



**December – January 2025 Full Insights Report**  
**Experiences of transport to health or care appointments for people  
affected by neurological conditions**

Brain & Spine  
Foundation

THE  
NEUROLOGICAL  
ALLIANCE

COMMUNITY  
FUND

## **About NeuroLifeNow**

NeuroLifeNow was launched in January 2021, enabling people to meaningfully share their daily realities of living with a neurological condition(s) to inform positive change to policy and services.

NeuroLifeNow aims to capture real-time evidence, at scale, from people across the UK. Working directly with people affected by neurological conditions through an innovative web-based technology has been developed and continues to evolve, along with ways for people that do not have access to digital technology to share their daily realities.

Through NeuroLifeNow people share how neurological condition(s) have impacted every aspect of their life. From accessing treatment, care, and support, to home life, work and finances. People do so with confidence that what they share is treated sensitively and handled securely.

## Foreword

Accessing healthcare should be straightforward. Yet for too many people living with neurological conditions across the UK, travelling to an appointment is a major challenge.

These findings from NeuroLifeNow show just how widespread the issue is. Nearly three-quarters — **71%** — of respondents said travelling to appointments for their neurological care is difficult. **39%** told us the journey is “very time-consuming,” and **14%** said the cost of travel alone makes it unaffordable. These barriers aren’t just inconvenient — they make it harder for people to get the timely care they need.

People shared their experiences in their own words.

**"I have to travel 60 miles to see my neurosurgeon — I can't manage the journey there and back in one day, so I need to stay overnight. It's exhausting and painful."**

**"A single trip to hospital costs me about £100 — taxis, ferry, hotel — just to attend one appointment."**

When facing journeys like these, missing care isn’t a rare event — **10%** of people told us they had missed appointments because they simply couldn’t afford to get there.

The problem is clear: transport systems, patient transport services, stressful financial support systems and healthcare delivery models are not keeping pace with the needs of people living with neurological conditions. Public transport isn’t reliably accessible. Patient transport services are often oversubscribed. And too much specialist care is centralised in hospitals far from where people live.

**"If I can't afford the trip, I don't get to see my specialist."**

**"I have to prioritise my spending to afford travel to appointments — even cutting back on heating."**

These are the kinds of decisions nobody should have to make.

There are practical solutions. We are calling on governments across the UK to ensure that transport to healthcare is **reliable**, **affordable** and **accessible** for people with neurological conditions. Care should be delivered closer to home wherever possible, reducing the need for long, exhausting journeys. Smart use of technology — including video consultations — can help cut down unnecessary travel. And financial support systems must recognise and respond to the real costs people face when accessing healthcare.

This is about **fairness** and about **designing a health and care system that puts people's needs first** — not one that creates avoidable barriers.

The people who shared their experiences for this report have made it clear: transport and care systems need to change. Their voices are powerful. Now, it's time for action.

We will continue to work together — and with people living with neurological conditions across the UK — to push for the changes that are so urgently needed.

If you need support, the Brain & Spine Foundation neuroscience nurses are here for you, providing practical and emotional support relating to any neurological condition(s). You can get in touch for free by calling our specialist nurse run helpline on 0808 808 1000 (Mon-Fri, 9am – 4pm) or email [helpline@brainandspine.org.uk](mailto:helpline@brainandspine.org.uk).

Thank you,

Ranulph Tees, The Brain and Spine Foundation (i-Neuro)

Georgina Carr, The Neurological Alliance (England)

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## Key Findings

**356 responses** were received in December 2024 to January 2025.

**46%** of people reported **living with more than one condition**.

We asked respondents to list the neurological condition they were primarily diagnosed with. **Multiple Sclerosis & Dystonia** were listed most often.

**44%** of the respondents were diagnosed of their **primary neurological condition more than 10 years ago**.

**49%** of people find it **somewhat difficult to travel** for their health or care appointments for neurological conditions. Those affected with **Fibromyalgia & Brain or Spine Tumours** were likely to respond this.

**22%** said it was **very difficult to travel** for their health or care appointments, and most respondents were those affected with **Migraines**.

**39%** of respondents find it **very time consuming to travel** to care appointment. Those affected with **Chiari Malformation & Fibromyalgia** were likely to respond this.

**86%** said the **cost of travel didn't stop them from attending** their health or care appointments.

**51%** said travels to their appointments were **affordable** against **36%** respondents who described those travels to be **sometimes expensive**.

## Qualitative Analyses

## Word cloud



Figure 1: word chart representing the relative frequencies of the 50 most used words in the 292 responses received to this question

## The different types of difficulties faced when travelling

Key themes that emerged from responses to this question include reliance on others for transportation, the exhausting nature of long-distance travel for specialist care, financial burdens, and accessibility issues. Emotional stress, symptomatic exacerbation during travel, and frustration with public and patient transport services further compound these challenges.

A minority of those who responded experience no travel hassles, underscoring varied experiences, which corresponds to one of our quantitative results below, where 71% of respondents found travel either somewhat (49%) or very (22%) difficult.

Additionally, parking challenges, impact of driving restrictions, and complications in travel logistics negatively affect patients' access to necessary healthcare, at times leading to appointment cancellations or a total avoidance of services.

## **Support from others**

People frequently need support from family and friends for transport due to restrictions on personal driving and public transport usage. This underscores the lack of autonomy and the essential role of personal networks.

“I can’t drive anymore due to seizures and can’t also be alone so I need someone available to take and support me.”

## **Travel Exhaustion and Specialist Care Accessibility**

The arduous nature of long-distance travel for access to specialist neurological care is a recurrent theme. The physical exhaustion associated with such travel reported to exacerbate people’s neurological symptoms, presenting an additional obstacle in their healthcare journey.

“I have to travel 60 miles to see my neurosurgeon... If I am going for tests, such as MRI, I also need to stay in a hotel overnight as I cannot tolerate travelling both ways and have the scan all in one day. (Too fatiguing and painful)”

## **Financial Implications of Travel**

Travel and accommodation costs represent a significant financial burden too. For some, these expenses are a deterrent to seeking timely and appropriate healthcare services.

