

## September - October 2023 Full Insights Report

**The impact neurological conditions have on lives, in addition to  
NHS strikes and the winter months.**



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 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

People affected by neurological conditions always tell us they are under considerable pressure over the winter period, as the ability to access health and care services often becomes even more difficult, fluctuating temperatures have a direct impact on symptoms, and mental health can, and often does, worsen.

### Concerns going into winter.

In September and October, hundreds of you told us just how worried they were going into winter 2023. The impacts on mental health and finances particularly stark.

**“I’m dreading the whole energy bills game again. As someone on legacy benefits, I don’t qualify for all the uplifts/cost of living handouts - this is discrimination on a wide scale.... I live alone, I don’t have a partner or family to bear the cost burden of rent, bills etc. Single disabled folk - where’s the help for us if we don’t tick the right boxes?”**

**“Dark, depressive thoughts.”**

**“Being isolated at home as the cold makes my symptoms worse.”**

### The impact of the NHS strikes

For many, strike action in the NHS only added to the pressures of winter. Whilst many of you spoke of your support for those striking - the importance of appropriate support and reimbursement for NHS workers is seen as critical to good care - you also spoke of waits for support being extended, sometimes as a direct impact of the strikes.

**“My botox injections will be over 6 weeks late, I am already in pain and tremors getting very hard to cope with.”**

**“Appointments cancelled and new ones made. Added negatively to my symptoms added to their intensity, duration and increased my stress levels hugely.”**

**“I stand with the people who strike. Their work has not been acknowledged for a long time. In this case, I would be happy to wait longer to get the care I need.”**

Together with NHS Healthwatch England, Age UK, NHS Confederation, National Voices and the Patients Association, we call on both Government and the British Medical Association (BMA) to get back to the negotiating table, believing that further strikes would be a major blow for the service already grappling with record waiting lists, winter pressures and the financial fall out of previous industrial action.

### **Living with neurological conditions**

Finally, and most importantly, you were clear in your exasperation and your pain of the daily realities of living with a neurological condition – the realities of daily unpredictable changes to how you think, feel and move, as well as how your condition takes its toll not only on you but also those closest to you.

**“I have changed completely, friends have gone, I look ok but inside I am scared all the time.”**

**“I can no longer enjoy the things I used to do, like walking, hiking, rambling, keep fit.”**

**“It is stopping me from living my life.”**

**“Friends & family not interested in my lived experience. It’s very lonely.”**



## Key Findings

**685** people with neurological conditions across the UK responded. **164 conditions were represented**. Multiple sclerosis (MS), Dystonia and Functional Neurological Disorder (FND) were the most common conditions represented.



Figure 2: Location of the respondents.

**Over 96.79% of respondents identified as White British.** Neurological conditions affect everyone, regardless of age, gender, sex, race or ethnicity. **Addressing the lack of ethnic and racial diversity of respondents is a key priority of the NeuroLifeNow programme.**

**28% of respondents said they had been impacted by strikes this year.** 36% of people with multiple conditions said this compared to 20% of respondents with one neurological condition.

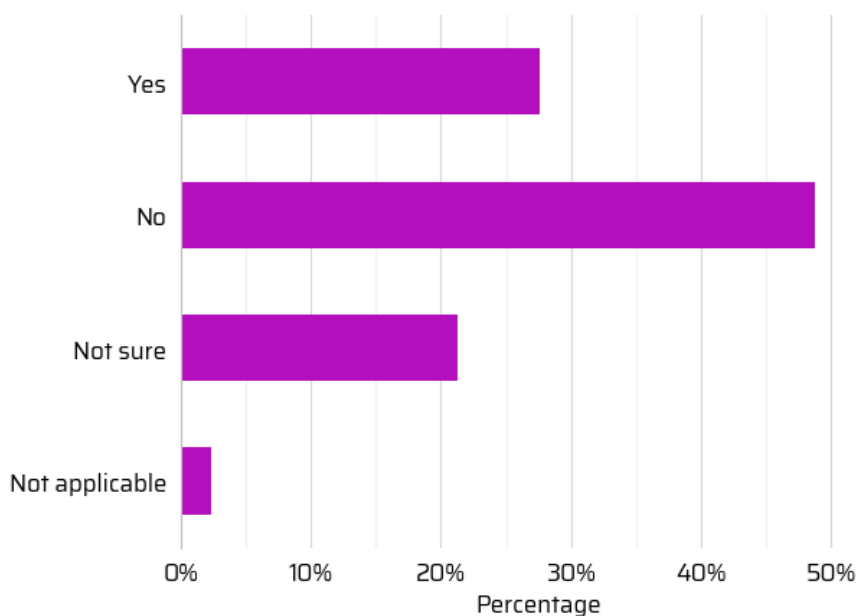


Figure 3: Have the NHS strikes had an impact on healthcare and support of people affected by Neurological Conditions?

