relative happiness with appointment formats and better satisfaction with the clarity of information provided by healthcare professionals. Understanding what is happening to you or a loved one is a critical step towards accepting a difficult diagnosis and being able to look after yourself within the 'new normal', so this is a very positive step forward, and one that we are happy to see.

We recognise that public finances are stretched and that our recommendations require investment. However, this area is too important not to take action. Greater investment across health and social care at both health board and health and social care partnership level is essential, particularly in light of our ageing population which means that incidences of neurological conditions are forecast to rise steadily[1].

Alice Struthers,
Programme Director

Foreword from the Carers' Trust

This important study published by the Neurological Alliance of Scotland gives us invaluable insights into those affected by a neurological condition in Scotland, including friends and family members who provide essential unpaid care. With three in five of us providing unpaid care at some point in our lives, and an estimated 800,000 unpaid carers in Scotland, the findings in this report are of all our interest.

This study makes clear, it is impossible to separate the health and wellbeing of those living with neurological conditions, and those friends and family members who provide unpaid care. We are seeing an increase in both the numbers of people caring and the hours of unpaid care being provided. The report demonstrates the challenges unpaid carers have in relation to home adaptations, hospital discharge and their own mental health and wellbeing. We need to act now to ensure that those living with neurological conditions and those caring are properly supported.

In Scotland, we have strong policy for supporting unpaid carers, and the recent announcement of the inclusion of right to breaks for unpaid carers in The Care Reform (Scotland) Bill should mark a significant milestone for unpaid carers. However, the findings published in this report join a body of evidence that demonstrates that there is a huge gap between the rights of unpaid carers and their daily reality. The recommendations detailed in this report are an important step in upholding the rights of Scotland's unpaid carers.

It is positive to hear of the improvement in the relationship with healthcare professionals. However, it is essential that unpaid carers are also seen by healthcare professionals as equal partners in care, particularly when considering the complexities of living with a neurological condition. Neurological services could play a pivotal role in helping identify unpaid carers and ensuring that they get the support they need by signposting to local carer support services.

Those living with neurological conditions and those caring for them are often invisible, and this report today ensures that their voices and experiences are heard. Thank you to each and every person who responded to the survey, and to the Neurological Alliance of Scotland.

Becky Duff
Scotland Director, Carers’ Trust

Policy Context

The timing of this report comes as the Scottish Government's five-year investment into neurology services through the Neurological Care and Support (Scotland) Framework for Action 2020-2025 ended in March 2025. The £3.185m investment (down from an initial commitment of £4.5m) funded a series of collaborative projects between health boards, third sector and private sector across Scotland. More information about the Neurological Framework can be found here.

Over the five-year funding period, eight out of 14 health boards were given funding to develop projects focusing on neurological care. In addition to projects supporting people affected by any neurological condition, specific focus was given to some of the more prevalent neurological conditions [2] :

- Acquired Brain Injury
- Cerebral Palsy
- Epilepsy
- Functional Neurological Disorder (FND)
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
- Migraine
- Multiple Sclerosis (MS)
- Parkinson's
- Progressive Supranuclear Palsy (PSP)
- Psychogenic Non-Epileptic Seizures
- Spina bifida/ hydrocephalus [3]

Unfortunately, the impact of the Covid-19 pandemic, which occurred in the first full year of the framework, in addition to the complexities of managing and implementing a framework of this scope, means that not all the priorities of the framework have been achieved. Some of this work, for instance, on mapping the neurological workforce and taking steps to track prevalence, continues now even though the framework has officially ended.

The end of the Neurological Framework this year coincides with government plans to move away from single condition strategies towards a much broader, single Long Term Conditions framework from 2026. Details are limited at this early stage of planning, and we will continue to advocate for investment into neurological service provision and the prioritisation of neurological conditions as a policy area.

Lack of support for the provisions in the National Care Service (Scotland) Bill that were designed to deliver systemic change will also have an impact on people affected by neurological conditions, many of whom rely on social and financial support, including access to care at home, day care opportunities, respite and Self-Directed Support budgets. The Bill originally intended to establish a new National Care Service to ensure the delivery of more consistent and equitable access to care and support across Scotland but it has not been possible to achieve the scope of reform set out in the Bill. More work needs to be done to address the inconsistencies and inequalities that exist in the delivery of health and social care. Instead, a more limited range of provisions has been delivered through the Care Reform (Scotland) Bill, including Anne’s Law and the right to breaks for carers. The effective implementation of these provisions will be an important step towards improving the experiences of people living with neurological conditions.

The Population Health Framework, a joint publication between COSLA and the Scottish Government in June 2025, represents a positive step forward. The framework aims to tackle health inequalities by promoting a cultural shift from treating illness to promoting wellbeing and preventing illness. This framework cuts across different policy areas to tackle the wider determinants of health, addressing poor-quality housing, lack of access to safe community spaces and other key social and economic factors.

However, adequate resources need to be made available to support policy plans which rely on early intervention for better population health management. This includes addressing the availability of a robust, skilled workforce and access to innovative technology, without which the challenge of delivering early interventions will be impossible.

While most neurological conditions cannot be prevented, a renewed focus on tackling some of these health inequalities will have a positive impact on everyone in Scotland.

Neurological conditions are now the leading cause of ill health worldwide and the estimated cost to the UK economy is £96bn [4]. It is not a question of patching things up whilst ignoring the bigger picture. The time has come to prioritise investment into building the neurological workforce and increasing service delivery. If not now, then when?

Our recommendations

1. INVEST IN NEUROLOGY SERVICES TO REDUCE DIAGNOSTIC DELAYS AND IMPROVE OUTCOMES

Targeted investment is urgently needed to strengthen neurology services by:
- Expanding the neurology workforce, including consultants, specialist nurses, and allied health professionals.
- Providing more localised care through networked multi-disciplinary teams.
- Increasing capacity for diagnostic tools, including MRI and CT scans, and recruiting more radiologists.
- Financially supporting third sector charities who already deliver specialist clinical services and meaningful social support.

This will lead to:
- **Faster diagnoses**, which reduce the anxiety and mental health distress caused by long waiting times and uncertainty.
- **Earlier access to treatment**, improving disease management and long-term outcomes.
- **Timely and local access to support**, including financial advice, physiotherapy, counselling, and peer support, all essential for building patient resilience.
- **Fewer emergency hospital admissions**, reducing pressure on acute services and delivering cost savings to the NHS.

2. INVEST IN CARE CO-ORDINATORS

Everyone diagnosed with a neurological condition should have access to a named Care Co-ordinator to provide consistent, specialist support. This is particularly necessary for people with co-morbidities and for young people moving into adult services for which no specialist services exist.