“I live on the Isle of Wight with no neurology department. I have to travel to Southampton, which includes: a taxi to the ferry port, a ferry, another taxi to the hospital and in some cases an overnight stay in a hotel and then the journey in reverse. The Isle of Wight ferries are very unreliable and expensive and you can never guarantee that they will be operational. It is a very long and painful day and totally exhausting. The average cost of this trip is about £100.00. I face also travel issues when trying to see a G.P., again needing a taxi both ways which costs at least £20.00 per return trip and a lot of waiting around with nowhere to rest.”

## **Accessibility and Parking Issues**

Responses highlighted concerns over accessibility, from parking space shortages, particularly for blue badge holders, to difficulties navigating building access, such as encountering stairs. These barriers pose extra challenges for those already coping with mobility limitations.

“Very few disabled spaces and I have difficulty walking.”

## **Emotional Stress and Transport Services**

The substantial emotional stress involved in managing travel was clear, from the anxiety related to symptom management during the journey to the distress caused by unreliable transport services. Dissatisfaction with the quality and affordability of patient transport services was voiced, signalling a gap in the provision of appropriate support.

“I use patient transport and I know how busy they are but having to wait for my home journey makes me tired and stressed.”

## **The different challenges in the cost of travelling**

Key challenges raised include the cost of petrol, parking, and public transport, as well as the loss of income and the need to take unpaid leave. There is a recurrent theme of people having to make difficult financial trade-offs to accommodate travel costs, impacting their quality of life and mental health. Additionally, accessibility challenges and logistical issues exacerbate the financial stress experienced.

### **Financial Constraints**

Many people express that travel costs for care substantially strain their finances. They cite expensive petrol, parking fees, and public transport costs as significant burdens. The need to regularly set aside money specifically for travel inhibits their ability to manage other living expenses. People who self-report as low or limited income find these costs particularly prohibitive, with several respondents highlighting that the financial pressure has forced them to forego essentials or other expenditures.

"If my appointment is on a day when my husband is working, he has to book a holiday day so he can take me. The petrol to my appointments is quite expensive & the parking at hospital is very dear."

### **Employment and Income Loss**

Travel for appointments not only incurs direct costs but also often leads to income loss. Respondents report having to take annual leave or unpaid time off work to attend appointments. This loss of earnings compounds the financial distress, especially when coupled with the inability to work due to their condition.

"Husband who is self employed has to take time off work losing money to enable me to get there for what maybe a 15 minute appt."

### **Accessibility and Logistics**

Accessibility challenges are a recurring issue, with many people unable to drive and reliant on others for transport. Difficulties in using public transport due to fatigue, cognition, and mobility issues are apparent, with some people using taxis as the only means of appropriate and accessible transport. For those requiring

hospital transport, stringent eligibility criteria and unreliability of patient transport are barriers, often leading to logistical complexities and additional expenses.

"I have never been able to drive due to health condition. If I can't get a lift from my partner or a friend. I tend to rely on taxis. This is because public transport is generally more problematic for me to use (impacts MS fatigue, cognition & mobility issues) when alone."

### **Lifestyle Trade-offs**

People frequently mention having to make difficult trade-offs, such as sacrificing food, heating, and other medical needs to afford travel for care. For pensioners and those living with terminal conditions, the stress of managing these trade-offs is even more pronounced. The essential nature of these appointments means people are forced to prioritise medical travel over other aspects of their lives.

"I have to prioritise my spending to ensure I can afford to travel. This has included cutting back on heating."

### **Mental Health Impact**

The stress associated with managing transport logistics and finances takes a toll on mental health. Anxiety and worry frequently accompany planning for care-related travel, with some people mentioning the "dehumanising" effect of being unable to afford proper help and the emotional burden of feeling like a 'costly burden.'

"I worry that if I am admitted, the cost of visiting will mean I don't get to see my family every day. Generates anxiety, uncertainty."

### **Potential for Rationalisation and Efficiency**

Suggestions indicate a need for the healthcare system to provide more localised services. Many express the desire for consultant-led services closer to home to reduce the need for lengthy and costly travel. Integrated, location-conscious scheduling could alleviate both direct and indirect costs faced by people affected by neurological conditions.

"If only even once a fortnight they had an outpatient consultant led pain clinic and fortnightly neuro team here it really would help, instead of countless people traveling an hour and back to see any of those."

### **Financial Support and Social Care**

Several responses note the inadequacy of current financial support systems, such as Personal Independence Payments (PIP) and Universal Credit and Employment and Support Allowance (ESA), in addressing the rising costs of travel. Additionally, cuts to social care funding deepen the financial strain, as some people must bear the expense of hiring personal assistance without adequate subsidisation.

"PIP is meant to help with these expenses but has not increased in line with travel costs."

### **Policy Implications**

There is an underlying call for policy changes that address these challenges. Better funding for travel expenses, revision of hospital transport policies, and greater, more appropriate financial support for carers are among the solutions people imply could significantly mitigate their hardship.

"Out of the area appointments should come with transport arranged."

## The Impact of Accessible Health and Care at or Near Home

### Thematic analyses

The primary themes identified are the demand for healthcare services closer to home, which would enable stress and financial cost reduction, improvement in condition management, and enhance overall quality of life. Although some people place a high value on specialist care even at the expense of travel, a significant number of participants expressed a crucial need for localised care options. Telemedicine and home-based care emerged as highly favourable solutions, particularly for those facing mobility and financial constraints in relation to travel.

#### Access to Localised Healthcare Services

A dominant theme in responses was the advantage of health and care services being more accessible and proximate to their living areas. This aspect of healthcare delivery was associated with positive outcomes such as reduced stress and travel fatigue, alongside quicker recovery from symptom exacerbation brought on by travel. Responses indicate that the presence of healthcare services nearby would not only be beneficial physically but also more economical for the patients.

"If I have an appointment with my consultant I have to travel nearly 200 miles as a round trip so having something closer would save me money and cause less stress. Also, attending appointments, especially with the travel can cause my symptoms to get worse; it can take days or weeks to recover."

