NeuroLifeNow
It's time to make your story heard

# July – August 2023 Insights Report

## Travel to appointments and Shared experiences

Brain & Spine Foundation
THE NEUROLOGICAL ALLIANCE
COMMUNITY FUND

The Brain & Spine Foundation registered charity no. 1098528

## 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 captures 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

Neurological conditions are remarkably diverse, affecting individuals from all walks of life. Despite this, this month you told us about shared experiences and symptoms that continue to have a huge impact on lives.

### Shared symptoms

Many people reported experiencing **fatigue, muscle spasms, stiffness, weakness, and pain**, affecting the lives of the majority of those surveyed. Additionally, 55% reported experiencing **anxiety,** and 44% reported **depression**. These are battles shared amongst many, but also represent shared opportunities for improvements to care.

### Access to treatment

Access to timely treatment and care is important for every one of the 1 in 6 living with a neurological condition. Yet far too many people this month expressed how difficult they find it to travel to their health appointments. **Four out of ten said it was difficult or very difficult to travel,** sometimes because the journey itself could exacerbate their symptoms. People living with multiple conditions, or an additional condition on top of their neurological condition, were more likely to report it was more difficult to travel.

> "....getting to the appointments is more stressful than the actual appointment."

> "I have to take 2 days off work 1 for appointment then another to get over the travelling."

Others told us about how expensive it was to travel, as well as the challenges of getting the time off to travel to appointments:

> "I cannot use public transport and have no friends or family to take me. Currently I pay for carer to take me which is expensive."

> "I have to use patient transport and have to be ready for pickup 4 hours before appointment time and return journey can only be booked once appointment concluded and have to again wait up to 4 hours for pickup to travel home. Just finished 30 sessions of treatment and each day was between 8-13 hours for 20 minutes of treatment."

> "I have to travel by train, and it is a 90 minute journey each way, so I have to take a while day off work to get to an appointment that might only be 10 minutes long"

## Drop in overall experience of healthcare

Really worryingly, the proportion of people reporting **a good or very good overall experience of healthcare has dropped markedly from May and June (from 37% to 27%).** A decrease in satisfaction is a clear signal that our healthcare system needs to change.

"2 year wait so paid private"

"Can't get in touch with the team. I seem to have been sent into a black hole"

**Many people reported not being able to access healthcare when they needed to.** Many people told us this was due to long waiting lists, an inability to attend appointments due to work commitments, mobility related problems and administration issues/complications.

"I was offered an appointment, but my specialist didn't turn up"

"I rang my neurologist's secretary after receiving a letter, cancelling my botox treatment appt and pushing that appt back 3 months. She explained that this was due to accommodating staff holidays. The secretary very kindly rang me a couple of weeks later, to offer me an ad hoc appointment, one month later than my original appt. Although grateful for this, it was deeply upsetting and distressing to receive that extremely lengthy appt delay."

Together, we have called for much needed change to address many of the issues highlighted here. Since last year, more than 100 organisations and 19,000 people across the country have called on UK Government's to establish a 'Neuro Taskforce' to address the shortcomings in treatment and care for the 1 in 6 living with a neurological condition in this country. We know the UK Government is considering this proposal – quite frankly, a commitment to a Taskforce, and to change, cannot happen quick enough.

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 **0808 808 1000** (Mon-Fri, 9am – 4pm) or email helpline@brainandspine.org.uk.

Thank you so much.

**Marc Smith, CEO Brain and Spine Foundation**
**Georgina Carr, CEO Neurological Alliance (England)**

## Key Findings

- **746 people from across the UK responded** to the July/August survey. **157 conditions** and neurological symptoms were represented. The most common were multiple sclerosis, dystonia and functional neurological disorder. **50% lived with multiple conditions.**