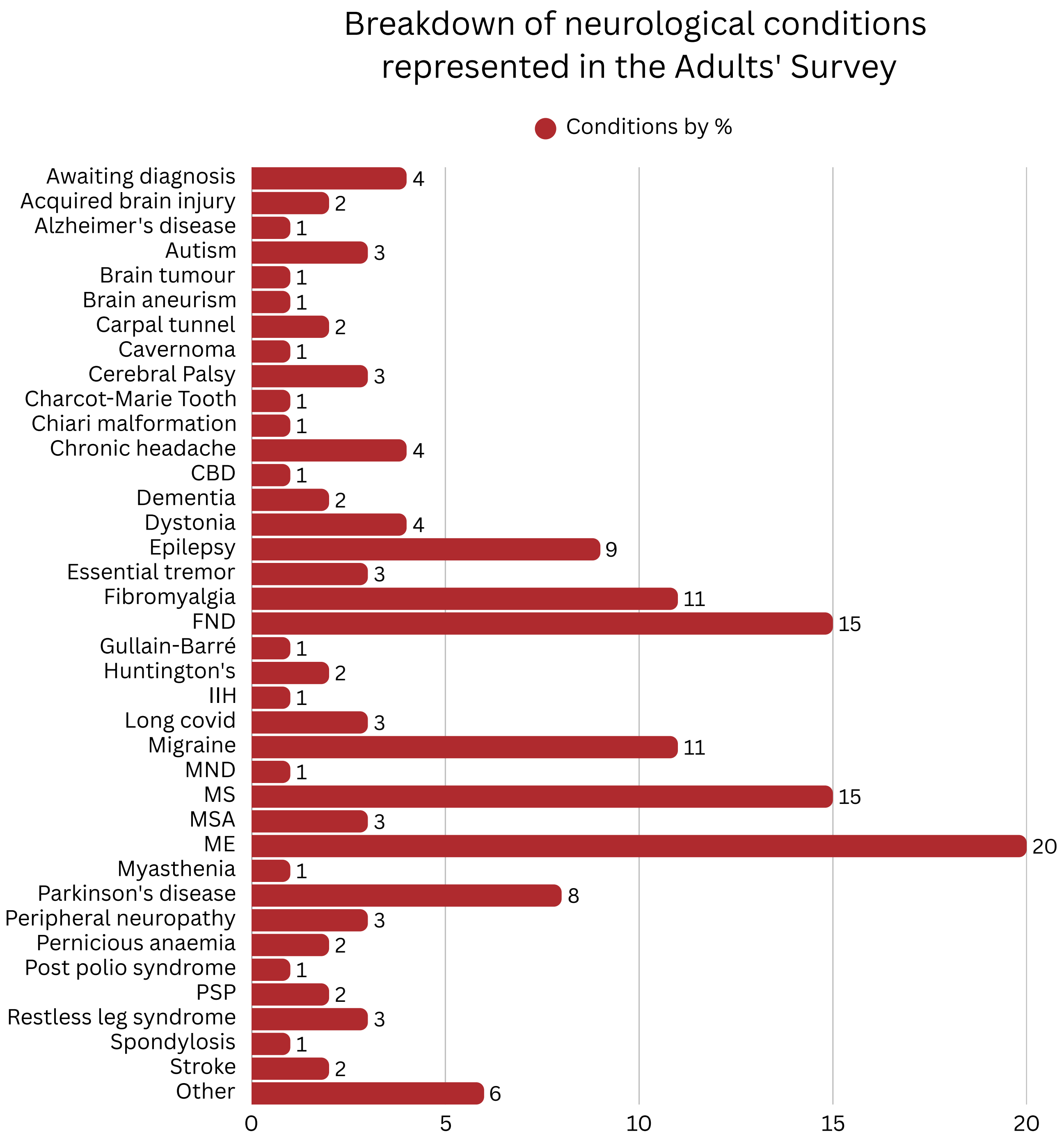
This will deliver:
- **Integrated care planning**, especially crucial at key transition points, such as from paediatric to adult services.
- **A reduction of inequity** of access to support between different conditions.
- **A single point of contact**, improving access to relevant professionals, including mental health support, and reducing stress and confusion for patients and families.
- **Fewer emergency admissions and lower healthcare costs**, by addressing issues before they escalate into crises.

3. STRENGTHEN SOCIAL CARE SUPPORT AND BUILD SYSTEM AWARENESS OF NEUROLOGICAL NEEDS

Improve accessibility to social care by ensuring all staff, particularly social workers, benefits assessors, housing officers, and school staff, are trained in the complexities of neurological conditions.

This will achieve:
- **Stronger carer support**, enabling unpaid carers to maintain their own health, stay in work longer, and reduce dependency on the welfare system.
- **Faster housing adaptations,** essential for safety, independence, and reducing isolation. This is particularly important for families with neuroprogressive conditions or severely disabled children.
- **Improved access to financial support**, including Disability Living Allowance for children, Adult Disability Payment (ADP), and flexible use of self-directed support, strengthening the resilience of both carers and those they care for, and reducing avoidable NHS demand.
- **Better support in mainstream schools** for children with neurological conditions or who are affected by family members living with neurological conditions, leading to greater attendance and educational attainment.

Conditions represented in this report



Children and Young People Data

Conditions reported by children and young people
n=11

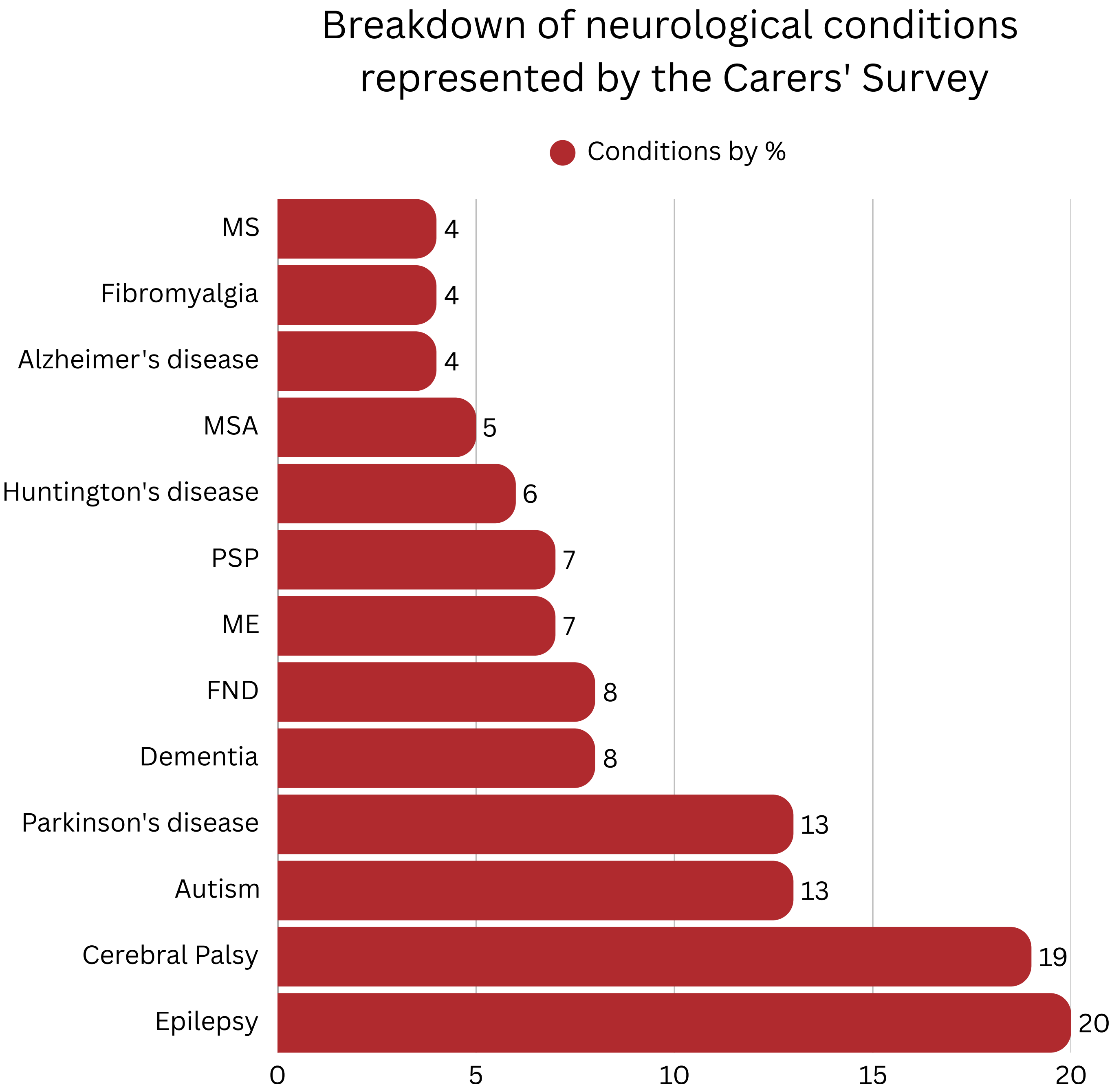
Cerebral Palsy	41%
Tourette’s	27%
Epilepsy	18%
Mentions for*	9%

Conditions reported by carers on behalf of children and young people
n=56

Cerebral Palsy	36%
Epilepsy	32%
Autism	21%
Other	21%

*

- Narcolepsy
- FND
- Migraine
- Head injury
- Carpal tunnel syndrome


Breakdown of neurological conditions represented by the Carers' Survey
● Conditions by %
MS
4
Fibromyalgia
4
Alzheimer's disease
4
MSA
5
Huntington's disease
6
PSP
7
ME
7
FND
8
Dementia
8
Parkinson's disease
13
Autism
13
Cerebral Palsy
19
Epilepsy
20
0
5
10
15
20

Key Insights

The impacts of neurological conditions are wide ranging, from bladder and bowel difficulties to visual impairment, they can cause whole-body difficulties. For more about how neurological conditions impact people, see our leaflet here [5].

1. Two out of three adults say life is difficult to cope with and their condition has an impact on their mental health
2. Four out of five of children with a neurological condition experience frustration and anger
3. Over half of adults feel unsupported by the healthcare system
4. Interactions with healthcare professionals have improved for those with the better understood conditions
5. The economic impact of neurological conditions is substantial
6. Carers are at breaking point with over half unable to access mental health support

Insight 1: Two out of three adults say life is difficult to cope with and their condition has an impact on their mental health

Overview

Two out of three (64%) adult respondents report that they are not coping well with their condition. Many find day-to-day life consistently challenging, with symptoms affecting all areas of their lives, from social and recreational activities to work, study, finances, and maintaining relationships.