#### Quality of Care vs. Proximity

Despite the overarching preference for local services, some people prioritised quality of care and the expertise of specialists over the convenience of proximity. These people expressed a willingness to travel greater distances to access higher standards of care, suggesting a nuanced view on healthcare accessibility where quality remains a high priority.

"I was formerly treated much nearer home, where I was able to make use of my free travel pass. But that centre was unable to offer any meaningful treatment, so I am now seeing a surgeon further away. I feel much more satisfied with my care now and the travel and cost are worth it."

## Mixed Current Consultant Care Experiences

Experiences with current consultant care varied significantly, impacting their preference for local or distant services.

"I was referred to a hospital I can get to by bus but the consultant was arrogant and dismissive so I went back to Queen Square."

## Continuity of Care

A recurring theme was the preference for continuity of care, which in the context of local services translated into a reduced necessity for people to repetitively acquaint new healthcare professionals with their medical history. Consistent care from a named local doctor or specialist was highly valued.

"A huge difference, obviously I can't have a consultant on call, but having easy access to an occupational therapist and a named local doctor would change things a lot, I have to explain my rare disease to each new health professional I encounter."

## Telemedicine as an Alternative

The effectiveness of telemedicine and remote consultations highlighted during the pandemic resonated strongly within the feedback. People who have experienced the convenience of telemedicine appointments desire the continuation of these services post-pandemic.

"My appointments were pre-pandemic so before zoom appointments. Looking back I can see that some appointments would have been suitable for zoom."

## Quantitative Analyses

### Timeline since primary neurological condition's diagnosis

How long has it been since you were diagnosed with your primary neurological condition?

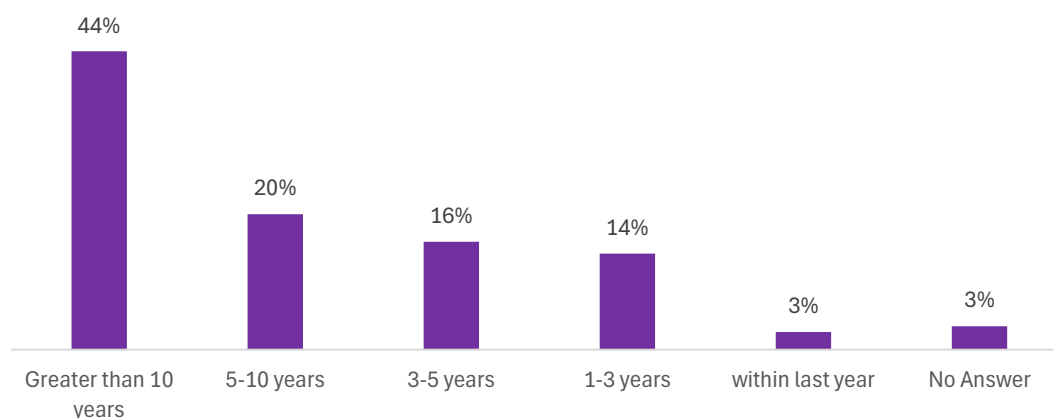


Figure 2 - Length of Time since Diagnosis

Table 1 - Length of Time since Diagnosis

Length of Time	Percentage	Respondents (346)
Greater than 10 years	44%	152
5-10 years	20%	69
3-5 years	16%	55
1-3 years	14%	49
within last year	3%	9
No Answer	3%	12

## First diagnosed neurological condition

Please tell us which neurological condition you were first diagnosed with.

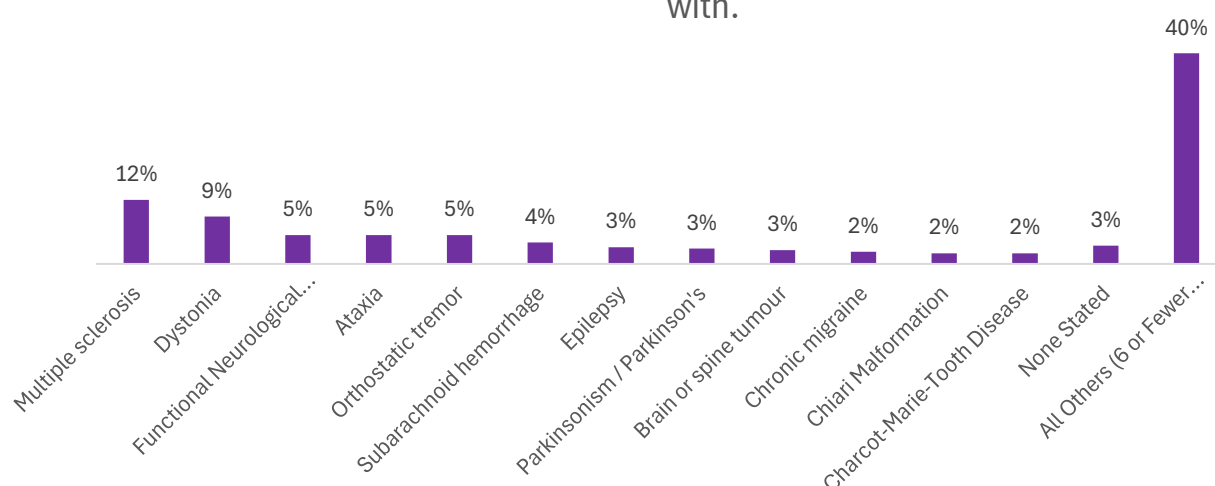


Figure 3 – First Condition Diagnosed

Table 2 – Length of Time since Diagnosis

Condition	Percentage	Respondents (346)
Multiple sclerosis	12%	42
Dystonia	9%	31
Functional Neurological Disorder	5%	19
Ataxia	5%	19
Orthostatic tremor	5%	19
Subarachnoid Hemorrhage	4%	14
Epilepsy	3%	11
Parkinsonism / Parkinson's	3%	10
Brain or spine tumour	3%	9
Chronic migraine	2%	8
Chiari Malformation	2%	7
Charcot-Marie-Tooth Disease	2%	7

None Stated	3%	12
All Others (6 or Fewer Responses)	40%	138

## Other neurological condition(s) and/or symptoms

Do you have any other neurological condition(s) and/or symptoms you would like to add?

