



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.

Thank you,

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

Georgina Carr, The Neurological Alliance (England)

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.

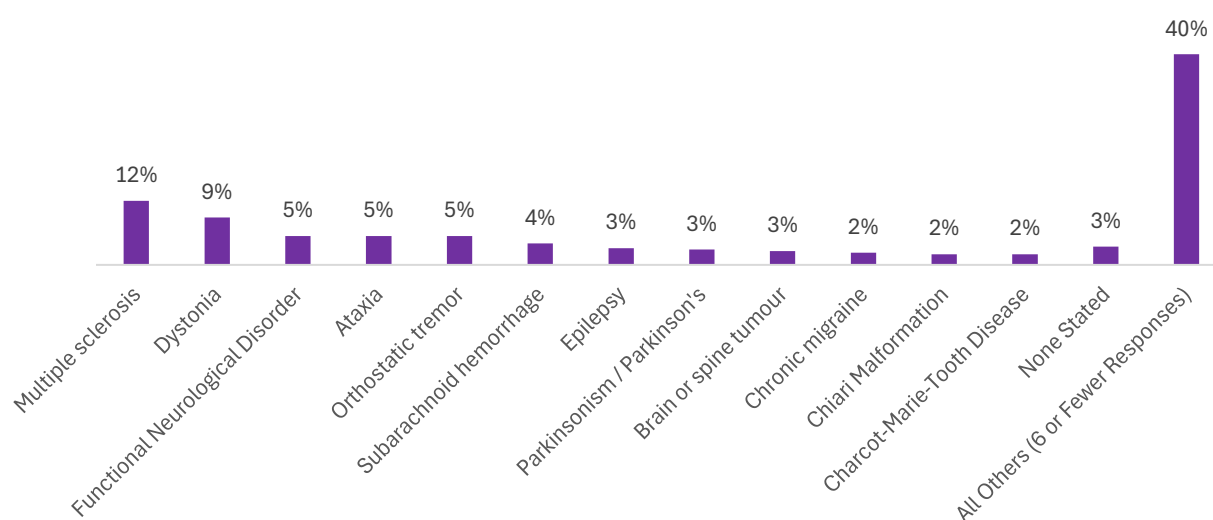


Figure 1 – First Condition Diagnosed

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

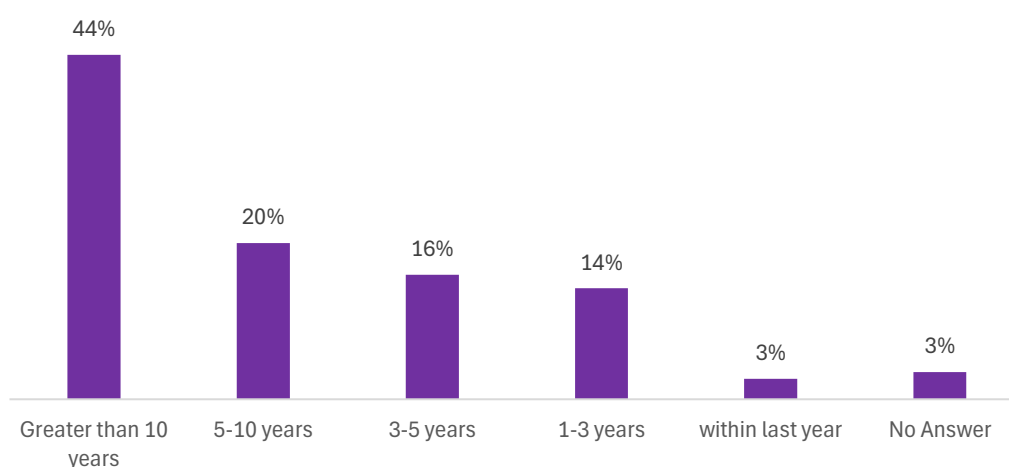


Figure 2 – Length of Time since Diagnosis

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.

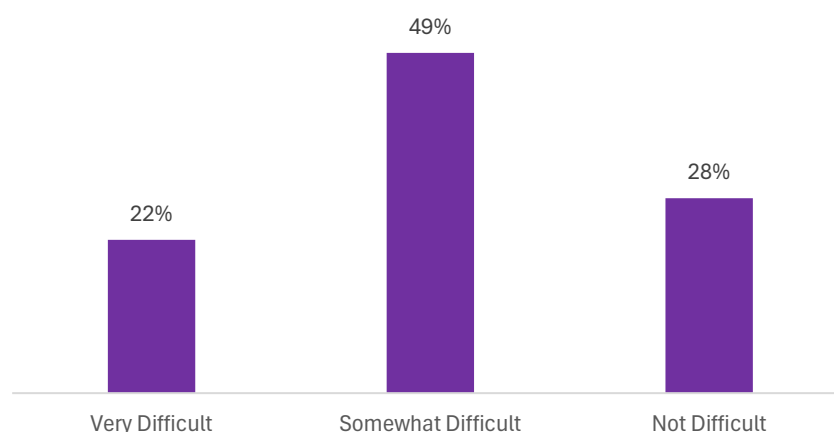


Figure 3 - Difficulty of Travel for Neurological Conditions

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.

Table 1 - 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

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

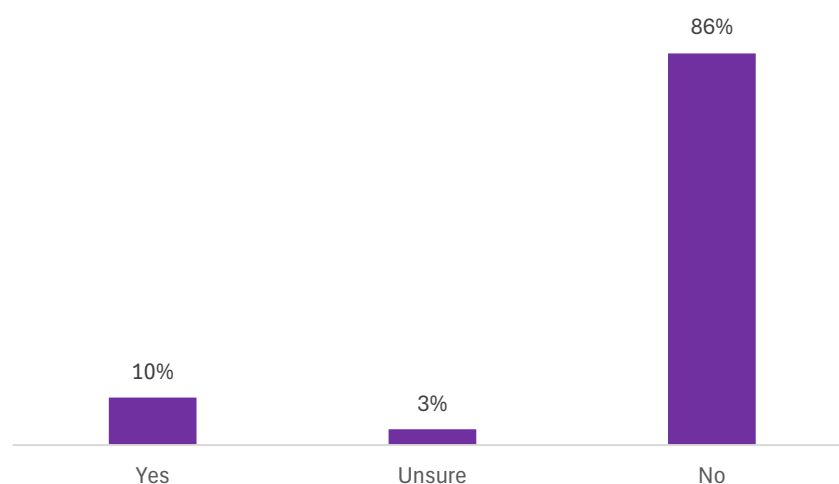


Figure 4 - Cost Prohibiting Travel for Care

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

Table 2 - 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