With many of our respondents living with conditions like ME/CFS, fibromyalgia, migraine and FND, it is perhaps unsurprising that the biggest areas of impact for our respondent sample include fatigue (87%), movement difficulties (83%) and poor sleep (77%). These challenges directly affect the ability to carry out daily tasks and maintain activity levels. Additionally, cognitive difficulties such as problems with thinking and memory (75%) and mood and mental health issues (68%) were reported by the majority of participants. Chronic pain was also a significant factor, affecting 61% of respondents.

Furthermore, 63% of adults said their condition impacted their ability to work or study 'quite a lot' or 'very much'.

Around 4% of respondents were awaiting diagnosis. People in this position are also likely to report high impact of their condition and low coping.

Duration, complexity and co-mobidities

60% of respondents have lived with their condition for more than five years. Many also live with additional health challenges: 41% reported a physical health co-morbidity, while 38% reported a mental health comorbidity. 27% reported no additional health conditions. The presence of co-morbidities is strongly linked to a reduced ability to cope with daily life.

The complexity of rare and poorly understood neurological conditions adds further strain. Limited knowledge of rare conditions among healthcare professionals, particularly GPs, can result in misdiagnosis, fragmented care, or delayed referrals for further care, treatment or support. Individuals are frequently left to self-manage, research their condition independently, and advocate for their own appropriate care. Many reported lengthy diagnostic journeys, with some waiting more than 20 years and seeing multiple specialists before receiving a diagnosis.

“It’s well known that each rare condition is rare, but the number of rare conditions means that having a rare condition is really common. It’s also well known that most are hugely underdiagnosed. So, there are a lot of zebras out there.”

Escalating Mental Health Challenges

It is perhaps not surprising that the number of respondents who say their neurological condition impacts their mental health has increased from 80% in 2022 to 87% in 2024.

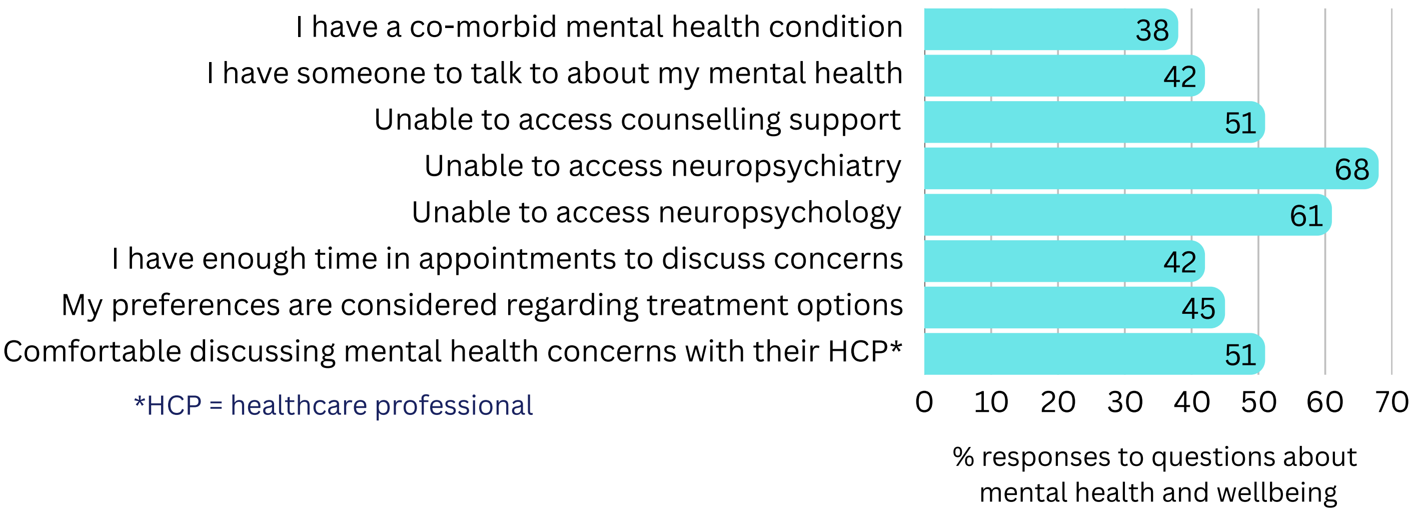
Co-morbid mental health conditions are common for those with a neurological condition. Being diagnosed with what is often a life-long condition is very difficult. Almost 1 in 4 (38%) of participants live with a mental health condition such as anxiety, depression, or OCD. However, only 13% reported that their mental health care meets their needs, and just 10% said they had seen any improvement in mental health support (e.g. counselling, psychiatric care, peer groups) over the past 12 months.

The fragmentation of healthcare services, where mental and physical health are treated separately, creates additional barriers. People often face challenges navigating both systems and are required to advocate for their needs in each, compounding stress and worsening mental health.

“I’m more or less on my own regarding migraine… these last 8 years have been difficult. The severity of migraine has increased and, combined with menopause and caring for my parents, I’ve been very close to breaking point on numerous occasions.”

In 2024, our report on neurological conditions and mental illness [6] outlined six key recommendations for system-wide improvement. Conditions such as epilepsy, Parkinson’s, MS, and Huntington’s, may include psychiatric symptoms such as hallucinations and psychosis. Unfortunately, for many people, these remain undiagnosed and untreated. Notably, people with epilepsy have a suicide rate three times higher than that of the general population.

Questions about mental health and well being



*HCP = healthcare professional

Gaps in Mental Health Support

People affected by neurological conditions need access to condition-specific counselling and mental wellbeing support, rather than general wellbeing advice. Support should be timely, appropriate, and provided in accessible formats. The findings in this report highlight the urgent need for greater investment in Scotland's mental health workforce and specialist neurological mental health services.

"I've never been able to access the necessary hospital or mental health services because of COVID. I was told the two to three year waiting list is now even longer. It could be many years before I see someone. I've found local and online support groups on my own—these are a lifeline."

More than a quarter (27%) of respondents said they do not feel comfortable raising mental health concerns with their doctor or nurse. One in four also reported having no one to talk to about their mental health, underscoring the pressing need for improved access to emotional support.

"With regards to mental health services, I don't know what word to use to describe how bad it has been. I worked with a Community Practice Nurse who often forgot my name and what medication I was on. I had to guide her, which left me with no confidence. I repeatedly asked for a different Community Practice Nurse and was never given one."

Insight 2: Four out of five children with a neurological condition experience frustration and anger

Overview

For most children living with neurological conditions, daily life can be emotional. An overwhelming 82% of carers report that the children in their care regularly experience frustration and anger due to their symptoms. This emotional strain stems largely from difficulties with movement (73%), communication (64%), and thinking and memory (62%), fundamental functions that their siblings and peers can take for granted.

These challenges cause significant barriers to independence and enjoying activities from the carers' perspective, with a significant proportion reporting "very much" or "quite a lot'" of impact on the ability to be active (80%), do fun things (77%) and complete daily tasks (70%).

Responses from the small sample of children who directly answered the survey appear more positive. Only 18% reported that their condition stopped them from doing fun things. This difference may reflect the emotional strain carers have of caring for a child with a complex neurological condition.

"As a parent you really have to push hard. All the fighting is on you. It's really exhausting. It shouldn't be this hard—and this is when your child has been diagnosed at an early age."

Schools and the quest for a 'normal childhood

A strong and repeated theme among parents and carers is the struggle to normalise life, especially within the school system. Too often, mainstream schools lack the training or awareness needed to provide meaningful support. Parents describe the frustration of watching their child be misunderstood or unsupported because teachers are not equipped to manage the realities of a neurological condition.

"All teachers should receive training on the impact epilepsy has on a child and how it affects their learning. Some of my son's teachers are excellent and clearly understand—but others are not interested."

Children and young people can be affected by a wide range of conditions, from common conditions like epilepsy, migraine and cerebral palsy, to less well understood conditions like FND, PANS/PANDAS, and ME. There are an estimated 600 neurological conditions. Each condition is unique, but what these families share is the exhausting effort it takes to navigate systems that are not designed for complexity or chronicity.

Children affected by a family members' illness

Another often overlooked group are children who live alongside a family member who is affected by a neuroprogressive condition. Conditions such as Huntington's (which carries a 50% genetic inheritance risk), Multiple System Atrophy, Motor Neurone Disease, MS and Progressive Supra Nuclear Palsy come with high emotional loads. These children will be witnessing a steady decline in their loved one's condition which will inevitably have a serious impact on their ability to concentrate and learn at school.

The Scottish Huntington's Association has demonstrated how targeted support can make a difference, reporting a 59% increase in school attendance and attainment among supported children [7]. These outcomes underline the urgent need for condition-specific resources in schools and early psychological support for children in these vulnerable families.

