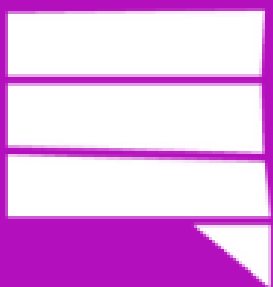


# Annual Report

## 21-22



# NeuroLifeNow

It's time to make your story heard

# Foreword

**There are more people in the UK living with a neurological condition than cancer, heart disease or diabetes. Change is needed urgently because the current system is under-funded, inadequately resourced, and fails individuals and families too often.**

NeuroLifeNow was launched in January 2021 as a vehicle for change. Through the innovative app and web-based technology, we have captured real-time evidence from people across the UK about the stark realities they face accessing treatment, support and care for their neurological condition(s). NeuroLifeNow is a research platform that unifies and amplifies your voice to drive improvements that could transform the lives of millions.

Between January 2021- January 2022, over 1,900 questionnaires were completed. **You told us that you feel invisible.** That you wish UK Governments, health and care services, the benefits system and society as a whole understood the pain and unpredictability of your condition(s), along with the life-changing and life-long impacts.

Your insights have been shared with UK Governments, healthcare services, Ministers, Westminster and Whitehall and **have contributed to important successes:**

- In late 2021, Prime Minister Boris Johnson confirmed that a UK-wide strategy for Acquired Brain Injury (ABI) and other neurological conditions will be developed and work has already started on the implementation process.
- NHS England and NHS Improvement prioritised neurology and neurosurgery services as part of elective care recovery.
- Insights taken from NeuroLifeNow have been shared with more than 450 health and care professionals, NHS managers, commissioners and providers across the UK.
- New educational materials are being developed to support mental health services to reach people with neurological conditions.

**But we will not stop there.** Too often you are having to fight for the treatment, care and support that could transform your life and help you to live independently.


Through NeuroLifeNow, we know that people are willing and determined to share their 'lived' experience to influence and inform positive change. Across all four nations of the UK we strive to deepen our engagement with health and care services and build collaborative relationships with organisations that can positively impact the lives of people affected by neurological conditions – at an individual, community, systemic and societal level.

**A huge thank you must go to all the people who have contributed to NeuroLifeNow, and to all organisations that have so generously supported this innovative project. Despite the very real challenges we face, we are confident that 2022 will be a watershed moment for our community and we hope to secure the changes needed to improve treatment, care and support for all.**



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



**Georgina Carr**  
CEO, The Neurological Alliance (England)  
 **THE  
NEUROLOGICAL  
ALLIANCE**

# 21-22 in a snapshot

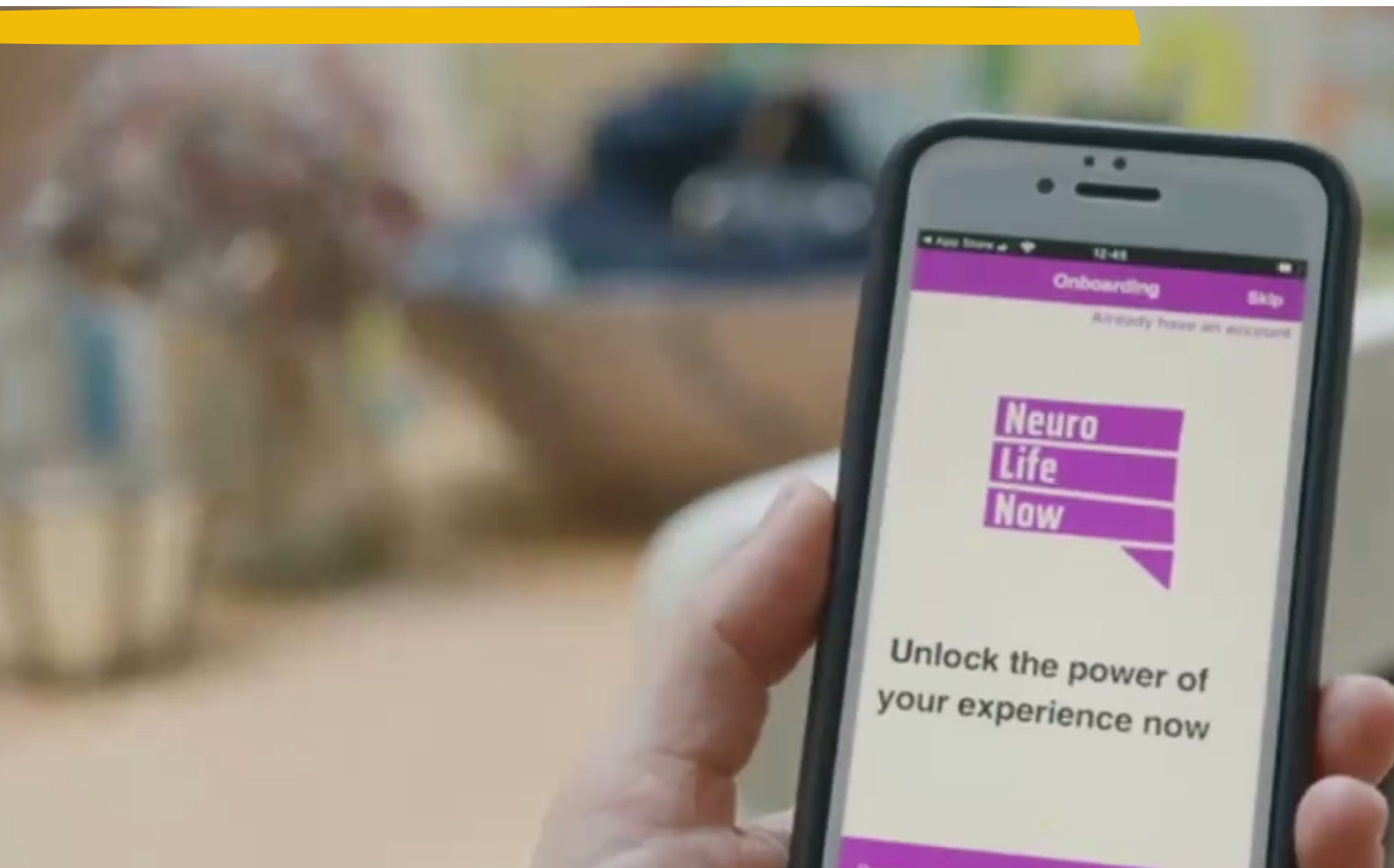
**9** research reports were published between January 2021 - January 2022