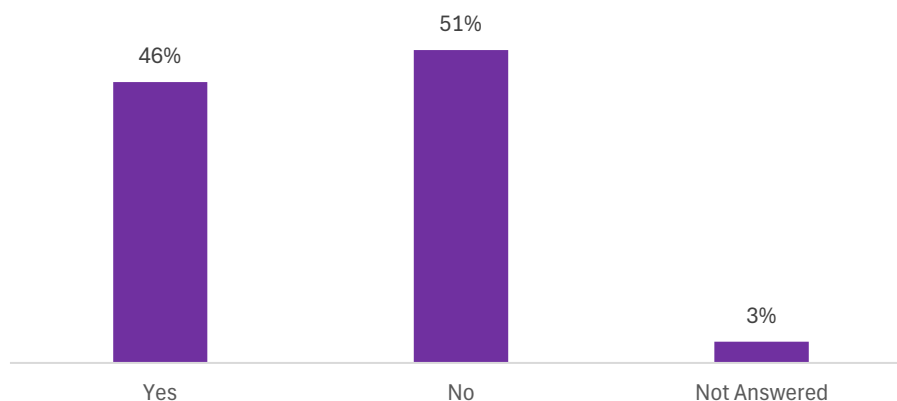


Figure 4 – Other Neurological Condition Presence

Table 3 – Other Neurological Condition Presence

Presence of additional Neurological Condition	Percentage	Respondents (346)
Yes	46%	158
No	51%	176
Not Answered	3%	12

## Other health conditions different to the neurological condition(s)

Do you live with any health conditions other than your neurological condition(s)? If so, how many:

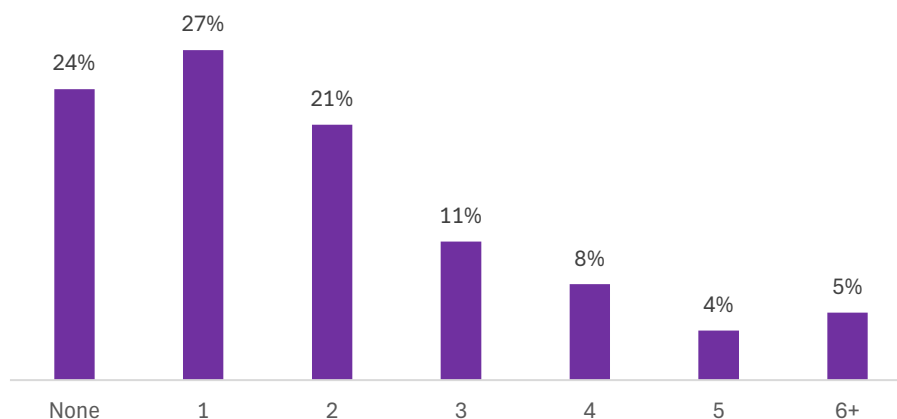
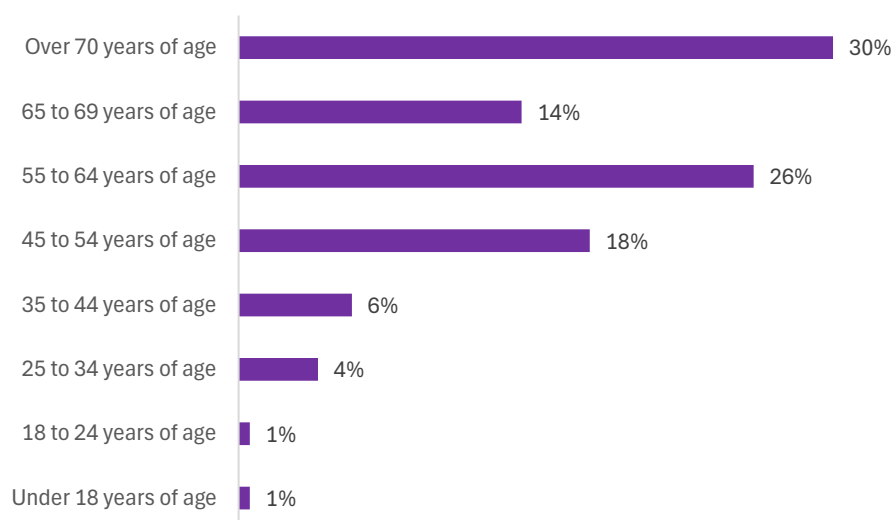


Figure 5 – Other Non-Neurological Condition Presence

Table 4 – Other Non-Neurological Condition Presence

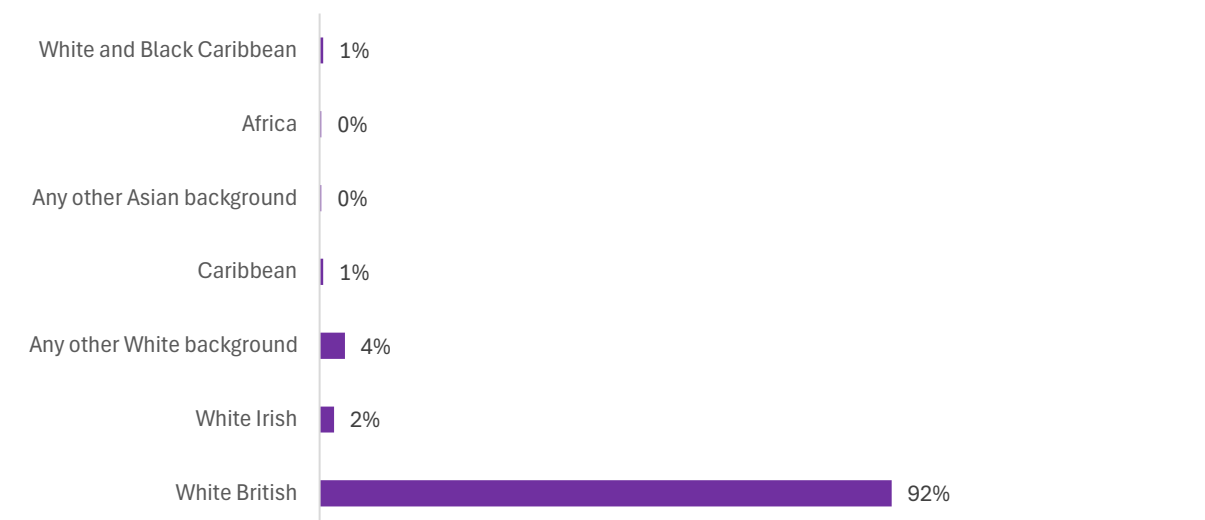
Number of Additional Non-Neurological Conditions Present	Percentage	Respondents (346)
None	24%	None
1	27%	1
2	21%	2
3	11%	3
4	8%	4
5	4%	5
6+	5%	6+