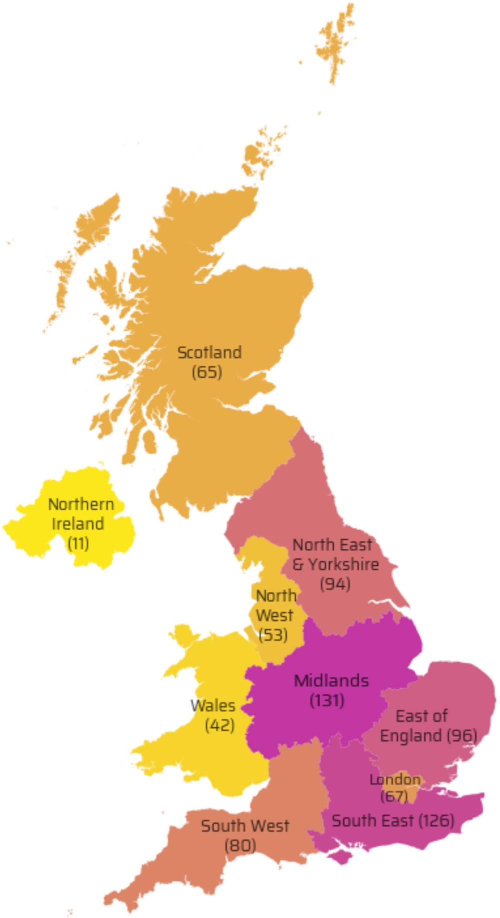

Figure 1: Location of the respondents.

- The most reported issues and symptoms were **fatigue** (80%)**, muscle spasms, stiffness and weakness** (70%)**, and pain** (61%)**.**

- **55% reported anxiety, and 44% reported depression,** which is in line with the findings of our previous surveys.

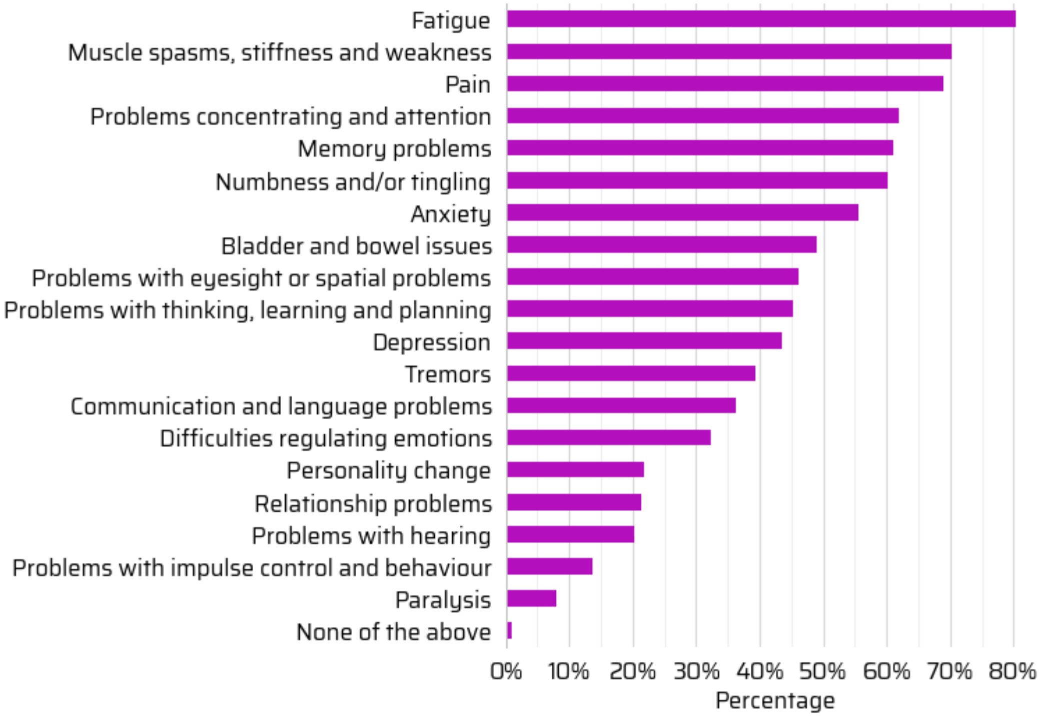

Figure 2: Shared issues and symptoms.