Inadequate access to mental health support

Despite the deep emotional impact of neurological conditions, the mental health support available for children is still falling short. Nearly seven in ten carers (69%) said that mental health services are not meeting their child's needs. One in five children cannot access any mental health support at all.

Although 40% of carers noted some improvement in services over the past year, access remains inconsistent and, often, inadequate. Referrals to CAMHS (Child and Adolescent Mental Health Services) reveal a divided experience. Some found CAMHS helpful, while others reported it made their child's condition worse.

"CAMHS made everything worse for her. They didn't seem to understand much about her condition at all."

"We currently have no NHS support other than the GP. CAMHS will not acknowledge the diagnosis of PANS following Long Covid, even when given by a private immunologist."

Children with complex neurological needs require mental health professionals who understand the intersection between neurology and psychology. Generic counselling or mental health advice often misses the mark and, in some cases, causes harm.

Emergency care and the risk of being undiagnosed

Children with neurological conditions are more likely than adults to require emergency care. Nearly a quarter had 1–2 emergency hospital visits in the past year, and 9% had been to the emergency department three to five times. Many of these visits involved children still awaiting a diagnosis, with symptoms not yet fully understood or managed.

"We have accessed emergency care for respiratory illness a lot in the past year, which is impacted by neuro issues."

Each emergency visit can be traumatic, not just for the child but for the entire family, and often signals gaps in preventative care and ongoing support.

Frequency of emergency visits in the past year

Adults		Children	
1 - 2 times	18%	1 - 2 times	24%
3 - 5 times	3%	3 - 5 times	9%
6 - 9 times	1%	6 - 9 times	5%
10+ times	1%	10+ times	5%

Broken transitions to adulthood

The transition from children's to adult services is a well-known issue. Adult services do not exist for some conditions, such as cerebral palsy, and adult services are fragmented into specialisms with no co-ordination of care, leaving an individual to navigate their healthcare on their own for the first time. For an effective transition to succeed, there needs to be a team around the person, not just the child. An example of good practice in England happens for those with MS which has a "ready, steady, go" format to assess an individual's suitability to transition to adult services. Those who are deemed to be less ready for transition are supported for a longer period of time in children's services, giving them more time to prepare for the change of healthcare provision [8].

82% of young people in our survey did not have a named worker [9]. Families describe being left to navigate this transition alone, often losing access to previously available support:

"We found the transition from child to adult services very difficult and were left with little support for our cared-for person for 6 months despite being assessed as needing it."

"Once we reach the age of 18, our wraparound services cease, and we no longer get to see the medical professionals mentioned in this survey apart from our GP, possibly wheelchair services and maybe a social worker or OT."

Those with the best experience of the health care system described having access to teams they felt able to contact with questions; they felt seen and taken seriously. Having access to a single point of contact provides enormous benefits to people living with a condition and their carers, including the ability to make follow up appointments, which nearly half our adult respondents said they were unable to do.

Delays to accessing services, equipment gaps, and the absence of social care

Families reported delays across 33 different services, particularly common when trying to access community support, home adaptations, and day services. Even basic needs such as safe furniture or equipment are unmet.

"My next challenge is lack of equipment as he needs a riser recliner as he isn't managing to get on or off the sofa safely."

These delays are not merely inconvenient, they put children at risk and add to the emotional and physical burden on carers, 45% of whom live with a physical health condition of their own.

"I worry about what will happen if my health deteriorated and I am no longer able to provide the care and support my cared for person needs."

Deep cuts to social care budgets have been having a big impact [10] . Only 7% of carers agreed that their child's care from social services had improved in the past year. 58% disagreed that current social support meets their needs at all. Losing the support of social services once children reach leave school or reach adulthood is a difficult transition for parents and carers too.

"As my child becomes adult the local authority involvement disappears. I have not had contact with social workers since my child left school."

Insight 3: Over half of adults feel unsupported by the health system

Overview

A significant portion of adults with neurological conditions report feeling unsupported by the health system, which is leaving their needs unmet.

In our survey, 53% of respondents confirmed that they do not get enough support, with 46% stating that the health system does not meet their needs.

Contributing factors include limited access to services, prolonged waiting times to get a diagnosis and treatment; restricted eligibility for social support; inadequate access to information; insufficient continuity of care; and insufficient information about their condition to allow for adequate self-management.

Limited access to support services

Individuals with multi-system conditions, such as ME/CFS, fibromyalgia, and FND, often find themselves without a clear pathway to care. These conditions may not fall neatly under specific medical specialties, leading to fragmented or non-existent support.

"This questionnaire assumes that if you have a need that you try to access help. There is no way I would go looking for the majority of my needs as my experience tells me most of the stuff just won't happen. So, I don't bother looking for it."

The lack of standardised guidelines for conditions like ME has exacerbated the issue. However, since May 2025, the latest NICE guideline has become the default clinical guidance for ME, which will hopefully lead to more consistent implementation across Scotland.

"When I was diagnosed with ME, I asked the GP if this was what I had, and he confirmed it in a way that implied I should already know I had it. But no one had ever mentioned it. I was given no support or advice and had to research it myself."

Many neurological and rare conditions still lack defined treatment pathways. As a result, care is often delivered in a fragmented, symptom-by-symptom manner. Patients are left to co-ordinate their own care, often through a process of trial and error and without the benefit of a joined-up or strategic approach.

"Having better access to neurology services, proper pathways for treatment, implementation of rare disease pathways and support would help me feel like I could have some control & decision making in my life. I'm tired of fighting for everything to do with the neurological stuff."

This lack of systemic planning is especially evident for adults with lifelong neurological conditions like cerebral palsy. While services for children with cerebral palsy are established within paediatrics, adult services are largely absent, leaving individuals without specialist care as they transition into adulthood. Many respondents described frustration that general practice often lacks the knowledge or resources to step in and provide adequate support.

"I find it weird that cerebral palsy is one of the most common physical and neurological conditions, but so little care or expertise is held within general practice."

"My GP says there is no suitable specialist service to refer me to and as I am 'managing' there are no suitable support services because they are for people whose condition is worse than mine... After my FND diagnosis it seemed to be assumed I didn't need their input anymore."

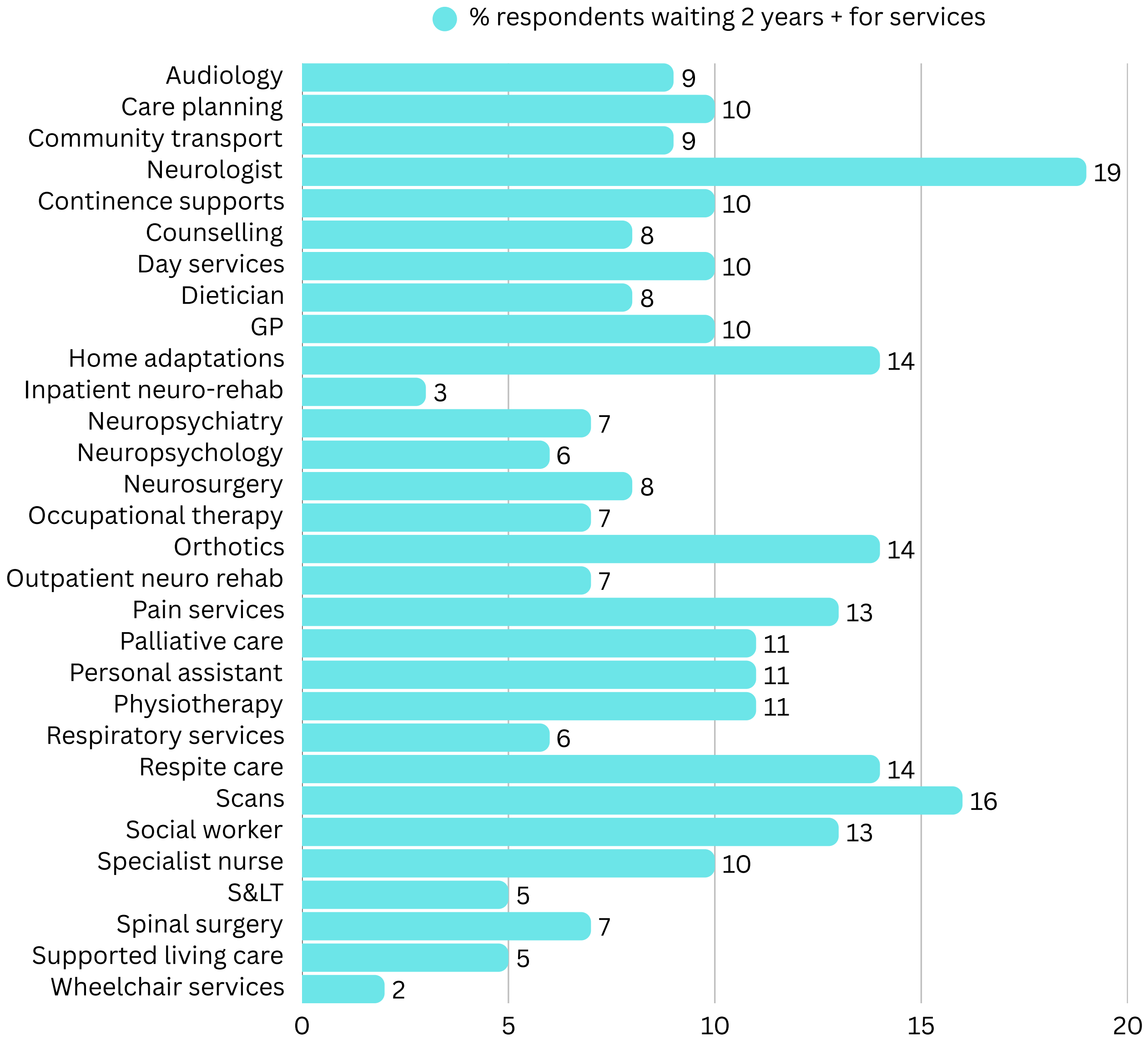
This mismatch between need and provision illustrates a deeper structural issue: people with lifelong or complex neurological conditions are falling through the cracks of a system that was not designed to support them beyond a certain point, or at all.

