

Brain & Spine
Foundation



Impact Report 22-23

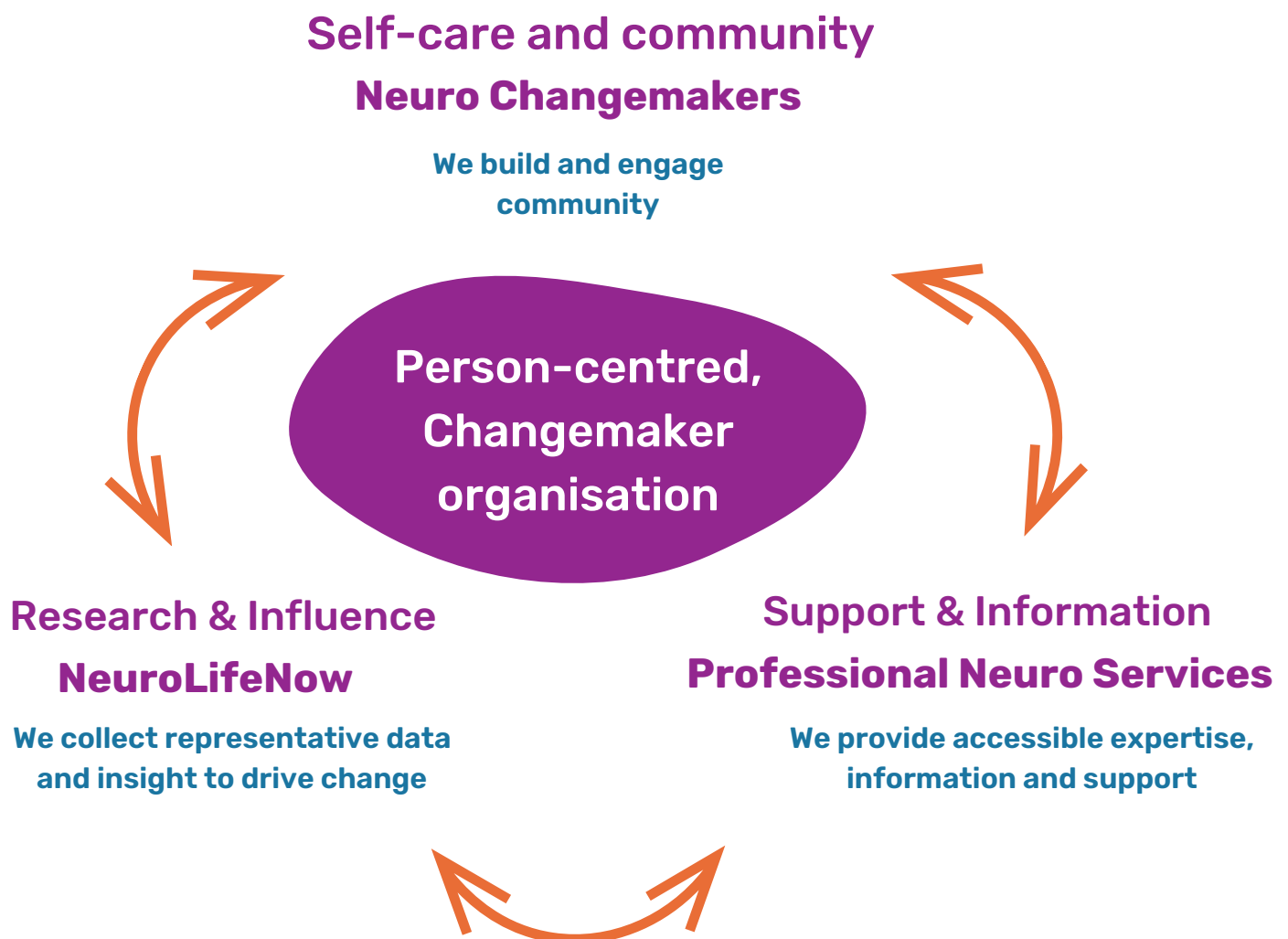
Your support transforms lives of people
affected by neurological conditions

Thank you for your support

Our mission is to transform the daily reality of each person affected by any neurological condition, anywhere in the UK: through frontline professional services, innovative social research, and bold campaigning for change.