- **50% of people said it was difficult or very difficult to travel to their health appointments** for their neurological condition. People with multiple neurological conditions, or conditions in addition to their a neurological condition, were more likely to report difficultly in travelling to their appointments.

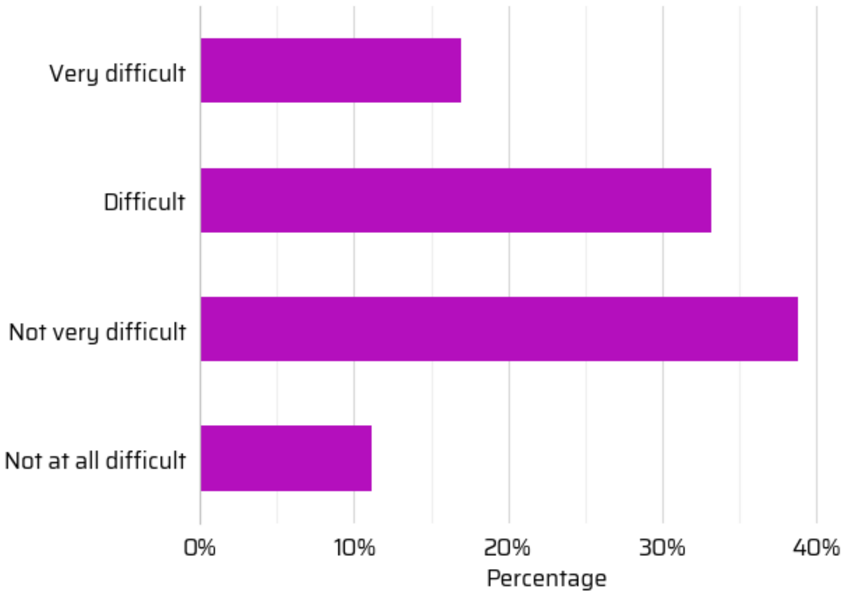

Figure 3: Difficulty travelling to appointments.

- **30% of respondents said it took more than an hour to travel to their health or care appointments** for their neurological conditions. People with multiple neurological conditions were more likely to travel **more than two hours compared to those with one condition.**

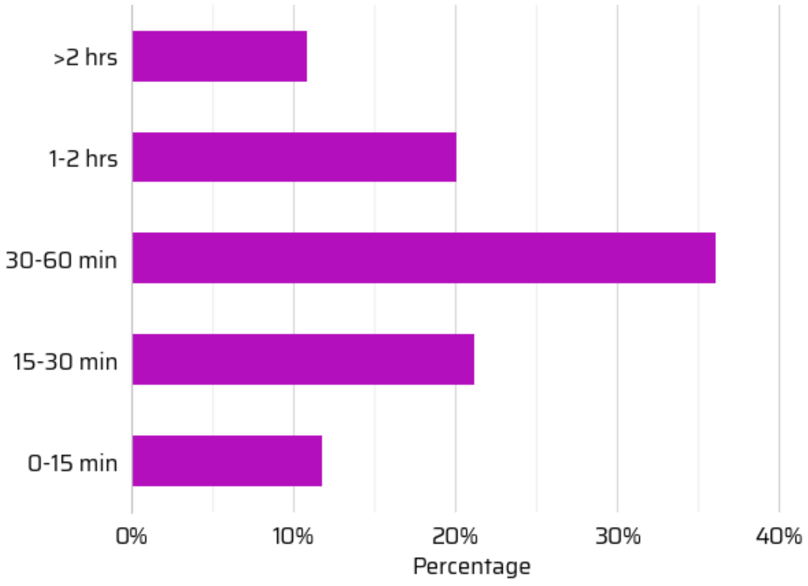

Figure 4: Travel time to get to appointments.

