



**'It's all in your head': Our report into  
the journey and impact of diagnosis**

**More than a roof: Help us raise £150,000**

**What is masking?**

# Join us at The Brain Charity's annual celebration

The Brain Charity's informal AGM and annual report launch takes place on Wednesday 22nd November this year from 4.30 - 7pm.

The evening will be a wonderful opportunity for our dedicated staff, volunteers, clients, trustees, stakeholders, funders, and other organisations associated with The Brain Charity to get together to celebrate our work over the past 12 months and get a glimpse of our exciting plans for the next year, spearheaded by our new CEO Pippa Sargent.

Also, you won't want to miss the 'soft launch' of our Neuro Gym and an exclusive preview of an upcoming ITN programme about The Brain Charity, '**Inside Neurology: Our Unique Brain**', which is set to air in late November or early December. We hope to see you there for drinks and nibbles - **please arrive at 4.30 for a 5pm start**.

RSVP by clicking the sign up button on this web page: [www.bit.ly/Nerve2212](http://www.bit.ly/Nerve2212)

## Liverpool Poetry Prize winners 2023

Having attracted over 200 entries, The Brain Charity's Liverpool Poetry Prize 2023 showcased the 12 shortlisted finalists at our Midsummer Poetry Night in late June.

Now in its second year, the prize was launched by The Brain Charity to amplify new, contemporary and neurodiverse voices, particularly from the neurodivergent community, and encourage creativity, which is beneficial to brain health.

There were two categories; the UniVerse Category, open to anyone writing on any subject, and the NeurodiVerse Category, designed to highlight the importance of artistic expression relating to neurological conditions.

**The winners from the shortlisted finalists were judged by Brian Patten, one of Liverpool's original Beat Poets.**

Brian said, *"The standard of the competition was spectacularly high. I enjoyed reading them all, and I'm glad to do my bit, however tiny, for The Brain Charity"*.

This year's NeurodiVerse category winner was **Carole Bromley**, a York-based poet, who writes for both adults and children. Her winning poem, **Lizard Hunt**, is about her grandson in Australia who is autistic.

The winner of the UniVerse category was Leicester-based poet **Nicholas Hogg**, whose poem **Missing Person** also triumphed overall to win the £1,000 prize.



Nicholas Hogg

You can read this year's winning poems here: [www.bit.ly/Nerve2309](http://www.bit.ly/Nerve2309)

# Funder and lightning

Under leaden grey skies, Liverpool's Anglican Cathedral played host to two groups of abseilers who braved the rainy July weather to take part in one of our most popular adrenaline challenges.

A total of 15 people abseiled from a height of 150ft from the cathedral's west door, many facing their fears in the process of raising funds for The Brain Charity. People came from all over the UK to participate on our behalf, including Tara who took the boat over from the Isle of Man. She said: *"It was a great day and an amazing experience. Thank you for letting me be part of it!"*

As the storm clouds gathered on both occasions, the cathedral was spectacularly lit with flashes of sheet lightning while the thunderous deluges of rain added to the general frisson of excitement.

Ray from the Malmaison hotel group embraced the challenging conditions. He said: *"I had a fantastic day. What's next? Parachuting? Or maybe a wing walk?"*

A group from HSBC in Yorkshire also took part, with two members of the team dressing up as the Mario Brothers. Rebecca said: *"It was so exciting, and we're so pleased to have raised as much as we have for The Brain Charity."*

In total, the abseilers raised an incredible **£13,000**, and we would like to thank everyone who took part for their generosity and support.

Next year's Liverpool Cathedral Abseil will take place in autumn 2024. To register your interest email [challenges@thebraincharity.org.uk](mailto:challenges@thebraincharity.org.uk)



Abseilers Julie and Tara



The team from HSBC in Yorkshire

## Free group counselling available

We provide 8-week courses of group therapy, in which you'll be able to speak openly about issues you are experiencing in a warm, safe and confidential space. By listening to others, it's possible to gain new insights, explore challenges and successes and feel less alone.

Group therapy is open to anyone who is neurodivergent or has a neurological condition, as well as carers and family members.