Thanks to your dedicated support, no one faces their neuro journey alone.

Our proposition



Our reach in numbers

257 people registered to join a peer support group

1,686 people contributed to NeuroLifeNow research

15,660 people directly and indirectly supported by the Helpline, including family, friends and unpaid carers

21,647 health information publications and fact sheets posted to our community and hospitals, or downloaded from our website

41,293 people support the 'neuro' cause by being part of our social media community

532,000 people visited our website to access professional, tailored support and health information, or to join our community of Neuro Changemakers

**Neuro
Changemakers**

600,000
people



Neuro Changemakers: raising the profile of what the neuro community lacks and involving this community in providing solutions.

We believe any person affected by a neurological condition is a Neuro Changemaker, including everyone who gives their time and energy to build connections between people.

We know from our Professional Neuro Services work there is an overwhelming lack of support that cannot be met by the state. We aim to mobilise a community of 'experts by experience' who can combine to create a network of local groups across the UK.

Neuro Changemakers, through the power of grassroots activity, will become a compelling voice of change that is urgently needed .



Paul Flitcroft, Director of Engagement, said:

Anyone who drives positive change for the 'neuro' community is a Neuro Changemaker. You can volunteer, donate, fundraise, set up a local group, campaign, contribute to research, and share your story. All these actions are valuable and much needed.



I rang the Helpline and the nurse listened to my symptoms. She gave me the drive to keep going and fight to be the healthiest I can be.

Free, professional Helpline

We know that asking for help is not always easy. Discussing your symptoms and diagnosis, or condition and the challenges you are facing can be emotional and difficult. Some people may have experienced stigma when trying to talk to others.

Our national Helpline service provides a trusted safe space where anyone can seek practical and emotional support, clarity and reassurance. Run by experienced neuroscience trained professionals, our nurses understand the complexity of neurological conditions and the difficulties that people can encounter.

We piloted a new emotional support service for people who are experiencing high levels of anxiety and distress on their neuro journey. Thanks to its success, we will expand this activity.



15,660

people directly and indirectly received life-changing support from a neuroscience nurse on our Helpline



Health anxiety

and lack of access to neurological services were the most common reasons for contacting the Helpline

I searched up quite a bit on the internet and that is where I found the Brain & Spine Foundation website. That was very useful and it is easily accessible.



Health information

We create and publish high quality, accessible health information for anyone affected by any neurological condition and for use by healthcare professionals. Recent surveys report that **more than 35% of people don't get written information at the time of diagnosis.**



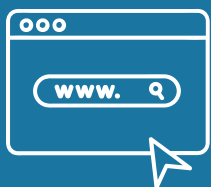
21,647

people downloaded or received one of our health information resources in the post



41

hospitals in the UK received expert health information to support patients, and their loved ones



532,000

people benefitted from the health information resources available on our website



I really enjoy the interaction with other people that don't judge me and can relate to me.



Peer support

In 22-23, we ran seven different weekly, bi-weekly and monthly online support groups - **Neuro Social (plus 3 regional groups), Neuro Creatives, Neuro Writing and Neuro Carers**. These groups enable participants to share personal experiences of neurological conditions, build new friendships, and tackle widespread loneliness and isolation.

Our **Neuro Creatives programme** is led by an experienced arts counsellor and aims to help people improve their emotional, social, and physical wellbeing. Using different art forms such as painting, drawing, and collage, these arts for wellbeing sessions support group members to express their emotions, reduce stress, and increase self-awareness. Being part of the group also improves people's social connections and provides a sense of belonging and community.

We also continued to welcome members to our two, condition-specific Facebook groups that provide peer support for people living with a Chiari malformation and for survivors of subarachnoid haemorrhage (SAH). These groups connect people with shared experience of these comparatively rare conditions, offering a safe and welcoming space where they can discuss experiences, share advice and offer mutual support.



