



NeuroLifeNow

May - June 2023 Report

Work experiences

Brain & Spine
Foundation



About NeuroLifeNow

NeuroLifeNow was launched in January 2021, enabling people to meaningfully share their stark daily realities of living with a neurological condition(s) to inform positive change to policy and services.

NeuroLifeNow 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 can 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.

NeuroLifeNow has enabled us to unify and amplify your voices to drive improvements that will transform the lives of millions.

Foreword

Every aspect of your life can be impacted by living with a neurological condition, and this is particularly true of work. Far too often, we hear from people who have not received the right support from their employer, aren't able to access the right adjustments for work, or aren't aware of the financial support they are entitled to. At worst, we hear about the stigma and discrimination people face in the workplace due to their neurological condition.

“I was bullied out of every single work job I ever had, purely because all colleagues could never be bothered to assist me during any of my lifelong fully uncontrollable epilepsy seizures.”

That's why we wanted to take a deeper dive into the relationship between work and living with a neurological condition this summer. One in five told us that they had to leave their job because their employer failed to make the right reasonable adjustments. Four in 10 said their manager and/or colleagues did not understand the challenges of living with a neurological condition. A quarter had experienced discrimination in the workplace. This has to change.

“I cannot financially survive on benefits and pay for the costs associated with being unwell as well as paying for care. I try to remain positive but it's a very bleak and isolating existence.”

You also told us about the impact of leaving work. About the loss of identity many experienced, and huge impacts on self-esteem. All of this could be avoided, with the right support to get into the right employment, the right adjustments and attitudes to enable people to stay in work as long as possible and the right support to leave work “well”.

“It's hard. Really hard. I've gone from being on top of my game to what feels like the bottom of the pile and it's heartbreaking.”

Your insights and evidence have informed a new programme to address these issues in the workplace. The Brain and Spine Foundation will launch this initiative in 2023 so that people affected by neurological conditions receive the support they need and deserve.

More broadly, the insights you have shared will help to campaign for improved financial support. The Department for Work and Pensions (DWP) is currently reviewing the way in which it supports people with disabilities to get into and stay in work, as well as how assessments for disability benefits (such as Personal Independence Payments) are carried out. Together with charities across the country, the Neurological Alliance is calling for much needed improvements for people affected by neurological conditions.

“It's so hard to explain to colleagues that for me to walk somewhere else in the building is like them running a marathon. People also struggle to understand the variability of my condition or how getting a cold affects me compared to them.”

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)

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Background

This report focuses on the findings of the survey running over May and June 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 experiences of work.

Key Findings

- **371 respondents** completed the May-June 2023 survey, with **67 conditions represented**. The top 3 most frequently reported conditions are Dystonia, multiple sclerosis (MS) and Functional Neurological Disorder (FND).
- **37.44% said they had not been able to continue to work** due to their neurological condition.
- **21.83% said they had to leave a job because of their employer's failure to make reasonable adjustments**. People living with multiple neurological conditions or conditions other than their neurological conditions were more likely to report this.
- **26.81% said they had been discriminated against at work** due to attitudes towards their neurological condition. Females, people living with multiple neurological conditions or conditions other than their neurological conditions were more likely to report this.