More than **850** people registered to take part in NeuroLifeNow research in 21-22

**1,903** questionnaires were completed

More than **62** different neurological conditions were represented

People from **all four nations of the United Kingdom** were represented





# Key wins so far

- Data shared from NeuroLifeNow has made the case for the **urgent recovery of neurology and neurosurgery services**; both were prioritised as part of NHS England and NHS Improvement elective recovery in 2021.
- We presented evidence from NeuroLifeNow to the Minister for Health, Edward Argar MP, in spring 2021. As a result of the discussion, **the Minister supported measures to aid the recovery of neurology and neurosurgery elective care.**
- Experiences taken from NeuroLifeNow have been shared with **more than 450 health and care professionals**, NHS managers, commissioners and providers across the UK.
- We're hopeful that National Clinical Directors for both neurology and neurosurgery and spinal surgery will be appointed in England imminently – **NeuroLifeNow data has helped to build the case for this.**
- Together, we have secured a new Cross Governmental, UK-wide strategy for Acquired Brain Injury (ABI) and other neurological conditions – **this is an important opportunity for change.**
- Croydon University Hospital has shared NeuroLifeNow as part of routine neurology outpatient care since May 2021. 16 appointments were reported against, including with a specialist nurse and neurologist. **These insights are now being used to consider areas for improvement to their service.**

**“We are proud to have strong patient involvement and work in partnership with the Neurological Alliance and neurological charities such as the Brain and Spine Foundation. NeuroLifeNow would provide crucial feedback from patients and we absolutely support this project.”**

Mike Dilley and Rachel King, of South London Neurosciences Operational Delivery Network (ODN)





"It is important to be treated fairly. People with neurological conditions **feel invisible**. They change the way you live your life..."

"It is a **constant battle** which society very often does not see, and the government needs to act on our behalf."

"Every day is a battle. I need help for every day things: dressing, washing, going to the toilet - **it is physically and mentally exhausting**. I shouldn't have to jump through hoops to get help when I was born this way."



"**We exist** - we were invisible **before the pandemic** and are becoming **invisible again now**."



"Self advocacy is vital in order to be seen and heard. **There is very little support for people with conditions such as ours**. The routes to finding a consultant who truly understands the complexities of neurological conditions and has time to listen, research and respond are so complex... this app seems a positive move towards finding a voice for those with neurological conditions."

**"It is critical that the experiences of people with neurological conditions shape how we deliver care. This platform – NeuroLifeNow – will enable us to do just that. I fully endorse the project and look forward to utilising this work as part of my role to drive forward transformation in neurosciences."**

Professor Adrian Williams, Chair of NHS England Neurosciences Clinical Reference Group & National Neurological Advisory Group

**Thanks to you, we have engaged with decision-makers, NHS commissioners and clinicians across the UK to influence how neurological services are delivered.**

However, more than 176,000 people in England were waiting for an NHS neurology appointment by December 2021 – that is more than a 54% increase since January 2021. More than 3,500 people have been waiting **more than a year**. More than 52,000 are waiting for NHS neurosurgery – 4 in 10 wait more than 18 weeks.

