



January - February 2024 - Full Insights Report
Priorities for the new UK Government to focus on for people
living with neurological condition(s)

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 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

As the dust settles following the UK General Election, and the new Labour Government establish their priorities, this report is a timely reminder of what the new UK Government needs to get to work on without delay, for people affected by neurological conditions.

In January and February, you were clear about your priorities for the new Government - improve access to specialists, and quickly. 9 out of 10 people who responded to NeuroLifeNow said this was a priority for them.

New Neuro Champions elected

At the Neurological Alliance, we are carefully thinking about how we can work together to ensure Labour prioritises the needs of people affected by neurological conditions. More than 1000 people wrote to their local candidates during the General Election to call on them to become a 'Neuro Champion' if elected - that means speaking up and out on the issues that matter to people living with neurological conditions, including improving access to specialists. 11 MPs have already signed up to become a Neuro Champion as a result, and many more are being approached about signing up now they have been elected.

In the January-February survey, many people indicated that they would be willing to play a more active campaigning role with the new Government - 27% said they would speak to the local press about their experiences, and 16% said they would speak up with their local politicians at an event. We will use these helpful insights to shape the next phase of the Neuro Champion campaign, ensuring we provide a number of ways for people to speak up and out about their experiences.

Access to support remains patchy, but important

71% of people said they found their medical appointments helpful, and 74% of people who had an appointment had face to face appointments. This is a distinct shift from the heights of the pandemic, where telephone and videoconference appointments were used more routinely. It is critical that people affected by neurological conditions are given a choice for appointment format - possibly avoiding lengthy travel, but also ensuring people are able to access face to face time with healthcare professionals when they need it.

Mental health needs are not being met

Worryingly, the percentage of people reporting that their mental health needs are not being met at all is high - nearly 4 in 10 reported this in January and February. The NHS in England has confirmed that no person with a neurological condition should be turned away for mental health support if they need it. We are working hard to ensure this is implemented, and that countries across the UK make a similar promise. Importantly, we want to see commitments from Governments across the UK to grow the health and care workforce for mental health too.

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,

The Brain & Spine Foundation Team

Georgina Carr, CEO, The Neurological Alliance, England

Key Findings

We received **650 responses** in January to February 2024. **109 conditions** were represented, and 46% of people reported living with more than one condition. We asked respondents to list any neurological conditions/symptoms that they experience that are not listed in the prior questions. **Anxiety** and **memory problems** were listed most often.



Figure 1: Location of the respondents.

45% of respondents were diagnosed 10 or more years ago. 76% said their neurological condition(s) **impacted their life to a great or large extent.**

90% of people said improving access to specialists was a priority for the next UK Government. 52% said access to appropriate **mental health support** should be a priority, and 51% said access to **financial support.**

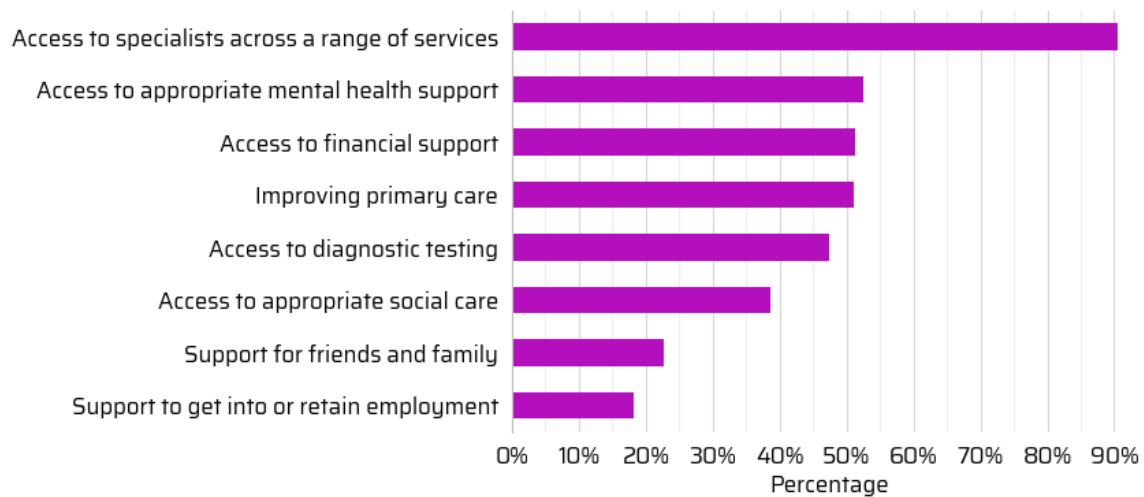


Figure 2: Priorities for the next UK Government.