Delays in diagnosis and treatment

Prolonged waiting times for diagnostic tests and specialist consultations are a significant concern. As of March 2025, 142,747 patients were awaiting key diagnostic tests in Scotland, with only 58.5% seen within the six-week standard [11].

For conditions like Motor Neuron Disease (MND), timely diagnosis is critical. The average life expectancy following an MND diagnosis is just 18 months. Delays in diagnosis can result in missed opportunities for interventions that could improve quality of life [12].

Roughly a sixth of respondents experienced unacceptable two-year plus delays accessing neurologists (19%), scans (16%) orthotics (14%), respite care (14%), home adaptations (14%), social care (13%) and pain services (13%).



"There is not an adequate respite solution in Scotland that has space for my son or his twin. Our local authority provision is wholly inadequate and not fit for purpose."

The escalating delays within the NHS are forcing an increasing number of patients to seek private healthcare, effectively creating a two-tier system that undermines the foundational principles of equitable access to medical services.

"I am lucky to have a family member who kindly pays for me to see a specialist privately, but most do not have this option."

The emergence of a two-tier healthcare system poses significant challenges to the NHS's commitment to providing universal care. As more patients turn to private providers out of necessity, there is a risk of exacerbating health inequalities and undermining public confidence in the NHS.

Restrictive eligibility for social support

Problems accessing social support are an integral part of today's challenge affecting many of our respondents.

"Currently had to challenge social work for a care package for my son who is consistently falling, not brushing teeth, not washing or changing clothes. They said he didn't meet criteria. This should not happen. Absolutely disgusting."

Accessing social support services, such as housing adaptations and respite care, is often hindered by restrictive eligibility criteria. More than a fifth (22%) disagreed that their housing is suitable for their needs. Delays in receiving necessary adaptations can significantly impact daily living and caregiver support.

"My mum lives with me in my one bedroomed flat. She sleeps in my sitting room/kitchen. She can't access the toilet or shower room anymore due to failing mobility, so the toilet is now in my sitting room/kitchen too."

Delayed discharge from hospital due to unworkable care package proposals is another area of concern.

“They fell 10 months ago and have been in hospital since waiting for a community care package. I'm exhausted with the daily arguments, accusations, refusals and efforts they make to reduce the care package to the bare minimum believing they can do most things for themself (which they can't now).”

Over a third of respondents (38%) disagreed that social support meets their needs, and nearly a third (27%) observed no improvement in social support over the past year.

“My accommodation is also highly unsuitable for me, being inaccessible for wheelchair use which leaves me confined mostly to bed. The NHS wheelchair service has told me I won’t even be added to their waiting list for a wheelchair until I can access accessible housing, which is impossible to find here in Glasgow.”

In the absence of meaningful social support, most respondents are having to rely on family and friends (82%). Family and friends help with paying for private healthcare costs, sourcing information about the condition, and local groups for social meet ups, and help with accessing benefits like Adult Disability Payment and exploring routes to access Self-Directed Support.

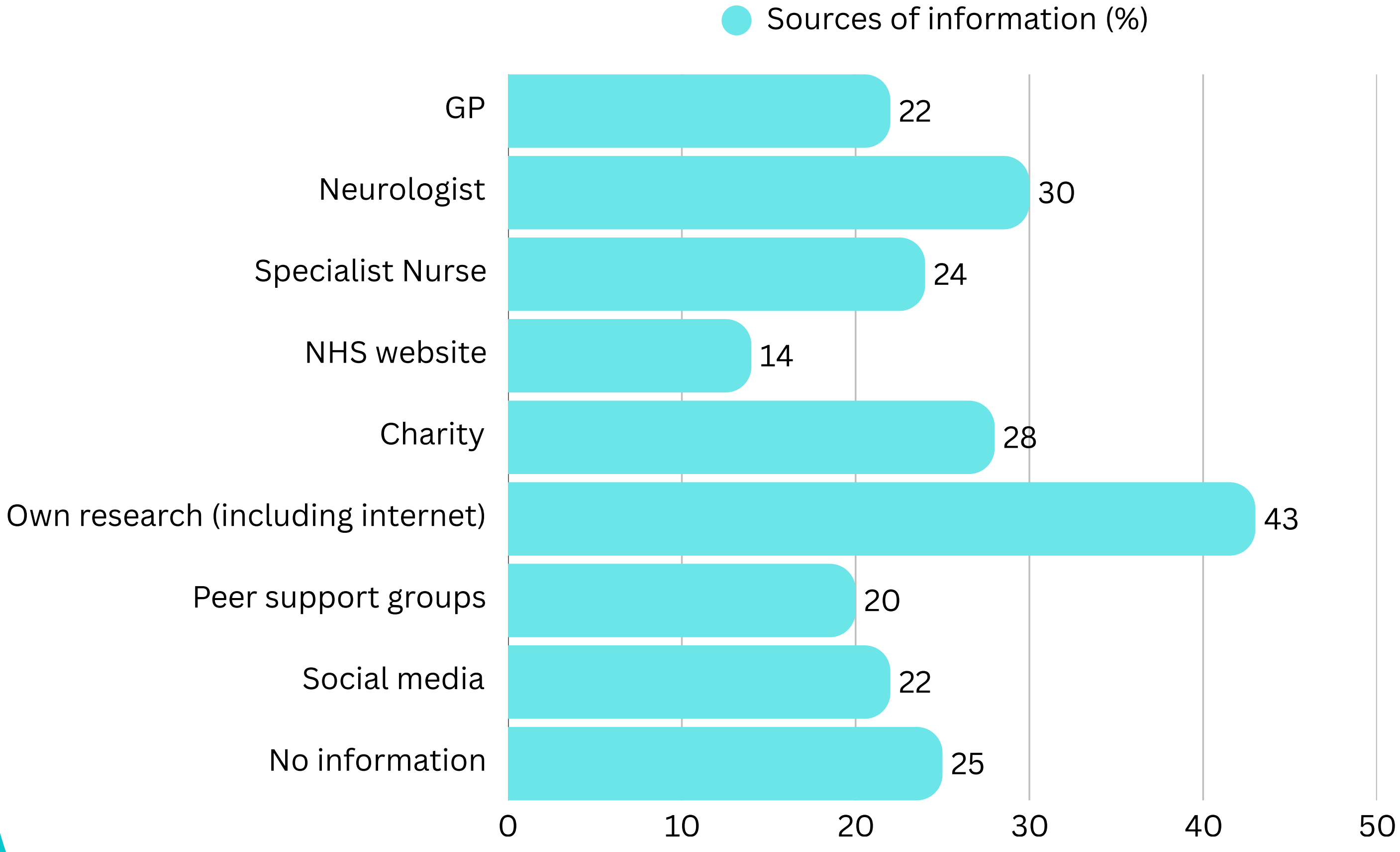
“Health and social care gave me a stool with suction that’s 15cm high for my over bath shower and told me to buy an air fryer.”

Inadequate access to information

Only a quarter of respondents received information about their condition in the previous 12 months, with 28% of respondents getting information from charities and patient organisations. Nearly half (43%) resorted to conducting their own research online. However, digital exclusion remains a barrier; 15% of Scotland's adult population lack foundational digital skills, and 9% of households do not have internet access [13].

“We should not have to rely on the internet to fill in the blanks, some people have no access to computers.”