The groups are facilitated by two qualified therapists and start on Wednesday 4th October. If you would like to take part, please email [counselling@thebraincharity.org.uk](mailto:counselling@thebraincharity.org.uk) or call **0151 298 2999**

# More than a roof: Raising £150,000 to secure the future of The Brain Charity



**The Brain Charity's centre in Liverpool has been at the heart of everything we do for the last 30 years.**

From this hub, our staff support thousands of people affected by neurological conditions from across the UK each year. Our centre is also a safe, judgement-free space where clients local to Liverpool can receive information and advice, attend a range of social activities, volunteer or simply spend time in our café.

*Unfortunately, in recent years all this is put into jeopardy every time it rains.*

**We are facing serious issues with the roof of The Brain Charity's centre, which is now more than 30 years old.**

Frequent severe leaks have caused significant damage to the building, resulting in ceiling collapses and damage to walls and flooring.

This has meant that at times we have had to close parts of our centre and staff have been unable to work in certain offices, disrupting our vital services.

We are therefore now launching an urgent appeal to raise £150,000 to replace our centre's roof and add solar panels to make our building more eco-friendly and energy efficient.

**With the weather set to get worse as we move into autumn and winter, this has never been more urgent.**

We are calling on our supporters to help us by making donations, offering practical help in kind or by sharing this appeal. Every donation, no matter the size, gets us a little closer to a new roof for The Brain Charity. This is about so much more than tiles, flashing and gutters – this is about creating a safe and welcoming space for our clients.

**It's about securing the future of The Brain Charity and our services for many more years to come.**



*Damage to our office ceilings following a leak*

**To donate now go to [www.thebraincharity.org.uk/new-roof-appeal](http://www.thebraincharity.org.uk/new-roof-appeal)**  
***Thank you in advance for your generosity and support.***



# “It really boosted my self-esteem”

## The Value of You helps 200 clients

A project run by The Brain Charity has supported nearly 200 people in building their confidence and getting back into the job market.

Thanks to a £59,608 grant from Life Rooms, we were able to provide free confidence-boosting sessions to clients. These focused on building self-esteem to improve employability and overall wellbeing, reaching people who otherwise would not have had access to support of this nature.

In total 199 people took part in the project, receiving more than 400 confidence coaching sessions. The sessions included both one-to-one and group sessions. Of the 199 who attended:

- **123 received confidence coaching in a group setting**
- **76 had individual coaching sessions**
- **101 were parents or carers**



During group sessions, participants had the opportunity to meet other people living with neurological conditions and form friendships. They told us meeting others who understand and empathise with their situations and health conditions has helped improve their social isolation and provided encouragement.

One attendee said: *“I’ve never found anything like this before. It has been very important and helpful to me, and helped me understand myself and how I can achieve my goals. It really boosted my self-esteem.”*

Since the sessions, 28 people have become employed, 17 have entered education or training,

16 have gone on to become volunteers and 47 are actively job hunting. In total, more than 50% have progressed towards employment.

Another attendee said: *“I have more awareness of my strengths, I’m proud of being honest and saying my thoughts and feelings out loud.”*

Others told us they experienced reduced anxiety, understanding of coping mechanisms and awareness of their strengths.

The Brain Charity worked with a variety of partners to help promote the sessions, including Job Centre.

Jenny, a Disability Employment Advisor at Job Centre, said: *“The Value of You has been very beneficial for our customers that attended. It has supported a lot of people to move forward which can be very difficult due to not realising their potential and value. The project has enabled participants to become more self-aware and knowing of their own strengths.”*



*The Brain Charity's Confidence Coach Emily*

Photo credits: David Jones, brainstrust

# The Brain Charity calls for independent review into diagnosis of neurological conditions

## Our 'It's all in your head' report examines delayed diagnosis and misdiagnosis of neurological conditions

There are more than 1 million hospital admissions per year due to neurological conditions, with individuals often arriving at A&E at the point of crisis.

Early diagnosis is key to reducing this number and supporting people experiencing neurological conditions on what can be an uncertain and frightening journey.

The Brain Charity surveyed more than 800 people affected by neurological conditions to learn about their diagnosis experiences from their first concerns to life after a diagnosis.

Three key themes have emerged from the report; long waits for diagnosis, a lack of information and support and a negative impact on mental health after diagnosis.

### Key findings about delayed diagnosis and misdiagnosis of neurological conditions

- Nearly half (48%) left their first GP appointment feeling poorly informed about the next steps towards diagnosis or treatment
- More than a third (37%) wait two years or more for a diagnosis of a neurological condition
- Half of people (49%) say a lack of support and information led to high feelings of fear for the future

### Our call to action

We believe a more streamlined system which improves standards of care and support for people with neurological conditions would not only save public money, it would save lives.