## Age



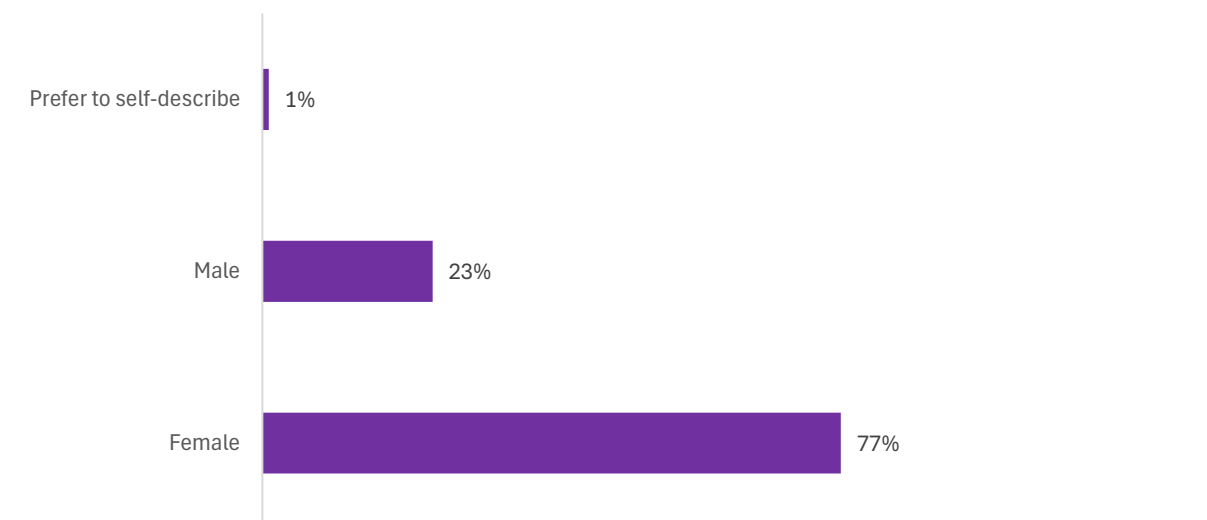
Age	Percentage	Respondents (346)
Under 18 years of age	1%	2
18 to 24 years of age	1%	2
25 to 34 years of age	4%	14
35 to 44 years of age	6%	20
45 to 54 years of age	18%	62
55 to 64 years of age	26%	91
65 to 69 years of age	14%	50
Over 70 years of age	30%	105

## Ethnicity



Age	Percentage	Respondents (346)
White British	92%	318
White Irish	2%	8
Any other White background	4%	14
Caribbean	1%	2
Any other Asian background	0%	1
Africa	0%	1
White and Black Caribbean	1%	2

## Gender



Age	Percentage	Respondents (346)
Female	77%	265
Male	23%	78
Prefer to self-describe	1%	3

## Challenges in travelling to health & care appointments

How difficult is it for you to travel to your health or care appointments for your neurological condition(s)?

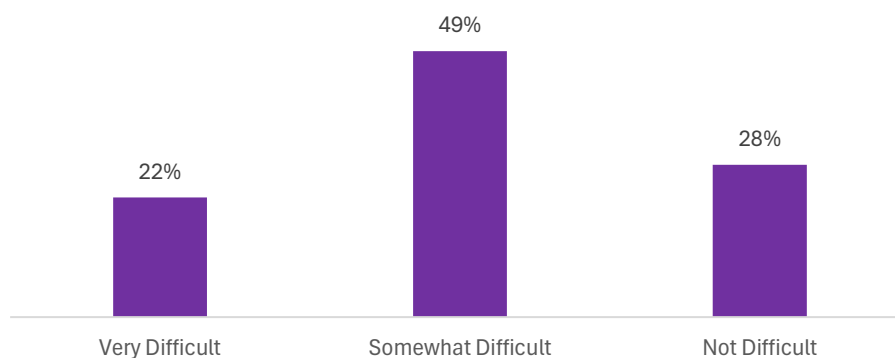


Figure 6a - Difficulty of Travel for Neurological Conditions

Table 6a - Difficulty of Travel for Neurological Conditions

Difficulty	Percentage	Respondents (346)
Very Difficult	22%	77
Somewhat Difficult	49%	171
Not Difficult	28%	98