4,595

members of our condition-specific Facebook groups sought support from their peers



257

people welcomed into one of our online peer support groups



Last year, we continued to advance our strategic transformation through the design, development and delivery of a digital engagement platform, [NeuroLifeNow](#). The social research platform captures lived experience in real-time and this insight helps **drive improvements in health and care** for the neurological community.



1,686

people living with neurological condition(s) contributed to research through NeuroLifeNow



2 in 3 people

shared feelings of hopelessness or anxiousness



1 in 5 people

reported having poor healthcare and social care experiences overall



It is critical that the experiences of people with neurological conditions shape how we deliver care. I look forward to utilising this work as part of my role to drive forward transformation in neurosciences.

Professor Adrian Williams

Finances 22-23

**85p of every £1
goes directly to
helping people in
need**

**Total income
£718,620**

**Your generosity funds life-changing
services, research, and change.**

**A huge thank you to all our supporters and
funders, including:**

The National Lottery Community Fund
Irwin Mitchell
Boston Scientific
UCB
Garfield Weston Foundation
Peter Sowerby Foundation



And our wonderful individual donors, volunteers and Ambassadors.



Sammy's story

I was 15 when I first started experiencing dizziness, spinning vision and nightly head rushes. By the age of 18, these dizzy spells became monthly occurrences, and I went to the doctors. They sent me for an MRI scan to 'rule anything out.' But that's when they discovered a benign brain tumour.

I was told it was low-grade and had probably been there since birth. It wasn't cancerous and for a long time they didn't even call it a tumour, referring to it as a "lesion in the fourth ventricle." I was put on a watch and wait plan with yearly MRI scans and told that I'd be discharged in 2018. But as genuine luck would have it, that "final" scan showed that the **tumour had doubled in volume** and was dangerously close to blocking the cerebrospinal fluid (CSF). The best solution would be to biopsy the tumour to assess the true grade and remove as much as possible.

In June 2019, I had brain surgery but as soon as I woke, I couldn't see or speak and knew something was wrong. I'd fallen into the 2% risk of suffering a cerebellar stroke, affecting my vision, mobility and **resulting in permanent facial nerve damage**.

I embarked on a long road to recovery, learning how to walk, write and feed myself again with daily physiotherapy. During this time, I founded my own brand of motivational quote jewellery, t-shirts and stationery that donate a percentage of profits to charity. Not only did every aspect of running a business aid my recovery – from handwriting labels to strengthen my weak right arm, walking to the post office and improving my cognitive function by writing blogs – it also gave me a real purpose by connecting to others, sharing experiences and holding on to the belief that life could still be wonderful even without following the original plan I'd created.

In 2020, I had two further eye surgeries to correct my double vision and to insert a weight in my eye lid so I could blink again. **I also became the first person in the UK to have a pioneering facial reanimation surgery that has helped restore some movement to my face.** Recovery was the hardest part for me. My friends were all at very different stages to me and I constantly felt behind relearning the basics again while they were getting married and buying houses.

But over time, I began focusing on my own path, realising that everyone goes at their own pace in life. I kept reminding myself that I wasn't behind in my life, I was simply living a new path and going at my own speed. And I became much more accepting of my situation.

I'm now on a mission to share that with others to support them in their own journey of challenges. I volunteer for the Brain & Spine Foundation as their Volunteer Lead for a social and peer support group in the South East of England.

Find out more: brainandspine.org.uk/sammys-story



Get in touch

There are so many ways you can make a difference to people living with neurological conditions, their families and carers.

Whether you choose to take part in an event, fundraise for us, make a donation, or leave a gift in your Will – your support, however big or small, will ensure no one faces their neuro journey alone.

We'd love to hear from you.

To make a one-off or regular gift, please visit brainandspine.org.uk/donate or call **020 3096 7880**

To take part in one of our charity fundraising events, please visit brainandspine.org.uk/event to find out more.

To speak to a neuroscience nurse for professional or emotional support, call free on **0808 808 1000** or email helpline@brainandspine.org.uk



Scan to find out more



Brain & Spine Foundation

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