Currently, mechanisms for more thorough nationwide consideration of these issues are lacking. We propose the need for action to support a strategic policy approach which will make a positive and sustainable impact.

The Brain Charity would like to see fuller consideration of the themes of the report in an independent review of the journey through and impact of diagnosis for people with neurological conditions.

Pippa Sargent, CEO of The Brain Charity, said: *"There are 1 in 6 people living with a neurological condition right now in the UK. "The findings of the **It's all in your head** report are stark, painting a picture of fear, isolation and helplessness. For too many people, delays and a lack of information and support exacerbates what is already a harrowing journey.*

*"It is imperative we improve the experiences of those who are seeking a diagnosis and provide reassurance and understanding at what is undoubtedly a distressing time."*

The **It's all in your head** report will be launched on The Brain Charity website on **Wednesday, 6th September.**

Link here:

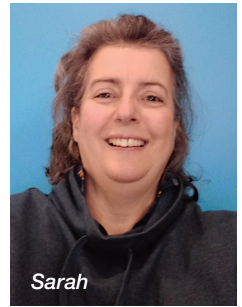
[www.thebraincharity.org.uk/its-all-in-your-head](http://www.thebraincharity.org.uk/its-all-in-your-head)

If you have any questions about the report, or want to learn how you can get involved in our campaign, email:

[campaigns@thebraincharity.org.uk](mailto:campaigns@thebraincharity.org.uk)

# Sarah's delayed diagnosis story

**Sarah, 55, lived with an undiagnosed neurological condition from childhood until the age of 53. Sarah has cervical dystonia, a neurological movement disorder which causes uncontrollable muscle spasms. Other symptoms she experiences are migraines, a tremor, pain in her neck and shoulder and depression - which she first experienced aged 8.**



Sarah repeatedly sought a diagnosis throughout her life and over the years was referred to five neurologists, but was still not diagnosed - despite having been hospitalised due to the severity of her headaches multiple times.

She went back to her doctor again after noticing her head was tilting in Zoom video calls during the pandemic. She was only diagnosed after making a request for referral to The Walton Centre NHS Foundation Trust, a specialist neuroscience hospital.

Sarah said: *"Despite multiple appointments I've had to wait decades for a diagnosis. I joke that I've seen a doctor from every single department."*

*"I was aware of the impact of being unwell, but I don't think the impact of how I had to work around it had really come home to me until recently."*

Sarah said she struggled before having a diagnosis as she had to 'formulate a way of dealing without one'. She said: *"I couldn't answer simple questions, like 'Why does your head shake?' or 'Why do you drop things?' 'You have to justify the way you are because you're trying to make sense of it yourself. 'You do end up saying 'It's just the way I am.'"*

When she did eventually receive a diagnosis, Sarah said she felt a sense of relief. She said: *"I was so happy as it put the missing piece in the puzzle. I do wonder how it went on for that long because 53 is very, very late for a diagnosis. I've never had any support. I wouldn't say there's been any holistic care."*

## 'Will you'... help the 1 in 6 with neurological conditions?

**On September 11th – 17th we celebrate Remember a Charity Week, joining 200 fellow charities to raise awareness of the importance of legacy gifts in wills.**

This is a great time to think about writing or updating your will, as well as the legacy you want to leave behind.

Having an up-to-date will can offer peace of mind knowing that your estate is inherited by those you choose, and your loved ones will be taken care of.

You can also leave a gift to The Brain Charity. A gift in your will costs nothing in your lifetime but can change the lives of those with neurological conditions in the future.

Although Remember a Charity Week is once a year, you can write a free will online with our partners Kwill at any time and choose to leave an optional gift to The Brain Charity. Follow this link to get started: **[www.thebraincharity.org.uk/will-you](http://www.thebraincharity.org.uk/will-you)**

# Unmasking the truth: inside the exhausting world of masking neurodivergence

**Research suggests that 15 - 20% of the population in the UK could be neurodivergent.**

**This means most people may know a neurodivergent person, but could they be masking their condition?**

## What is masking?

Masking is the act of suppressing or concealing neurodivergent traits in order to appear neurotypical. It is often experienced by autistic people.

With ableism, stigma, judgement and potential discrimination sadly still widespread, it often feels habitual for a neurodivergent person to change their behaviours in public settings, regardless of the challenges they may face by doing this.