## Challenges in travelling to health & care appointments – by condition

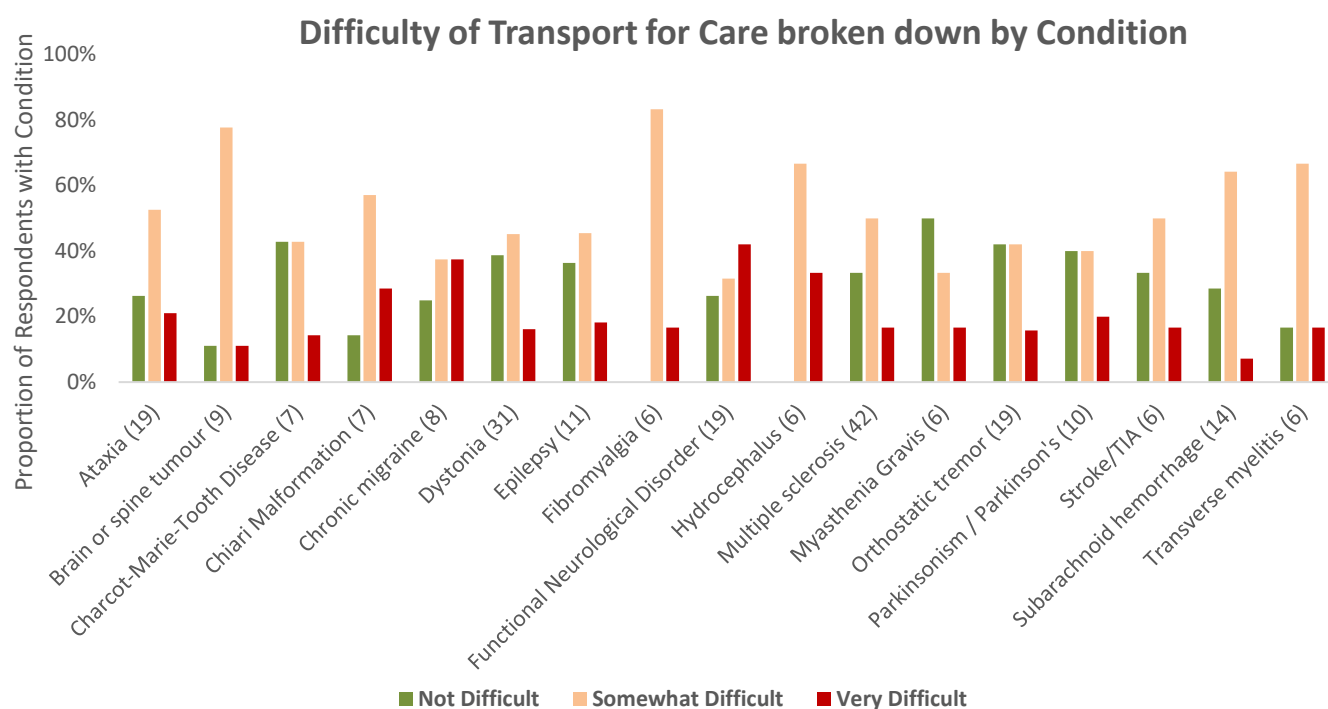
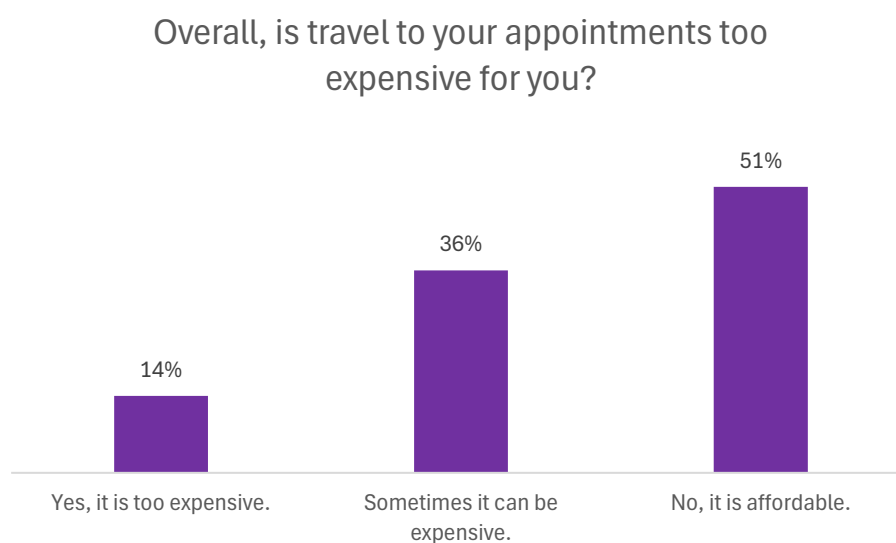


Figure 6b - Difficulty of Travel for Neurological Conditions broken down by Condition

*Table 5b – Difficulty of Travel for Neurological Conditions broken down by Condition*

CONDITION	Not Difficult	Somewhat Difficult	Very Difficult
<b>Ataxia (19)</b>	26%	53%	21%
<b>Brain or spine tumour (9)</b>	11%	78%	11%
<b>Charcot-Marie-Tooth Disease (7)</b>	43%	43%	14%
<b>Chiari Malformation (7)</b>	14%	57%	29%
<b>Chronic migraine (8)</b>	25%	38%	38%
<b>Dystonia (31)</b>	39%	45%	16%
<b>Epilepsy (11)</b>	36%	45%	18%
<b>Fibromyalgia (6)</b>	0%	83%	17%
<b>Functional Neurological Disorder (19)</b>	26%	32%	42%
<b>Hydrocephalus (6)</b>	0%	67%	33%
<b>Multiple sclerosis (42)</b>	33%	50%	17%
<b>Myasthenia Gravis (6)</b>	50%	33%	17%
<b>Orthostatic tremor (19)</b>	42%	42%	16%
<b>Parkinsonism / Parkinson's (10)</b>	40%	40%	20%
<b>Stroke/TIA (6)</b>	33%	50%	17%
<b>Subarachnoid hemorrhage (14)</b>	29%	64%	7%
<b>Transverse myelitis (6)</b>	17%	67%	17%

## Affordability of travel to health or care appointments



*Figure 7a - Expense of Travel for Neurological Conditions*

*Table 6a - Expense of Travel for Neurological Conditions*

Expense	Percentage	Respondents (346)
Yes, it is too expensive.	14%	47
Sometimes it can be expensive.	36%	124
No, it is affordable.	51%	175