Patient experience library (2022), Waiting lists tracker, <https://www.patientlibrary.net/cgi-bin/library.cgi?page=WaitingLists> (accessed 5 April 2022)

- 2,001 health and care appointments were shared with us last year. On average, **1 in 5 were considered unhelpful**.
- **58%** of you said you felt **anxious or hopeless**
- On average in 21-22, **47% of you said your mental health needs were not being met**
- 1 in 5 people said they were **struggling financially** in November/December 2021.
- In November/December 2021, nearly 1 in 4 people were reporting **delays to their care**
- By November/December 2021, **60% of respondents** said their experience of neurology services was good. **But, 1 in 5 reported their experience of their neurology services was poor.**

NeuroLifeNow data

**As of October 2021**, 1 in 4 first neurology outpatient appointments in England were delivered remotely. 46% of follow-up outpatient appointments were delivered remotely. Overall, neurology outpatient activity in October 2021 **grew by 1.2%** compared to October 2019. However, some regions are still catching back up from the impacts of the pandemic – the East of England neurology outpatient activity decreased by 3.8% in October 2021 compared to October 2019, and the West Midlands decreased by 5.4%.

Public Health England (2021) Wider Impacts of COVID-19 on Health (WICH) monitoring tool <https://analytics.phe.gov.uk/apps/covid-19-indirect-effects/> (accessed 5 April 2022)

# Jan's story

**I have never stopped living my life and fight to continue to do the things I love until I can't.**

I was finally diagnosed with Chiari malformation in 2000. Like many, I had had a few years of misdiagnosis and then the suggestion that symptoms were psychosomatic. I never had severe headaches but had symptoms similar to multiple sclerosis and was struggling to work as a ward-based nurse at the time.



I had foramen magnum decompression in March 2001. It is known that approximately 20% of people do not have long-term relief from symptoms and get worse. I fall into this category. **Over the last twenty years** have been investigated for the usual associated conditions of Chiari such as syringomyelia and other neurological problems, **with no answers as yet**. I am currently having further tests for a second diagnosis, however, I am aware there may not be a diagnosis as it could be related to Chiari and that neurology is a complex field.

Over the last four years I have become significantly disabled, which was a shock. I am told I have complex symptoms by my specialist physician who has been absolutely fantastic in his care of me, he and my GP are extremely supportive which I know I am very fortunate to have.

