



# NeuroLifeNow

**March - April 2023 Survey Report**  
**Your priorities for the NHS**

**Brain & Spine**  
**Foundation**

 **THE**  
**NEUROLOGICAL**  
**ALLIANCE**

 **COMMUNITY**  
**FUND**

## Foreword

Waiting. That is perhaps the daily reality of most people affected by neurological conditions right now, as they wait to access the right treatment, care and support. Since the start of the pandemic, the NHS neurology waiting list in England has more than doubled, but not the investment and workforce to deliver those services. In this context, it is easy to see why people are waiting, but it does not make it less stressful or devastating.

“I haven’t seen my Dr for 5 years and even then she said my unsteadiness & falling over were vit D deficiency. I felt it was me being Lazy why I was getting weaker. If it hadn’t been for phoning and speaking to nurses practitioner I would never have been referred to a neurologist. By time I got Anti-MAG diagnosis, much of my nerve damage is irreversible.”

In our latest survey, we delved deeper into people's daily realities of waiting and accessing care. Two thirds of people told us that they disagreed with the statement "While I wait for the treatment and care that I need, I am kept informed and feel supported", with nearly a third saying they strongly disagreed. People with multiple neurological conditions, females, and those not in employment were more likely to disagree.

More than 4 out of 10 people told us they couldn't see a specialist when they needed to - this was for a variety of reasons, including the fact that they couldn't book ahead, cancellations to their existing appointments, a lack of specialists with the right expertise or just waiting to see someone.

We also wanted to know more about what people wanted to see from the NHS. Treatment, care and support for people affected by neurological conditions has changed dramatically. Of course, we now know more on how to treat many neurological conditions in a better way - the challenge is making sure we have the people and services in place so people can access support.

Your message was clear - you want to see an NHS where staff know more about neurological conditions, shortened waiting times, action to tackle overstretched staff and measures to make it easier to see your GP.

“Because the staff are so stretched, it makes it hard to do what they need. So the way things are run need to be sorted to help everyone”

The NHS turned 75 in July, and we are heading into a General Election. We will be calling on leaders across the UK to do all they can to address these priorities. People with neurological conditions have waited too long.

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](mailto:helpline@brainandspine.org.uk).

Thank you so much.

**Marc Smith, CEO Brain and Spine Foundation**

**Georgina Carr, CEO Neurological Alliance (England)**

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## Background

NeuroLifeNow is a platform designed to support people and share their daily realities of living with neurological conditions. Insights are shared with NHS Commissioners, UK Governments, and clinicians to influence how neurological services are delivered and to drive positive change.

This report focuses on the findings of the survey running over March and April 2023. Along with the health and care related questions we ask about consistently to monitor change over time, this survey focused on finding out about your priorities for the NHS, and access to care and support services.