There's a strong demand for accessible, condition-specific information in various formats from digital, print, as well as audio and visual, covering topics such as medication management, pain management, genetic testing, how to exercise, prognosis, and available support services.



Need for continuity of care

If getting a referral to a neurologist and being seen before symptoms worsen is the initial challenge, being able to access follow-up appointments is the next battle. This was felt across all conditions, but more so for those for whom there are no specialist services.

Continuity in healthcare is crucial for managing neurological conditions. Nearly half of respondents (48%) reported difficulty accessing follow-up appointments. This can be due to not knowing who to contact for a repeat appointment and not being able to schedule appointments without conflicts from other commitments. This lack of continuity can lead to unplanned or emergency hospital admissions; 18% of respondents experienced such admissions in the past year.

"There have been two occasions in the last 12 months, when he had to use A&E. One was an issue with Sodium level, causing him to pass out and the second was an overnight stay due to a blocked bowel. Both could have been diagnosed by a GP if there were regular health checks carried out, which used to happen under Paediatric care."

Effective co-ordination between healthcare providers is essential, especially for patients with multiple conditions.

"To receive tests, we have had to use private services. We do not have an NHS paediatrician to co-ordinate care"

"There is no joint care either, my conditions overlap several systems, yet I can only see one doctor at a time, and none of them are speaking to each other to create a care plan."

Insight 4: Interactions with Healthcare Professionals have improved for those with better understood conditions

Overview

There has been a notable improvement in people's experiences with their healthcare professionals since our 2022 report. Receiving a diagnosis is often life-changing, and accurate information about the condition is vital to ensure the individual is a partner in their own care and support.

In our previous report, one-third of adults told us they left consultations with no information about their condition. This time 58% of respondents now agree that healthcare professionals explain medical information clearly and in a way they understand. This marks a significant shift towards more person-centred communication.

Better relationships with healthcare professionals...for some

Relationships with healthcare professionals are also moving in the right direction, with the majority of respondents stating that they are comfortable talking to their healthcare professionals (51%) and are also happy with their appointment format (57%) whether in person, on the phone, or online.

The main challenge is getting follow up appointments easily and when needed (28%). Delays here often mean delayed diagnoses, worsening symptoms which may lead to emergency hospital visits, or unmanaged pain, all of which can have a lasting impact on quality of life.

Access to healthcare

Some of the starkest gaps appear when the appointment format is not appropriate. For those who are digitally excluded, or those who are bedbound and cannot get home visits, this can mean entire areas of healthcare become inaccessible, including routine tests like smear tests or blood tests.

Noise sensitivity is another hidden barrier. Several respondents mentioned that telephone appointments were distressing or simply impossible due to sensory sensitivities, especially common among people with conditions like ME, POTS, or migraine, and yet home visits were not always available to them.

"She needs GP home visits, but these are generally denied. Phone calls taken by the carer are the only other option. She is unable to speak on the phone due to noise sensitivities."

The value of specialist nurses

For conditions which have specialist nurse support, people find this support invaluable, particularly in having a point of contact to ask questions in between appointments. For those for whom access to a specialist nurse is relevant, around half of adults were able to access one and said this met their needs (53%). Only 12% who had access to a specialist nurse said it did not meet their needs. However, a third of adults for whom it would be relevant, said they have been unable to access specialist nurse services (31%).

Our survey shows 10% of respondents have been waiting more than two years to see a specialist nurse.

"Neurologist and specialist nurse service cannot be faulted. The issues lie with other services such as podiatry and neuro physiotherapy which cannot be accessed due to a lack of resources."

"My main lifeline of support is my MSA nurse. I always know no matter what question I can reach out to her."

"The service from the multidisciplinary team is excellent, but could be enhanced by offering access to a specialist nurse for support."

Appointment difficulties

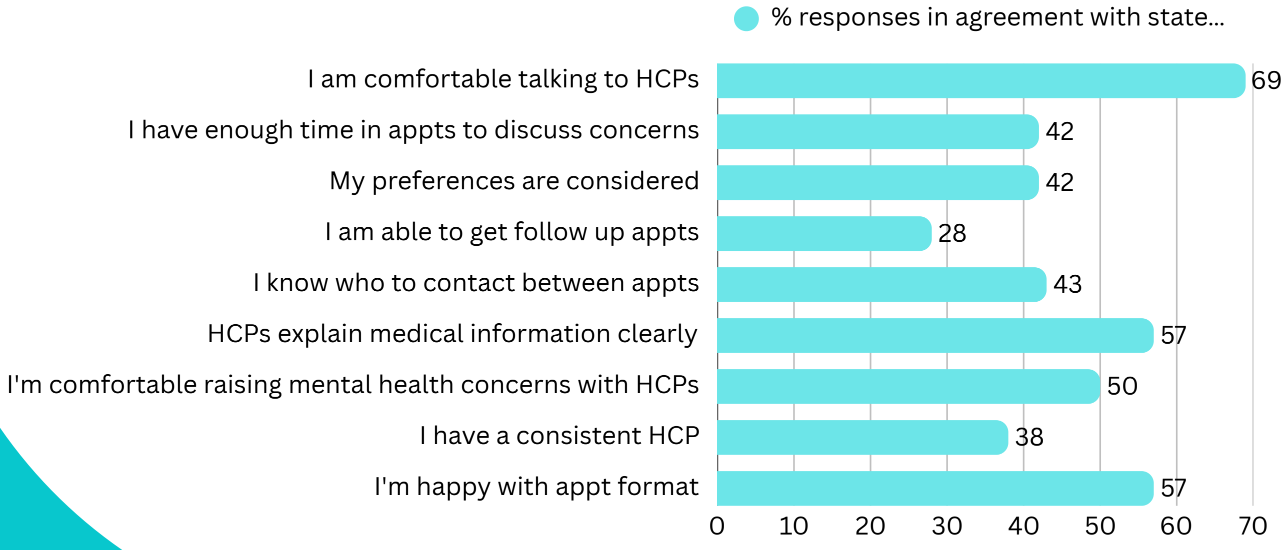
When it comes to feeling seen and heard, 42% of adult respondents said they have enough time in appointments to discuss their concerns, while 45% said they do not.

Unfortunately, we are still seeing that for conditions for which there are no treatments or pathways, or NHS support, there is still an element of not being believed. Or, as multiple respondents said, "gas-lighting" from medical professionals.

"I am articulate and perfectly able to talk and ask questions in a medical appointment. However, owing to the repeated medical gaslighting that I have experienced, I do not feel comfortable talking to medical professionals. This is because I feel unsafe around medical professionals who have repeatedly questioned my lived experience, doubted me, given me false information, and who have taken no action to educate themselves around my conditions."

Abrupt or rude interchanges between healthcare professionals and individuals with neurological conditions are also likely to occur where professionals have substantial and difficult to manage patient case-loads; where they may be having to prioritise calls for the most urgent cases leaving little time for everyone else; or where they do not have a good understanding of the condition.

"I haven't received any support at all. I had one phone call from an epilepsy nurse that lasted 30 seconds. All she asked — in a very rude manner — was 'Are you taking your medication?' When I replied yes, she hung up. I haven't heard from anyone since."



Insight 5: The economic impact of neurological conditions is substantial

Overview

Neurological conditions affect approximately one in six people in the UK and are a significant economic burden, estimated at £96 billion annually, equivalent to 4.3% of the UK's GDP[14].

Disrupted employment and financial strain

Despite nearly half of respondents holding degree-level or postgraduate qualifications, 49% reported a household income below £34,999. Consequently, nearly a third of respondents (29%) say they are not 'at all' managing financially. In our survey, 58% of respondents receive financial support in the form of welfare benefits but 17% said they didn't know how to access financial support.

Managing to remain in employment with a neurological condition can be challenging and the greatest successes are where employers have provided specific support to allow individuals to continue in their role. The fluctuating nature of conditions like epilepsy, migraine and MS can lead to unpredictable absences from work, and those who experience a worsening of symptoms over time have greater requirements for flexibility and support. Unfortunately, 53% of respondents have had to leave employment because of their condition.

"My situation is complex as I had a fall relating to my condition, and the resulting injuries have caused great difficulty in treatment. This led to lengthy absences from work, and a great deal of anxiety and depression over my situation."

Notably, 33% experienced workplace discrimination, and 21% left employment due to employer actions or inaction. Conversely, 29% remained employed with specific support from their employers.

"It also makes it really difficult to find and stay in work because your employer doesn't know how they can help you. Eventually they give up and let you go when there could be an easy fix."

Insight 6: Carers are at breaking point with over half unable to access mental health support

Overview

Unpaid carers are the backbone of our health and social care system, saving the Scottish economy an estimated £15.9bn through the care they provide [15]. Yet, while provisions to support for carers are completely inadequate, the reliance on unpaid carers is growing, with a fifth of carers in our survey looking after more than one person, and over half of carers (57%) providing more than 50 hours of unpaid care every week, more than a full-time job. This leads to significant levels of responsibility and exhaustion, impacting on all areas of life.