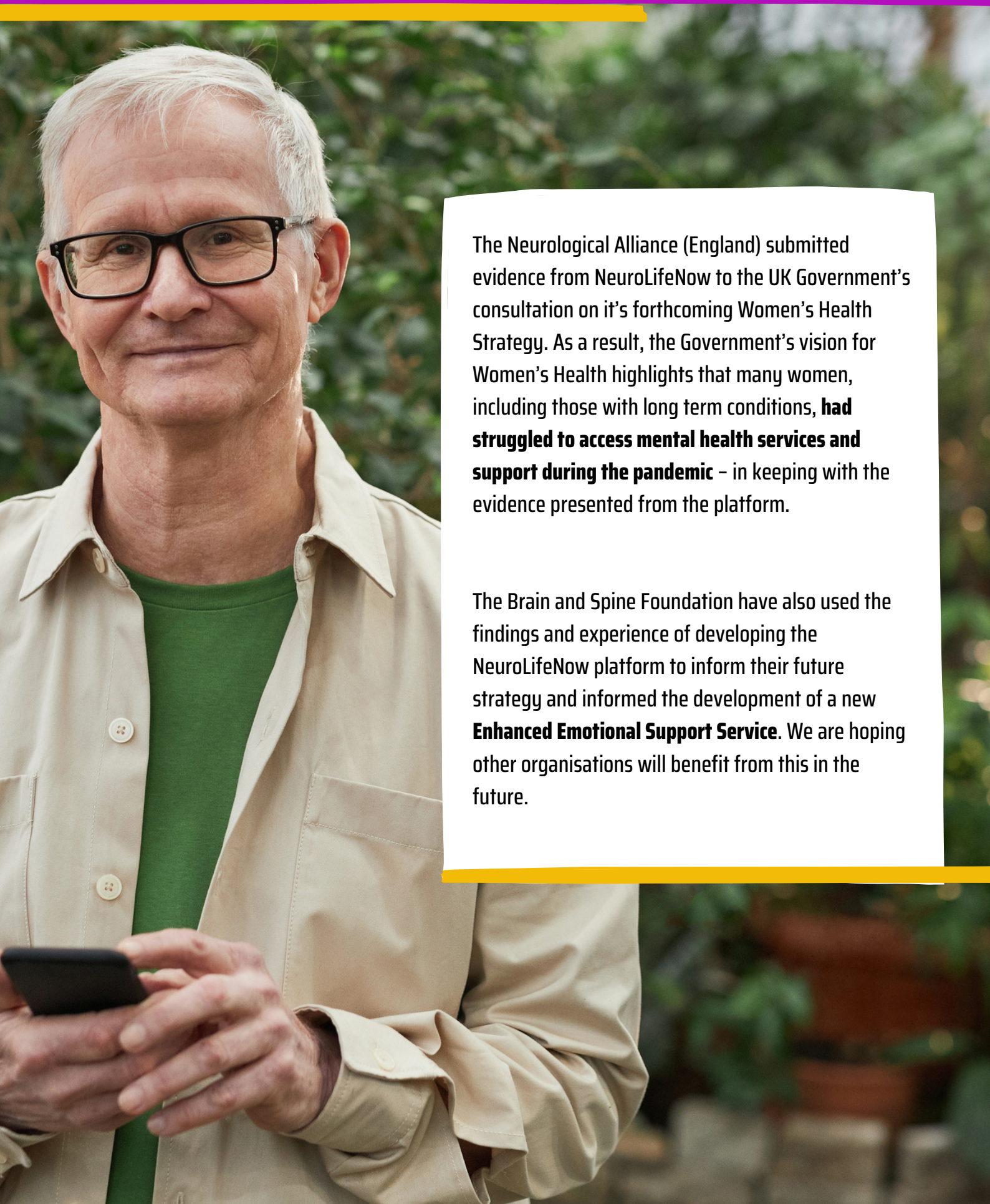
The **complete lack of information** (either written or when I have appointments with neurologists or neurosurgeons) for people living with this deteriorating disability and the daily symptoms, I have found so disappointing. The surgery didn't fail, as far as I know, this is just how it is for some people with Chiari. I don't blame anyone for that part. But where is the specialist support now? **It feels like they have given up on me.**

Wanting answers is not unreasonable and for a specialist to say "I really don't know, but we will support you" is also an honest and welcome response should it ever be forthcoming. **It's fair to say that I am angry about the lack of neurological care** and they do not seem to appreciate how much of an impact uncertainty, worsening disability & symptoms have on me. I know the symptoms and disability can't be reversed but it does not feel right to be **abandoned by experts.**

Despite the daily struggles and the uncertainty I face there have been many positives. In essence: living my life, spending time with those I love, doing the things I enjoy and having my wishes and preferences for when I get worse is the only control I have and is vitally important to me. My philosophy in life is: **everyone is fighting a battle you know nothing about, be kind always.**



# Further impact



The Neurological Alliance (England) submitted evidence from NeuroLifeNow to the UK Government's consultation on its forthcoming Women's Health Strategy. As a result, the Government's vision for Women's Health highlights that many women, including those with long term conditions, **had struggled to access mental health services and support during the pandemic** – in keeping with the evidence presented from the platform.

The Brain and Spine Foundation have also used the findings and experience of developing the NeuroLifeNow platform to inform their future strategy and informed the development of a new **Enhanced Emotional Support Service**. We are hoping other organisations will benefit from this in the future.

## In the next 12 months

- The NeuroLifeNow platform is designed to amplify your thoughts, feelings and experiences. **A new engagement panel led by people affected by neurological conditions** will be created to enhance the platform's capability and improve digital experience.
- We will develop **new ways for people who are less digitally confident or lack access to digital technology** to engage with NeuroLifeNow and ensure their voice is heard.
- We will grow the NeuroLifeNow community to 2,500 people and ensure that a **diverse range of people with neurological conditions are represented from across the UK.**
- We will work to **improve our ability to analyse and present insights** of the lived experiences shared for maximum impact.
- We will work with local, regional and national levels of Government to influence and **inform change at individual, community, system and societal levels** across the UK.

## In the next 1-3 years

- Your **interactions with health and care professionals are more helpful.**
- You will report **fewer delays to care and support**, and that your needs are being heard and acted upon.
- Additional **investment in research and services is secured** so that we can understand more about the causes, treatment and potential cures for neurological conditions, while improving services in the here and now.
- **Families, friends and carers have ways to connect with and share their lived experiences** through NeuroLifeNow.
- You **feel less isolated and better supported.**





**Thank you for your support**  
[neurolifenow.org](https://neurolifenow.org)

Brain & Spine  
Foundation



Brain & Spine Foundation registered charity no. 1098528  
The Neurological Alliance (England) registered charity no. 1039034