## Your Priorities for the NHS

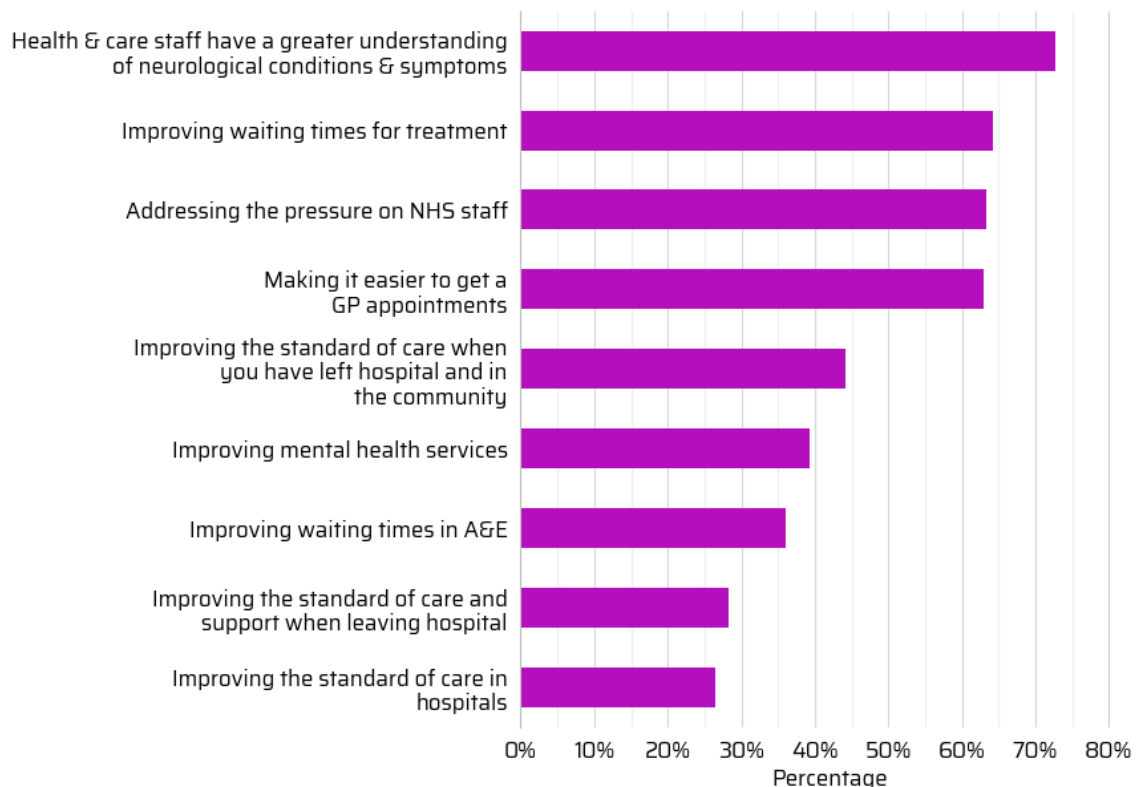


Figure 1: Priorities for the NHS.





### **“Patients are suffering.”**

“The NHS is in crisis and we are all suffering.”

“Without these improvements, it is what is keeping me permanently covered in multiple old and new head and body injuries. My worst injury is more than 6 months old and still has not recovered any treatment....”

### **Based on personal or peers’ experience**

“Because I provide peer-peer psycho education where people always talk about these issues and have experienced them myself.”

### **Poor health service experience**

“My recent personal experience: 11 hours in A&E; another 2 hours to be further assessed by a doctor and admitted; 3 weeks in the Emergency Assessment Unit with no windows, no way of getting out (had lost use of left limbs within days of admission), two patients in bay had severe dementia with challenging behaviours and should never have been there.”

“After having to spend a night in A&E it was a very scary experience when they seemed to have literally no idea about my condition.”

### **Importance and relevance**

“They have the greatest impact on my life.”

“These seem to be the most urgent.”

### **Theme 2: Long waiting time**

Long waiting time, lack of regular appointments, difficulty in getting appointments and appointment time being too short were also listed as the reasons that motivated the respondents to pick the priorities they have chosen.

“Waiting times for treatment have to be improved as people are losing their lives.”

“Waiting for help for nearly 2 years for a brain condition is not acceptable!”

“Waiting times for A&E and hospital appointments are way too long, it causes more damage and deterioration in health.”

### **Theme 3: Lack of support**

This theme reflects the poor aftercare and community care after respondents’ diagnosis or discharge. This lack of support made them feel abandoned and impacted their mental health.

### **Lack of support after discharge or diagnosis**

“There is a lack of care once you are back in the community. Follow up for chiari malformation is practically non-existent.”

“I feel the service of care when you are in hospital is often second to none, but the minute you are discharged, your on your own.”

### **Feeling abandoned**

“I know I feel abandoned, slowly deteriorating. Sometimes, instead of having to , I just want to feel looked after for a change.”

“I felt completely dumped by the Hospital post op. A phone call for physio after spinal surgery for a spinal surgery. Letter to GP from surgeon took 3 months to arrive. I only found about a local gym’s hydrotherapy pool by chance”

### **“Theme 4: Overstretched NHS**

Another reason respondents cited is that NHS is overstretched, with their staff needing more support to ease their pressure. Given that NHS is under-resourced, some also expressed that it needs to be restructured.

### **NHS staff need more support to ease their pressure**

“Nhs staff have worked very hard over the past 4 years and many are exhausted.”

“Because the staff are so stretched it makes it hard to do what they need. So the way things are run need to be sorted to help everyone”

### **NHS is under-resourced and needs to be restructured.**

“The NHS is underfunded and under resourced. The staff are unable to supply the care which we, the public need.”

“The system is failing and going under. Immediate help is needed. There is no point further educating about condition if its virtually impossible to see a doctor/specialist anyway.”

### **Theme 5: Lack of awareness of neurological conditions**

There is also a lack of awareness and understanding of neurological conditions. This is reflected by the lack of training for health professionals.

“NHS staff have to have a greater understanding of traumatic brain injury, although it is very difficult with invisible disabilities.”

“Even though it is a chronic & progressive spinal cord injury, because it is incomplete, it is not well understood by my GP, Spinal Nurse Specialists or my neurosurgeon.”

“I waste 90% of my time at appointments explaining my rare condition before I can get to the reason why I’m there.”

” Perhaps awareness, more empathy, understanding and patience could be offered by those especially those working in a neurological setting.”

### **Theme 6: Poor communications among health professionals**

Another theme that emerged is that there is poor communication among health professionals. The respondents expressed that a more holistic and personalised approach is needed.

“Co-ordination between GPs and specialists appears limited and disjointed- I have barely seen a doctor since 2019 and can only speak to a neurological consultant through a GP referral. If they then don’t see a problem on a CT scan, I’m referred back to my GP to live in pain/exhaustion and with limited mobility.”

” I really need specialised care that’s absolutely tailored to my needs, and I also need for it to be easy to access. I’m struggling with things such as getting to appointments and then finding it was not worthwhile because of the gaslighting trend amongst insincere and arrogant medical practitioners. My conditions aren’t even rare!”