- When people were unable to speak to anyone, **32% went without any healthcare input at all.**

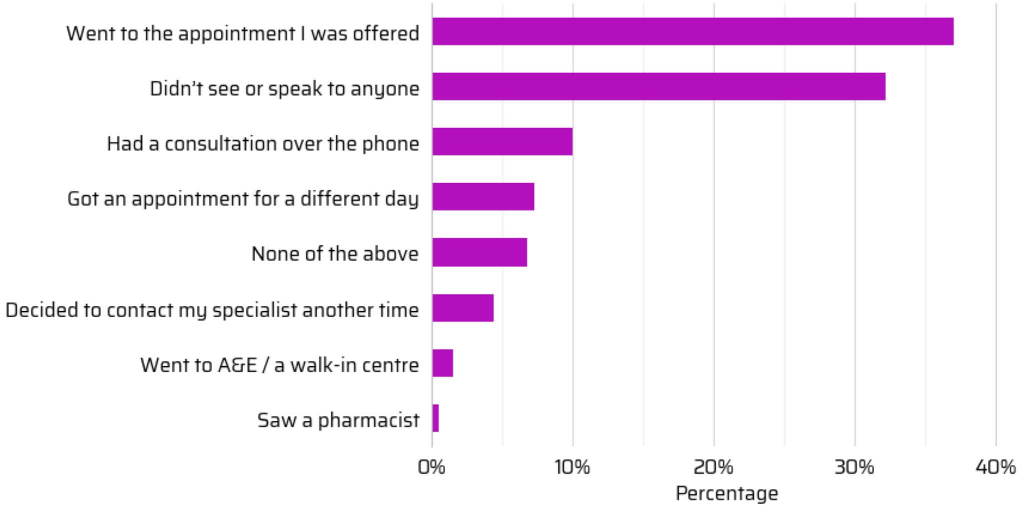

Figure 5: Action taken following not getting an appointment or not offered a convenient one.

- Multiple reasons were cited as making the journey problematic, including **poor availability of accessible facilities; cost inappropriate/non-existent public transport; and the journey aggravating symptoms** associated with their condition.

"There is no train or bus service"

"Simply sitting up is difficult for me to do for long periods. By the time I arrive at an appointment I'm already exhausted and struggling."

"Parking is an issue. Hospital with outdoor paths which are narrow and difficult to use as a wheelchair user especially if pedestrians on them. Waiting rooms cramped...no available space to put wheelchair in. Not all hospitals seem to have changing places bathroom and some have small disabled toilets with little room for standing pivot transfer with carer."

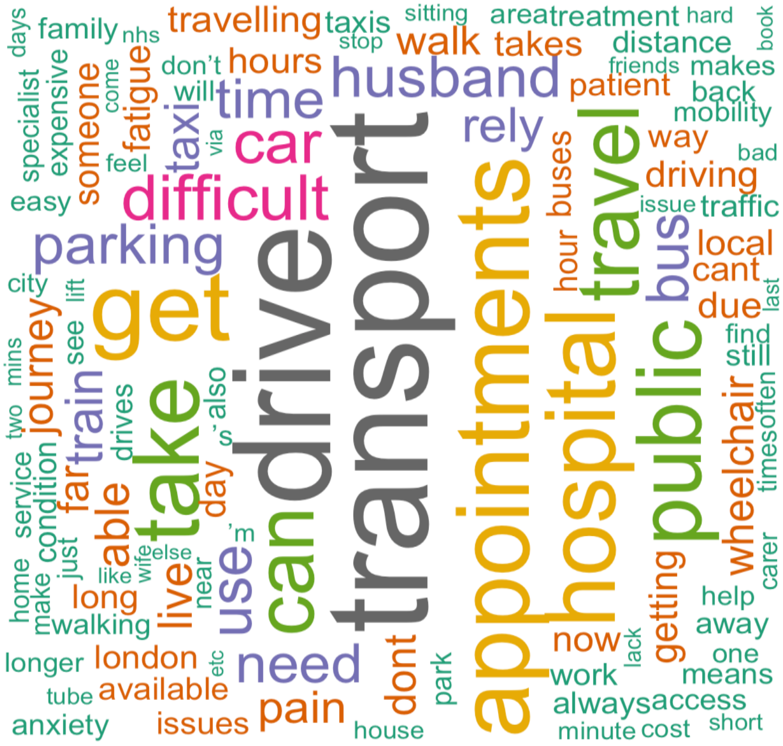

Figure 6: Word cloud showing key words used by respondents related to the reasons for their difficulty in travelling to appointments.