“I can't work because of my care responsibilities. I feel incredibly restricted and trapped.”

Growing emotional cost to carers

We have been struck by the emotional cost of caring, and the fact that whilst the majority of carers feel able to meet the day to day and health needs of the person they care for, very few feel ‘confident and capable’ in their own lives (15%). A third of carers said they are unable to manage their own health and wellbeing (34%). Over half (55%) have not been able to access mental health support for themselves over the past 12 months.

“We live with the fear that today might be the day/night that we lose her, every day and night. I would really like to have access to therapy as I think this would really help my mental health and wellbeing. It is so expensive to access privately.”

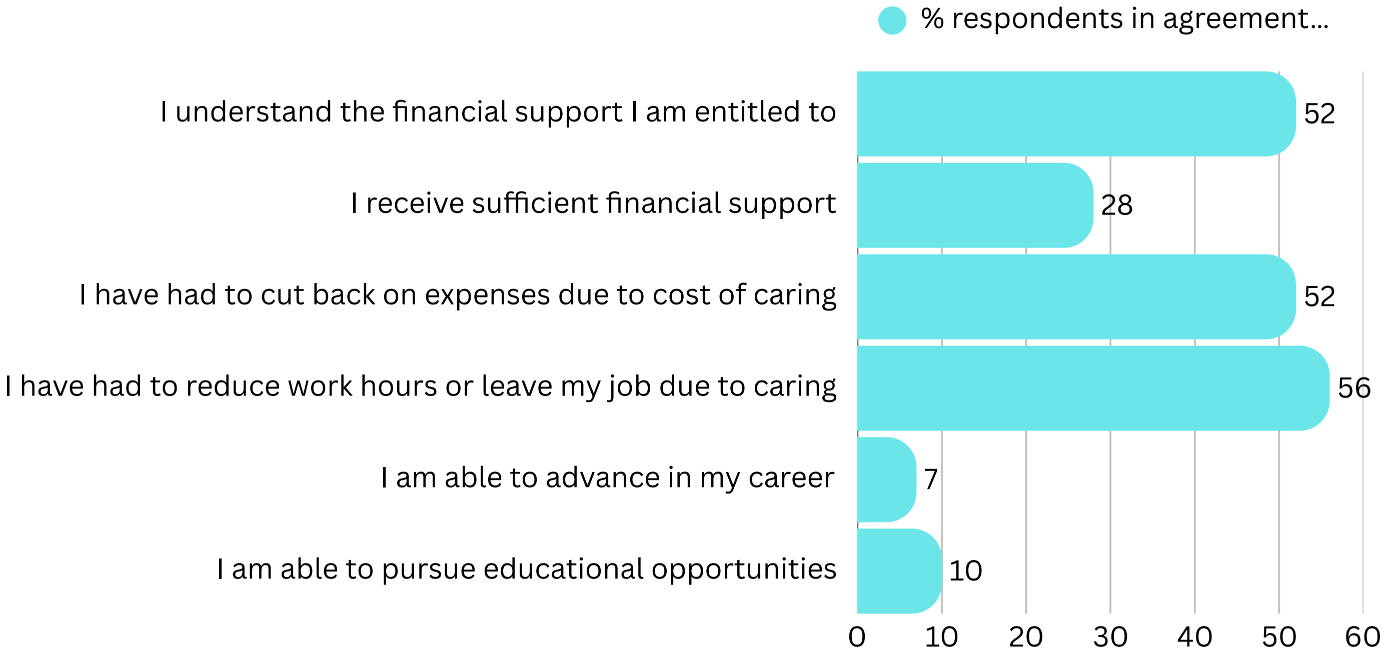
Caring causes a substantial financial burden

The financial burden on carers is substantial. Many are forced to reduce working hours or leave employment entirely (56%), leading to decreased household incomes. More than half (52%) have had to cut back on expenses to support the cost of caring.

"Our local council has been very unhelpful in financially supporting adaptations to our house for our daughter, they actively delayed and caused obstruction to starting building work, did not know or actively denied legal requirements to build and also has not filled [their] obligation to find alternative funding sources."

Furthermore, the cost of necessary adaptations and equipment is frequently borne by carers themselves, exacerbating financial pressures. One carer shared:

"Our youngest of three children has Quad Cerebral Palsy, autism and a severe learning disability. We have no access to a bathroom for him. We can't afford to adapt [our house] ourselves. Local council can't help as adaptation costs too much. I have to carry him at age 13 and over 50kg into the house."



Over a third of respondents had been caring for more than 10 years and 44% of carers were looking after people who are completely reliant on them, requiring assistance with most, if not all, daily activities. Two thirds (66%) were fully involved in all decision making for the person they care for, which causes significant mental load and highlights the pressures they are under.

However, the biggest barrier to caring, reported by 42% of our respondents, is the lack of access to a healthcare professional who understands and can advise on the condition of the person being cared for.

"Local health care and social work services are stretched to breaking point and are unable to provide any meaningful support that would impact positively on any of the three family members I support."

Carers are compromising their own health

Over half of carers (53%) live with a long-term health condition of their own, such as arthritis or heart disease, which can impede their ability to provide care. Despite this, they often lack access to appropriate support services.

"Social work advised they wouldn't get involved unless I couldn't cope any longer."

Carers are overwhelmed and in desperate need of a break. More needs to be done across all areas to improve life for carers. A quarter of carers said they don't understand the financial support available to them but many illustrate the challenges with not having enough time to research eligibility criteria. A lack of time and the substantial mental burden of caring is a big obstacle for carers being able to access support.

"We have had a respite break from our local carers association, but my child needed to come too, as they can't stay with anyone else. While it was good to get away for a couple of days, it was not really respite. I am exhausted."

Appendix A

ABOUT THE SURVEYS

This Scotland report is part of a bigger UK and Ireland project, of which all four UK national neurological alliances and the Neurological Alliance of Ireland participated. The surveys gather data on understanding the lives of adults, children and carers with neurological conditions, with deeper dives into mental health and wellbeing, involvement in decision-making, financial support, children's transition to adult care, and access and confidence to participate in research.

The surveys were open to the public from July to November 2024, and people could participate either through an online link, or completing a paper copy available in certain clinics. Clinic involvement in the survey was done on an opt-in basis, and we recognise that the response rate from clinics was low. The majority of our responses came through online links shared by our member charities, and the member charities of the other national neurological alliances.

Collectively, we have data from 38 named conditions, with 6% of the sample choosing 'other' if their condition was not named in the drop-down menu.

There is greater representation from people with multi-system conditions like ME/CFS, Functional Neurological Disorder and Fibromyalgia, as well as multiple sclerosis and migraine. This is a doubling of the proportions of people with ME/CFS from the previous iteration of our research, no doubt one of the impacts of the Covid-19 pandemic. It is important to bear this in mind as the impact of living with a difficult to diagnose and fatigue-causing condition comes across in the results.

The gaps in condition data can be explained in part by:

- Low clinic involvement in Scotland
- Lack of awareness of the survey among the general public
- Difficulties reaching and engaging with children and young people

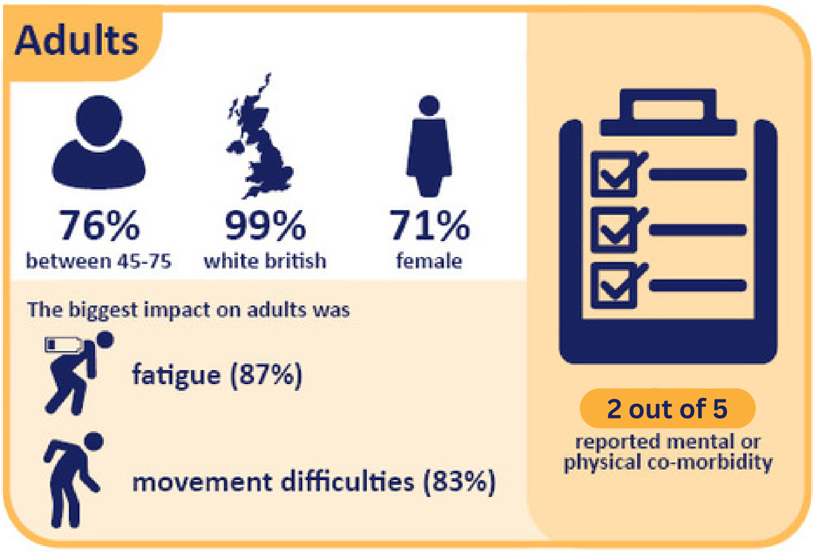
The range of conditions we captured in 2024 is similar to the condition samples we had in the last iteration of our survey in 2022.