**69% of people said their neurological condition impacted their life to a great or large extent.** This increases to 77% for people living with multiple neurological conditions.

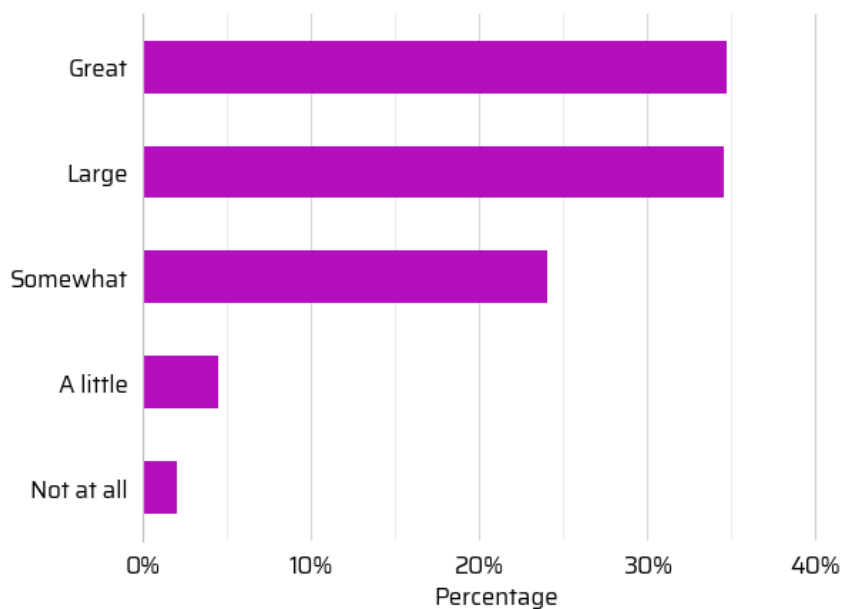


Figure 4: Overall impact of neurological conditions on quality of life.

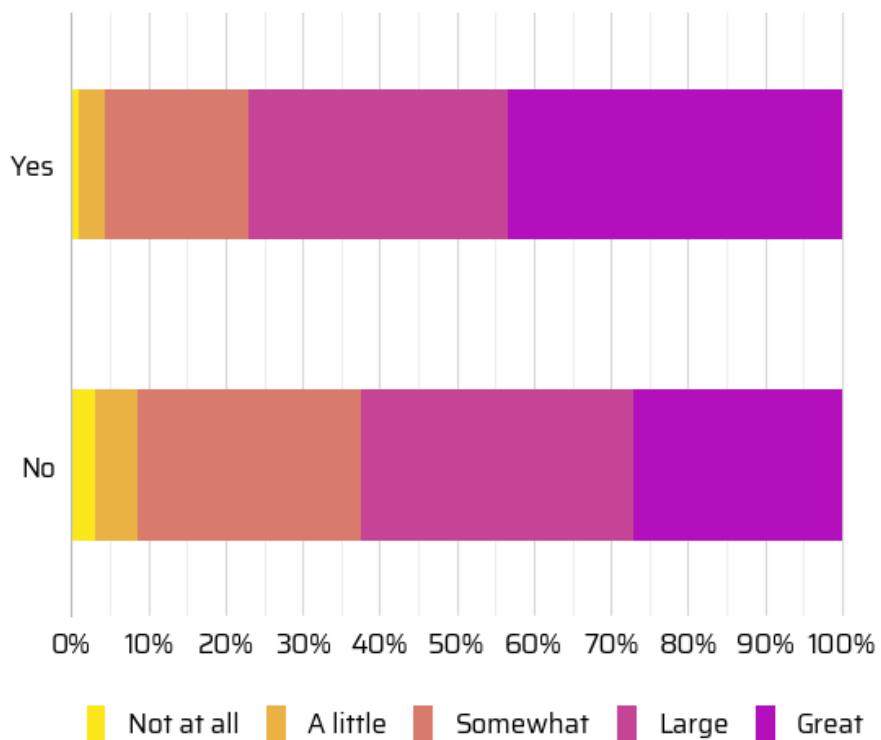


Figure 5: Impact on quality of life among people with vs without multiple neurological conditions.



Nearly half (48%) of people said they felt anxious. A quarter (25%) said they felt hopeless. **57% of people said their mental health needs were only being met** to a small extent or not at all.