50% of respondents said they would use email candidates to campaign for change, 47% said they would use **key messaging** and 44% said they would use **social media templates.**

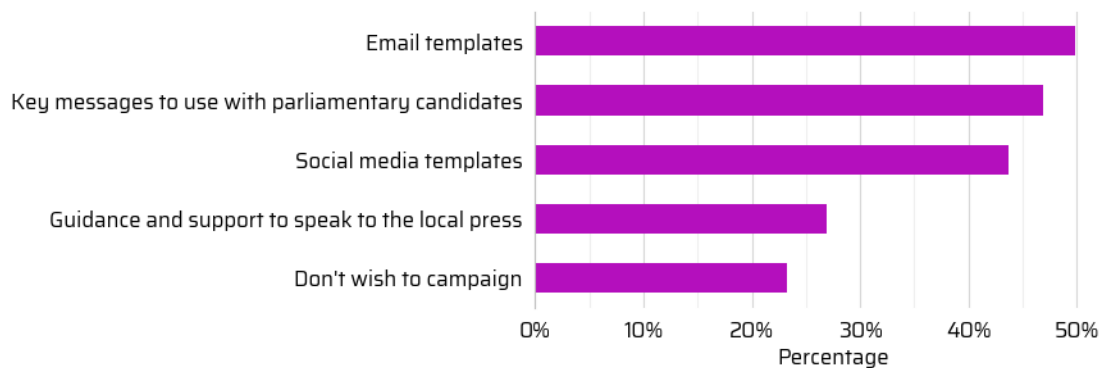


Figure 3: Support from charities to campaign.

16% of people said they were confident enough to write to their local candidates by post, 43% said they were confident to write to them using email.

7% said they were confident enough to **take part in a stunt or protest to campaign**, 16% said this about speaking to the local press.

64% of respondents said they had at least one medical appointment in the eight weeks before taking the survey. 25% said they had three or more appointments.

Table 1: Access to medical appointments in the last eight weeks.

Appointments	Respondents	Percentage
Yes	415	63.85
No	60	9.23
Don't know	2	0.31
No response	173	26.62

72% of those who had appointments said they found them helpful. 38% had an appointment with their GP, 17% with their specialist nurse and 14% with a neurologist.

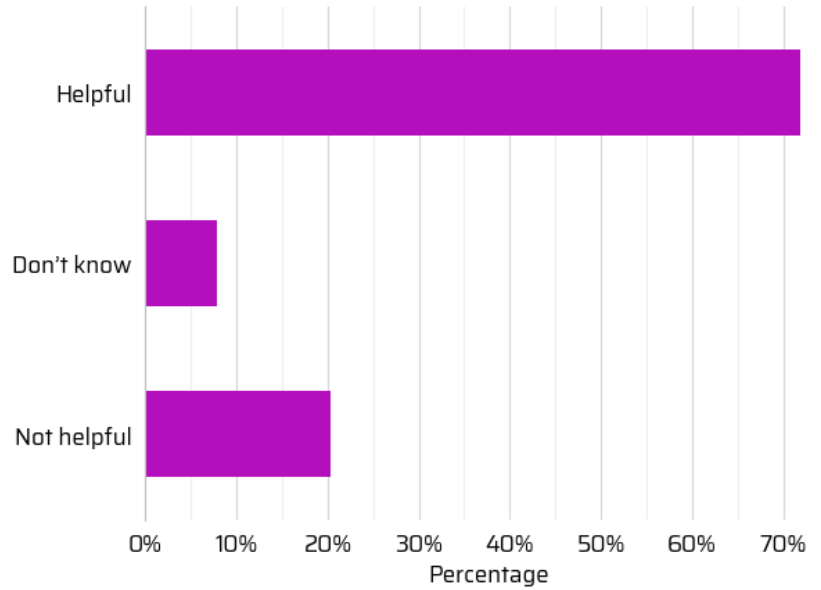
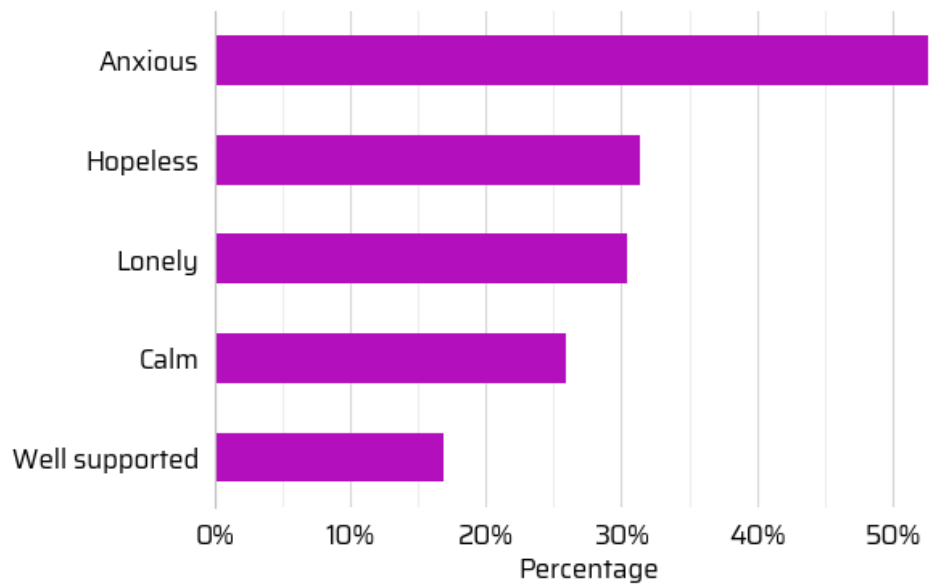


Figure 4: Helpfulness of medical appointments held in the last eight weeks.

74% reported having a **face-to-face appointment**.

57% said they felt anxious, 31% said they felt hopeless. Just 17% felt well supported. In parallel, 39% of people said their mental health needs were not being met at all. Those with multiple neurological conditions were more likely to report this (46%).



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