“The communication between different hospital departments and GP’s surgeries does not fill me with confidence. There needs to be a more holistic approach and way that information is passed around.”

### **Summary of other key Findings**

- 283 respondents completed the March-April 2023 survey, with 65 conditions represented. The top 3 most frequently reported conditions are Dystonia, Functional Neurological Disorder and Chiari Malformation.
- Nearly half (48.41%) of people disagreed with the statement "I feel listened to by my health and care professionals".
- Nearly 4 out of 10 (39.22%) said they disagreed with the statement "I know who to contact if I have a question about my neurological condition or if it changes".
- 66.79% of people disagreed that "While I wait for the treatment and care that I need, I am kept informed and feel supported".



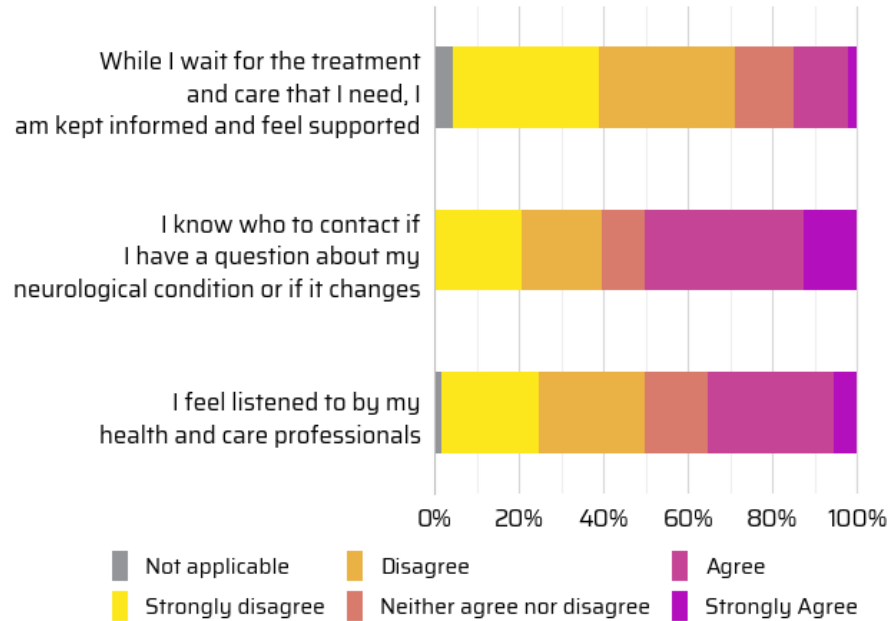


Figure 3: Access to health and care.

- Females were less likely to agree with all statements, as were those with multiple neurological conditions.
- When respondents did speak to a specialist, 84.82% said it was convenient to do so. 6.35% said it was not at all convenient.
- When people were not able to speak to a specialist when they wanted to, 46.64% went without any support, 27.92% went to an appointment in the future, and 11.31% had a consultation over the phone. 1.77% went to A&E or a Walk-in Centre.
- 63.96% of respondents had access to medical appointments in the last eight weeks. 65.02% were found to be helpful (down from three quarters in January and February). Most people had one or two appointments in the past 8 weeks.
- 35.33% said they felt their experience of healthcare in the past 8 weeks had been poor or very poor.

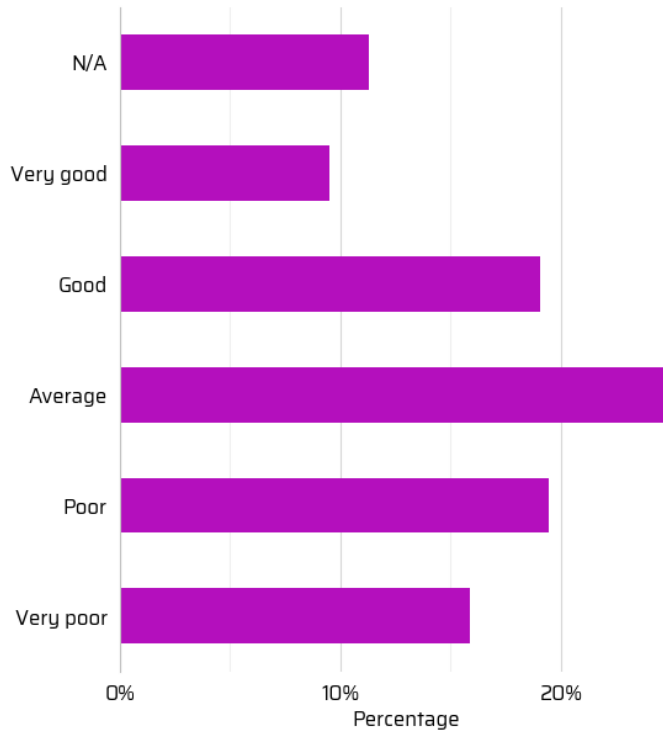


Figure 4: Overall experience of healthcare.

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