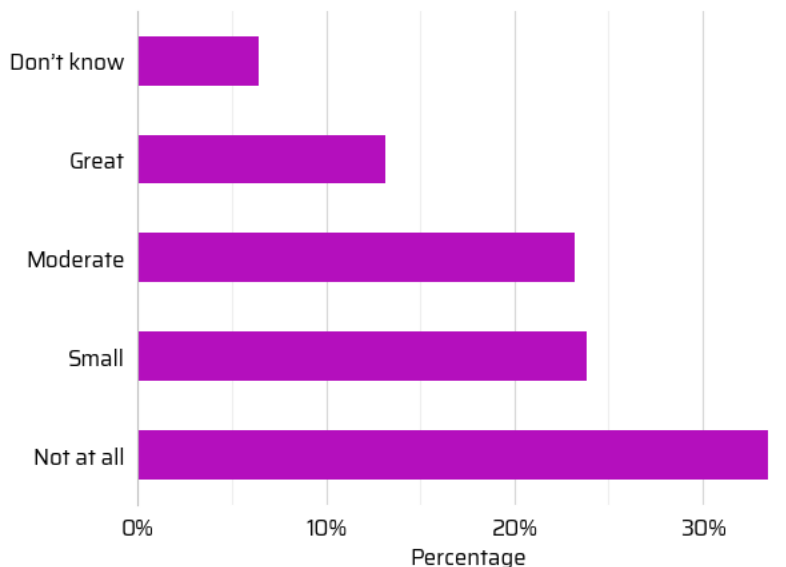


Figure 6: Extent respondents reported their mental health needs were being met.

**Half (50%) of people said they had a good or very good overall experience of healthcare in the past eight weeks.** 7% had had 6 or more medical appointments.

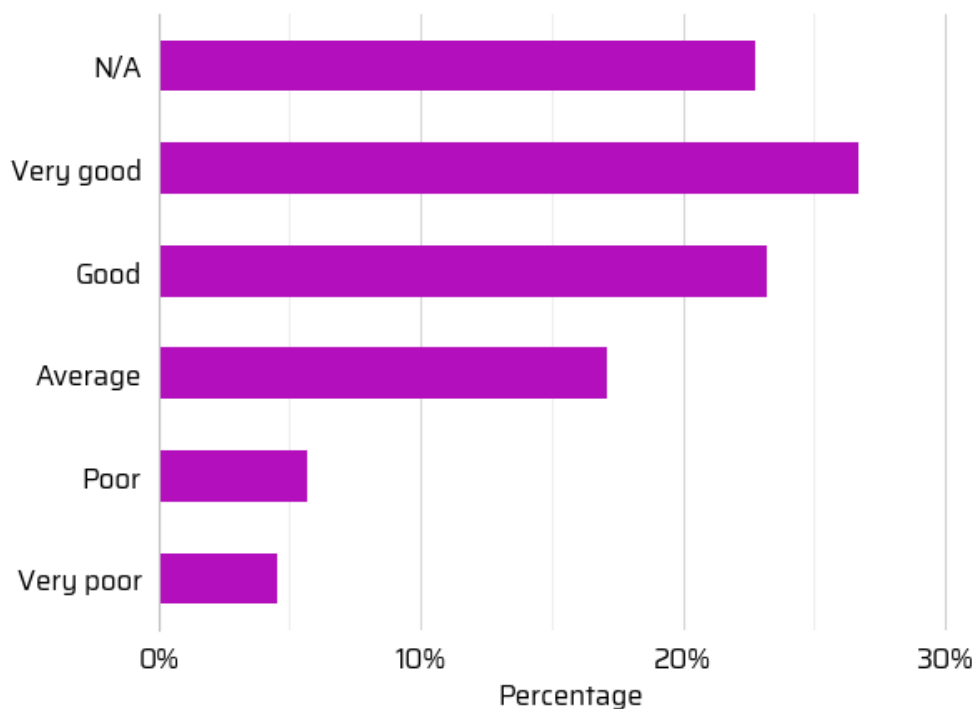


Figure 7: Respondents overall experience of health and care.