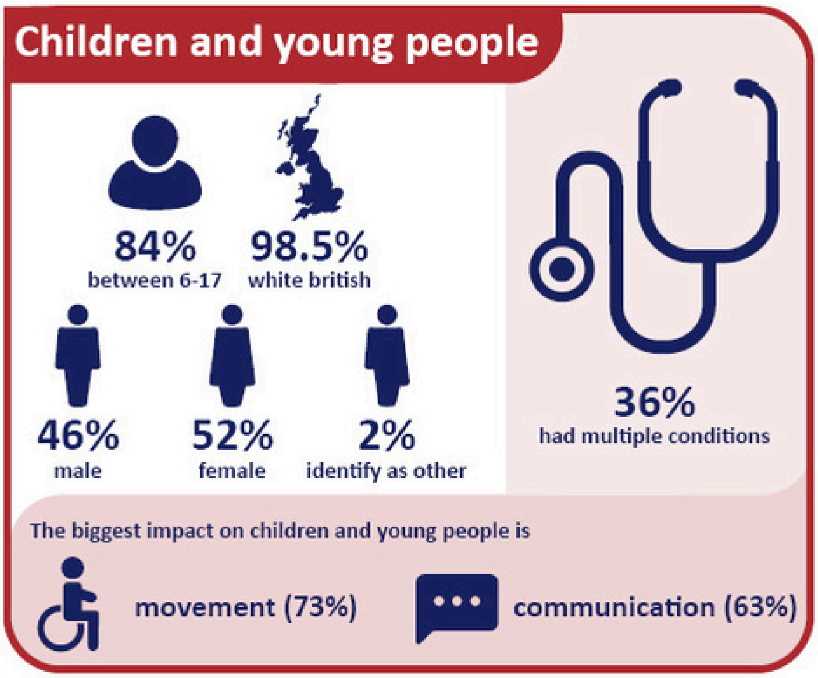
This report builds on the data from the first wave of research in Scotland in 2022, highlighting areas that remain a concern and areas where there have been improvements to people's experience of neurology services.

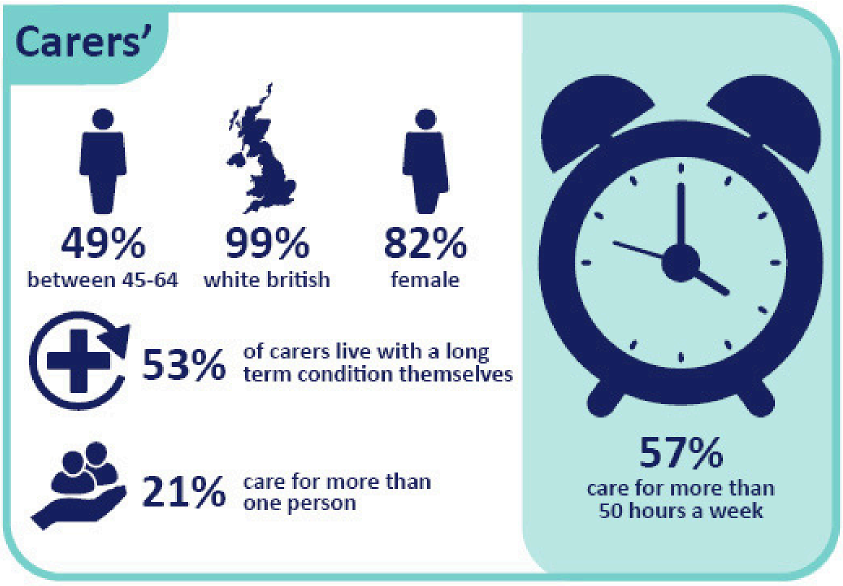
The three surveys can be seen here:
Survey for adults with a neurological condition
Survey for children and young people with a neurological condition
Survey for carers with a neurological condition

Appendix B

DEMOGRAPHICS OF RESPONDENTS







Notes

We note the difficulty in reaching some communities, for instance, BAME, LGBT+, gypsy travellers, and asylum seekers.

Our thanks to Lauren Hay at Alzheimer Scotland for the creation of these demographic infographics.

Appendix C

REPRESENTATION FROM HEALTH BOARDS

We received responses from all 14 health boards in Scotland, although with only a limited number from island boards, NHS Orkney and NHS Shetland.

Health Board	Adult responses	Child responses		Carer responses
		CYP	Carer OBO	
NHS Ayrshire & Arran	47	1	2	10
NHS Borders	22	0	1	2
NHS Dumfries & Galloway	32	0	0	7
NHS Fife	54	2	6	10
NHS Forth Valley	48	0	4	15
NHS Grampian	78	3	9	19
NHS Greater Glasgow and	125	1	8	29
NHS Highland	73	1	2	6
NHS Lanarkshire	66	2	7	22
NHS Lothian	115	1	4	24
NHS Orkney	3	0	1	1
NHS Shetland	4	0	0	0
NHS Tayside	66	0	10	18
NHS Western Isles	43	0	2	7

Appendix D

ABOUT THE NEUROLOGICAL ALLIANCE OF SCOTLAND

The Neurological Alliance of Scotland is a diverse coalition of nearly 60 charities of all sizes that support an estimated one million children, adults and older people with neurological conditions, and those who are closest to them. Our aim is to inform and connect the neurological community and influence systemic, sustainable change for those living with neurological conditions in Scotland.

It is estimated that 1 in 6 people in the UK live with a neurological condition, which has a huge impact not only on them, but also on their carers. Neurological conditions, which can be life-long, unpredictable, degenerative, complex and painful, often bring significant physical, emotional and mental health challenges as well as financial burdens and a need for specialised care.

Accessing the right treatment, care, and support is essential to improving the quality of life for individuals with neurological conditions and enabling them to manage their conditions effectively. However, many face substantial barriers, such as delays in diagnosis, a lack of sufficient care, and inadequate emotional and mental health support.

In partnership with our members we inform policy, raise awareness and support improvements in services. We aim to make sure that the experiences of people with neurological conditions - and those around them - are recognised.

We do this by raising these issues directly with the Scottish Government, NHS bodies and other groups; and by contributing to publications and consultations, sharing information between members, and working with other bodies on common issues.

Appendix E

OUR MEMBERS

ACTION FOR M.E.

Alzheimer Scotland
Action on Dementia

ATAXIA

Brain & Spine Foundation

brainstrust
the brain cancer people

BritishPolio Fellowship

cerebral palsy scotland

Child Brain Injury Trust
hope for tomorrow – today

CMTUK

Compass

The Scottish Centre for Children with Motor Impairments
Craighalbert Centre
Enabling Children to Achieve

Dystonia UK

EDINBURGH HEADWAY GROUP

epilepsy connections

epilepsy scotland

FASD hub Scotland

FND HOPE
FUNCTIONAL NEUROLOGICAL DISORDER

Funding Neuro
Pioneering Treatments
Accelerating Cures
Saving Lives

Headway
the brain injury association

Headway
the brain injury association
Headway Dundee & Angus
Supporting people with Acquired Brain Injuries

Headway Glasgow
25 YEARS CELEBRATION
2000-2025

Inflammatory Neuropathies UK

Leuchie
THE NATIONAL RESPITE CHARITY
Reimagining Respite

LONG COVID Scotland

#ME ACTION SCOTLAND

THE ME ASSOCIATION
me

MND Scotland
Making time count

MS Society | Scotland

MS Therapy Tayside

MS CENTRE - MID ARGYLL

Multiple Sclerosis Trust MS

Multiple System Atrophy Trust

neuro therapy network

MUSCULAR DYSTROPHY UK OUR MUSCLES MATTER

myaware Fighting Myasthenia Together

Narcolepsy UK

NERVE TUMOURS UK

Neuro Central

Neuro Hebrides
Supporting people living with neurological conditions

Trembling Aspen
Orthostatic Tremor UK Support Group
Together we can make a difference

PANS PANDAS UK

Parkinson's UK Scotland
For every Parkinson's journey

PSP/
CREATING A BETTER FUTURE FOR PEOPLE LIVING WITH PSP & CBD

revive MS

Scottish Huntington's Association
Specialist support for Huntington's disease families

SCOTTISH HEAD INJURY FORUM

SPPN
Scottish Post Polio Network

the scottish tremor society

Spina Bifida Hydrocephalus Scotland

THE BRAIN TUMOUR CHARITY

the B12 society

the migraine trust

THE 25% ME GROUP
SUPPORTING THOSE WITH SEVERE M.E

TOURETTE SCOTLAND
SUPPORTING WHAT MAKES US TIC

QUARRIERS

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