- **27% of respondents said their overall experience of healthcare** was good or very good in July and August (**10% down from May/June**).

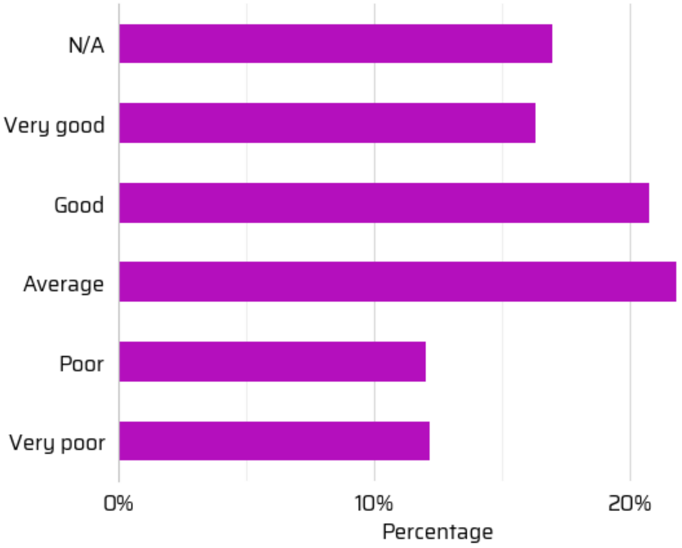

Figure 7: Overall experience of healthcare.

- **Many people reported not being able to access healthcare when they needed to.** This was due to long waiting lists, an inability to attend appointments due to work commitments or mobility related problems or administration issues/complications.

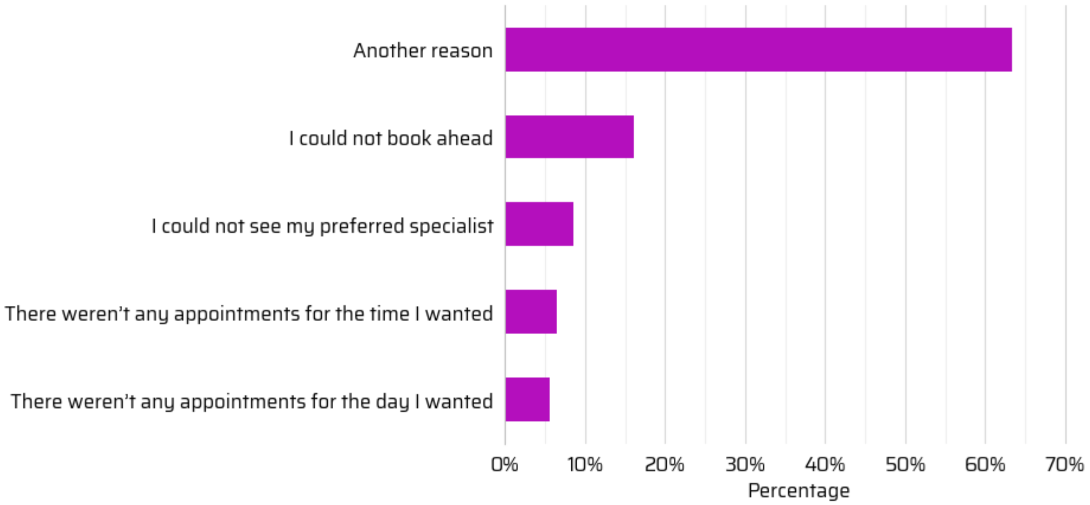

Figure 8: Reasons for not getting an appointment or a convenient one.

**This is a summary of the full report. To view our full report, click here.**