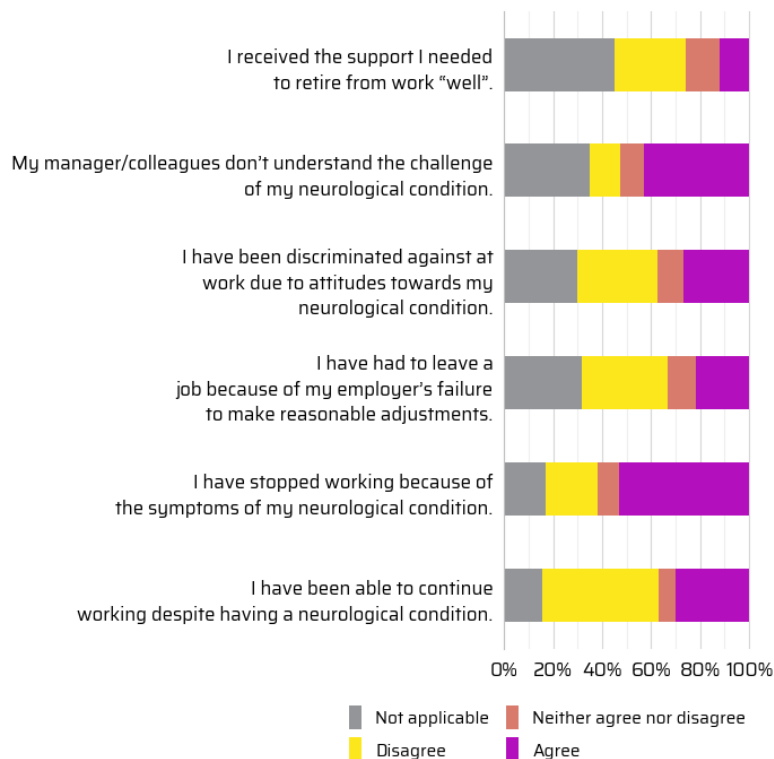


Figure 1 : Workplace experience: overall.

What you told us about your workplace experiences...

Theme 1: Inclusive hiring process.

“Celebrate diversity. Be transparent on the support and adjustments they can offer.”

Respondents suggested that employers should be non-discriminating and transparent during the hiring process. Ideally, they should state in the job advertisement that they are an inclusive workplace.

“During the recruitment process it would be helpful for employers to demonstrate awareness of health conditions (not just neurological) and give example of how they might make adjustments so that potential employees aren't afraid to ask.”

Theme 2: Improve understanding on neurological conditions.

Educate themselves.

Employers should educate themselves about neurological conditions to improve their understanding.

“More understanding of these conditions my manager googled RLS and was shocked she she said. Then understood why I couldn't work when I'd had not slept.”

Ask and listen.

Improve their understanding on neurological conditions is to ask and listen to their employees with neurological conditions.

“Just by asking how to support me and try to accommodate adaptations”

Staff awareness training

It is important to raise awareness and understanding about neurological conditions in workplaces, which can be implemented by providing awareness training.

“I didn't talk much about reason for poor memory, I took lots of notes, my boss joked about my notebooks, if there was online resources that employees could bring to the attention of their employers if would be great.”

Show understanding, compassion, and acknowledgement.

Show understanding, support and acceptance towards employees with neurological conditions. Employers should acknowledge the hard work and impact of people's conditions.

“They need to be active in their support rather than segregate people with neurological conditions.”

Research

Employers are also urged to conduct more research to understand how to make their workplaces more inclusive, such as by forming focus groups and reaching out to charities.

“Research, ask questions, form a focus group, speak to charities. Invite open communication.”

Theme 3: Offer support proactively

Make reasonable adjustments

“Some basics could include level access, hand rails even on flat corridors, disabled toilets with alarm cords....”

Employers should offer support proactively by making reasonable adjustments for employees with neurological conditions. This includes providing specialist provisions, occupational health, disable-friendly facilities (wheelchair access, disabled toilet, and automatic door), quiet space, and disabled parking spaces.

“Provide wheelchair access and disabled toilet as minimum and compulsory.”

“Arrange parking spaces at work and a 'quiet room' for sleep/rest.”

Support group/disability network

Support groups or disability networks should be formed.

“start support group” or “Having a disability network....”

Supplementary support e.g., Insurance claims

Supplementary support that employers can offer.

“Having...disability passports” or “Assisting with insurance claims”

Regular check-ins

Having regular check-ins with the employees with neurological conditions.

“Regular assessments as neurological conditions change frequently and this would help both the employer and me living with a neurological condition adapt where necessary.”

Legislation and policies

Having protective legislation and implementing inclusive policies.

“By properly implementing their inclusion and diversity rules and not just playing lip service to them.”

Theme 4: Flexible working

“Allow flexi-time/reduced hours/ permission for "time-out" during working hours to rest and recuperate.”

Employers should offer more options for flexible working to make their workplaces more inclusive for individuals with neurological conditions. This includes option to work with reduced hours, part-time, flexitime, having time-out, having disability leave, option to work from home, and option to consider an alternative role.

“Having disability passports and disability leave for those days you are sick because of your condition. So this is dealt with differently to ordinary sicknesses.”

“by allowing time off for medical appointments.”

Theme 5: No “one size fits all” solution

Some respondents have to acknowledge that neurological conditions are complex and there is no “one size fits all” solution.

“It would help if they were more open to acknowledging differences. Management training seems to instill a one-size-fits-all approach instead of one that encourages managers to be sensitive to differences between people.”

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