## Affordability of travel to health or care appointment - Broken Down by Condition

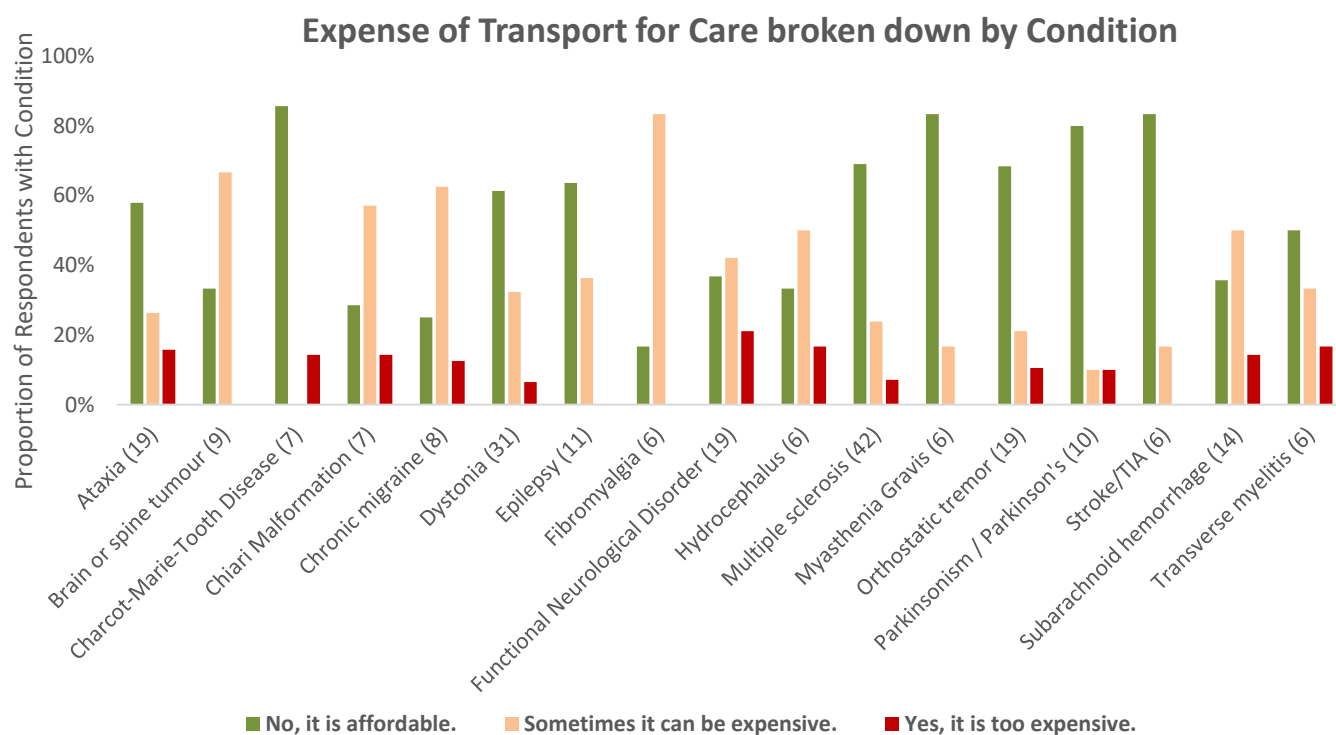


Figure 7b - Expense of Travel for Neurological Conditions broken down by Condition

*Table 6b - Expense of Travel for Neurological Conditions broken down by Condition*

<b>CONDITION</b>	<b>No, it is affordable.</b>	<b>Sometimes it can be expensive.</b>	<b>Yes, it is too expensive.</b>
<b>Ataxia (19)</b>	58%	26%	16%
<b>Brain or spine tumour (9)</b>	33%	67%	0%
<b>Charcot-Marie-Tooth Disease (7)</b>	86%	0%	14%
<b>Chiari Malformation (7)</b>	29%	57%	14%
<b>Chronic migraine (8)</b>	25%	63%	13%
<b>Dystonia (31)</b>	61%	32%	6%
<b>Epilepsy (11)</b>	64%	36%	0%
<b>Fibromyalgia (6)</b>	17%	83%	0%
<b>Functional Neurological Disorder (19)</b>	37%	42%	21%
<b>Hydrocephalus (6)</b>	33%	50%	17%
<b>Multiple sclerosis (42)</b>	69%	24%	7%
<b>Myasthenia Gravis (6)</b>	83%	17%	0%
<b>Orthostatic tremor (19)</b>	68%	21%	11%
<b>Parkinsonism / Parkinson's (10)</b>	80%	10%	10%
<b>Stroke/TIA (6)</b>	83%	17%	0%
<b>Subarachnoid hemorrhage (14)</b>	36%	50%	14%
<b>Transverse myelitis (6)</b>	50%	33%	17%

## Impact of Travel Costs on Attending Neurological Care

Has the cost of travel ever stopped you from attending a medical appointment for your neurological condition?

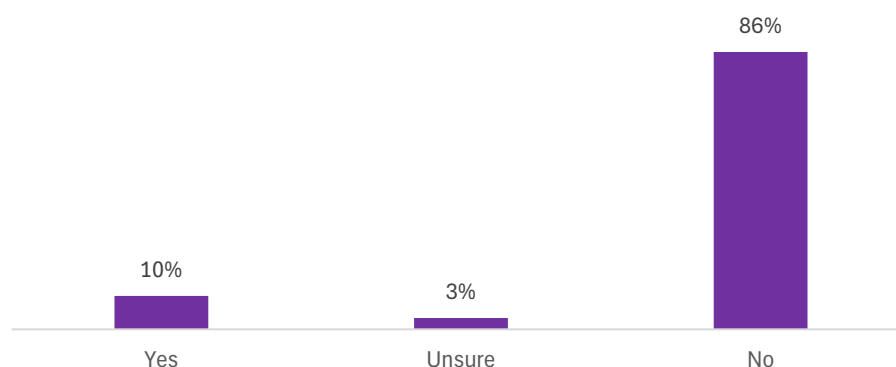


Figure 8 - Cost Prohibiting Travel for Care

Table 7 - Cost Prohibiting Travel for Care

Prohibited due to Cost	Percentage	Respondents (346)
Yes	10%	36
Unsure	3%	12
No	86%	298

There is no major variation to these answers when broken down by Condition.

## Time consumption of travel to care appointments

How time-consuming is it for you to travel to care appointments?