**77% of people found their appointments useful.**

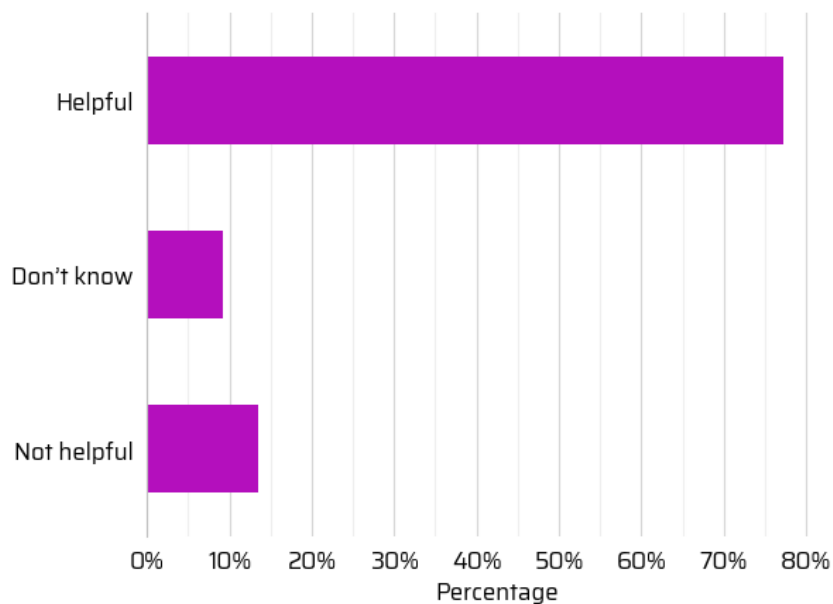


Figure 8: Helpfulness of medical appointments held in the last eight weeks.

**Three quarters (75%) were held face to face, 22% were held on the telephone.**

Most appointments reported to us were with a GP.

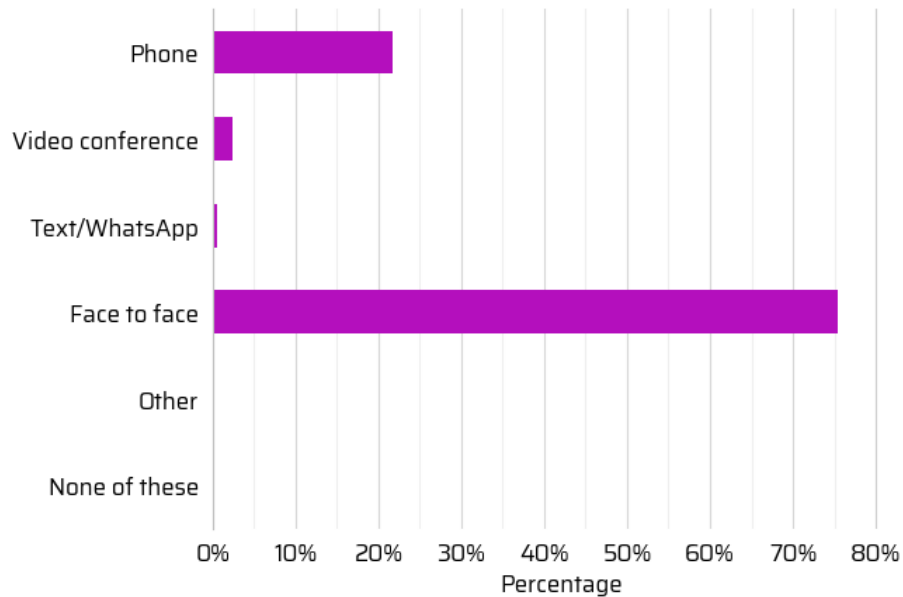


Figure 9: Mode of medical appointments completed in the last eight weeks.

**10% of people with multiple neurological conditions had visited A&E in the past eight weeks,** compared to 5% of people with one neurological condition.

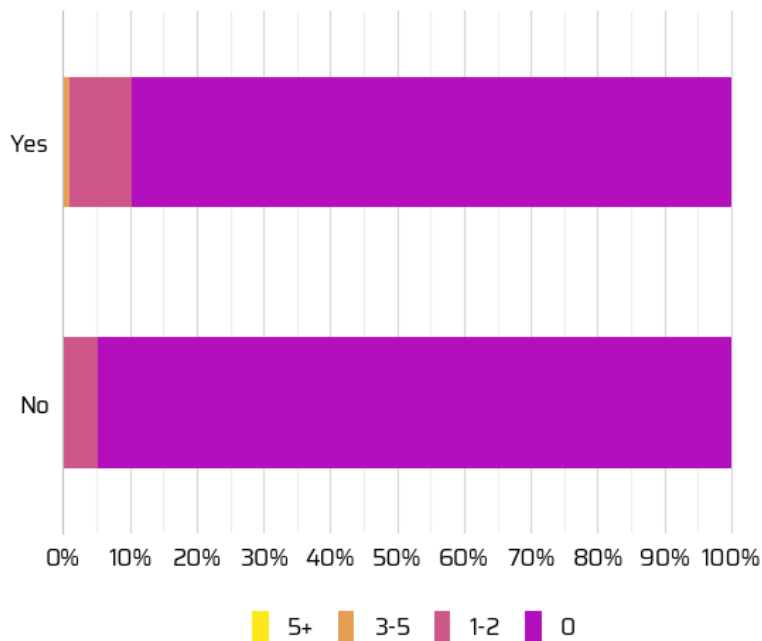


Figure 10: Frequency that NHS A&E/emergency services were sought, broken down by whether diagnosed with multiple neurological conditions.

**This is a summary of the full report. To view our full report, click [here](#).**