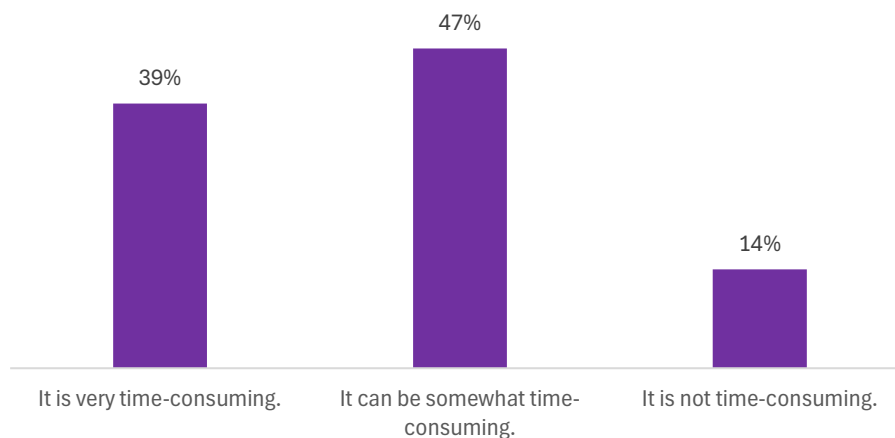


Figure 9a - Time-consumption of Travel to Care

Table 8a - Time-consumption of Travel to Care

Time Consumption of Travel	Percentage	Respondents (346)
It is very time-consuming.	39%	134
It can be somewhat time-consuming.	47%	162
It is not time-consuming.	14%	50

## Time-consumption of travel to care - Broken Down by Condition

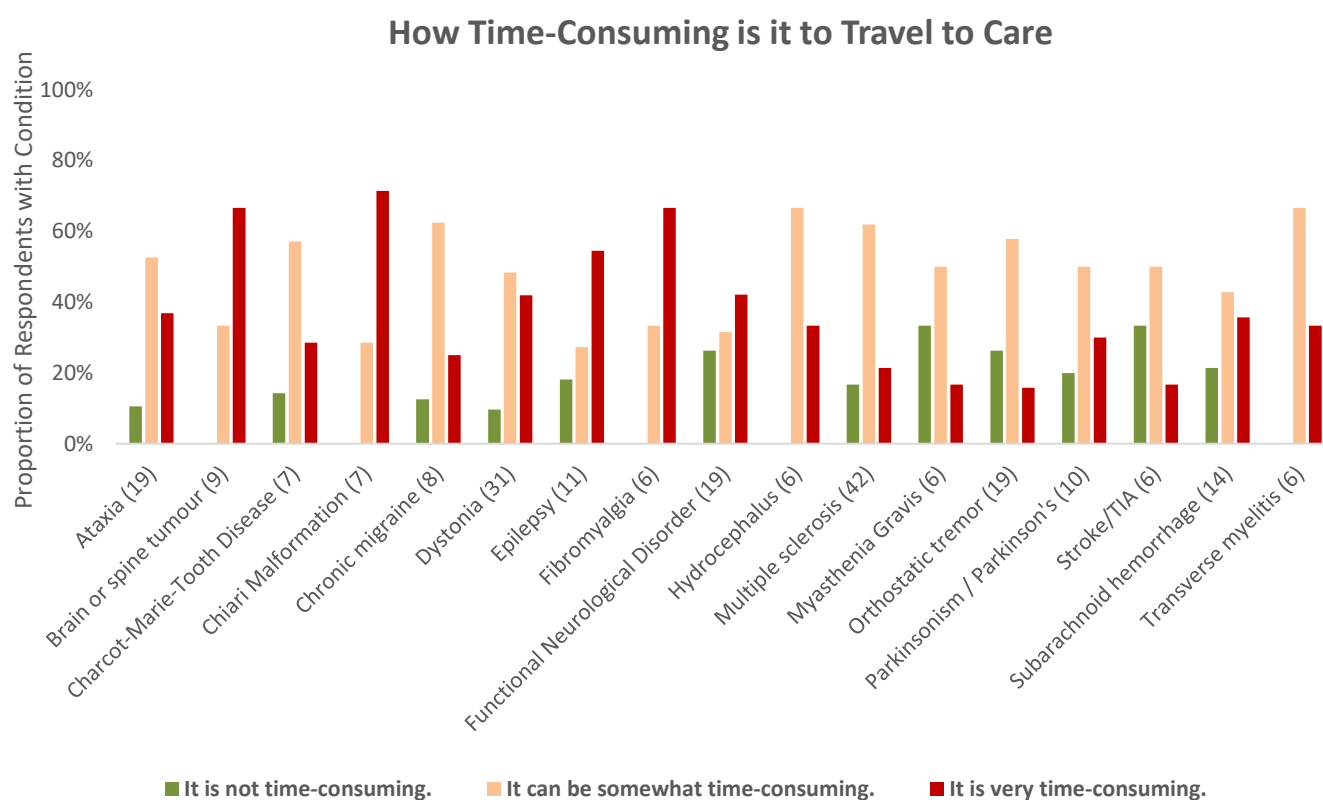


Figure 9b - Time Consumption of Travel to Care for Neurological Conditions broken down by Condition

*Table 8b – Time Consumption of Travel to Care for Neurological Conditions broken down by Condition*

CONDITION	It is not time-consuming.	It can be somewhat time-consuming.	It is very time-consuming.
<b>Ataxia (19)</b>	11%	53%	37%
<b>Brain or spine tumour (9)</b>	0%	33%	67%
<b>Charcot-Marie-Tooth Disease (7)</b>	14%	57%	29%
<b>Chiari Malformation (7)</b>	0%	29%	71%
<b>Chronic migraine (8)</b>	13%	63%	25%
<b>Dystonia (31)</b>	10%	48%	42%
<b>Epilepsy (11)</b>	18%	27%	55%
<b>Fibromyalgia (6)</b>	0%	33%	67%
<b>Functional Neurological Disorder (19)</b>	26%	32%	42%
<b>Hydrocephalus (6)</b>	0%	67%	33%
<b>Multiple sclerosis (42)</b>	17%	62%	21%
<b>Myasthenia Gravis (6)</b>	33%	50%	17%
<b>Orthostatic tremor (19)</b>	26%	58%	16%
<b>Parkinsonism / Parkinson's (10)</b>	20%	50%	30%
<b>Stroke/TIA (6)</b>	33%	50%	17%
<b>Subarachnoid hemorrhage (14)</b>	21%	43%	36%
<b>Transverse myelitis (6)</b>	0%	67%	33%