## What does masking look like?

Neurodivergent people who mask their conditions tend to do this by mimicking or mirroring the behaviours of neurotypical people around them. This could include:

- Developing social scripts.
- Rehearsing conversations in advance.
- Trying to suppress stimming behaviours.
- Forcing eye contact.
- Acting outwardly as if they are not affected by sensory overload.
- Downplaying special interests.



## Why do neurodivergent people mask?

For some neurodivergent people, masking may begin unconsciously as a child through a desire to fit in.

Autistic adults may mask in order not to be discriminated against or harassed, or due to a perceived fear of being held back if they reveal their neurodivergence.

Masking can also be a coping mechanism to manage the challenges they feel may arise from their neurodivergent traits in a workplace setting, such as fear of asking for accommodations.

## How does masking affect people?

Masking can be detrimental to mental health, leading to burnout, depression, anxiety and 'imposter syndrome'. It can also make it harder for autistic people to share their true sense of self.

Masking from a young age can mean diagnosis may be delayed and people may miss out on necessary support.

## How can we help support neurodivergent people with masking?

It's important to create a supportive and enabling environment so neurodivergent people can thrive and feel able to be their true authentic selves, without needing to mask.



# SPOTLIGHT ON...

## Incurably Wonderful

**Incurably Wonderful** was founded by Liverpool local Rocio Castellero, who has experience with long-term chronic health conditions that previously left her house and bed-bound.

In 2020, during the COVID-19 pandemic and seeing the distress faced by others in her situation, she volunteered with the NHS Responders service, offering support to chronically ill people. These conversations revealed how many were struggling in Merseyside.

Rocio decided more was needed beyond individual phone calls, and created an organisation to help adults with disabilities and chronic conditions work towards wellness, improved social lives, and self-confidence.

Today, **Incurably Wonderful** provides enriching activities in Liverpool. As well as supporting patients, it works to bring important knowledge and understanding to the public, businesses, and service providers.

**Incurably Wonderful (IW)** users can meet both online and in-person to talk, relax, and share experiences. Regular events are held in accessible local venues, including discussion groups on topics such as fibromyalgia and CFS along with fun, adapted exercise sessions like chair yoga.

Their book club holds fascinating discussions on a wide range of books. All activities are free to attend with advanced booking. Online, **IW** has a lively social media presence and hosts discussions and events like the 'Let's Lose Together' weight loss programme. It also hosts online wellbeing programs and patient-led conferences on coping strategies.

Incurably Wonderful began as a warm, understanding community for people isolated through chronic conditions. With thousands of participants and regular events, Rocio said her organisation is a beautiful example of how to come together, look forward to a better future and create opportunities for growth and wellbeing.



Find Incurably Wonderful online at: <https://bit.ly/Nerve2391/> and [www.facebook.com/IncurablyWonderful](https://www.facebook.com/IncurablyWonderful)  
For enquiries and to join the mailing list, email: [Incurablywonderful@gmail.com](mailto:Incurablywonderful@gmail.com)

## Proud to march at Pride in Liverpool

Our staff and volunteers were proud to be part of the Pride in Liverpool march through the city in July to support inclusivity and diversity.

As you can see from these pictures they went all out with their rainbow outfits this year and enjoyed the community spirit on the day.

**We look forward to next year's Pride event and continuing to foster an inclusive environment at the Brain Charity**



## Why volunteering matters

### Alan started volunteering with The Brain Charity in 2003

#### Here's his story:

**"I was the victim of a road traffic accident, I got knocked down, which left me with a head injury and my solicitors (Slater and Gordon) recommended The Brain Charity to me.**

"I attended lots of courses, such as English and confidence building, and they helped me to get my life back. It was all so good, I mean, my speech was limited back then, and now I get told I never shut up! To say thank you, after all the support I received, I signed up to volunteer and I have been in the café ever since.

"The Brain Charity, it's not just the place, it's the people. You can talk to any of them about anything and become friends with everyone."  
We would like to say thank you to Alan! Nothing is ever too much trouble, and he's a real an asset to The Brain Food Café.



If you would like to volunteer your time, we are looking for flexible volunteers to be based in our centre, and remote telephone befrienders.

Contact Suzanne: [volunteering@thebraincharity.org.uk](mailto:volunteering@thebraincharity.org.uk) or call **0151 298 2999** to get more information.

## Neurovision goes to London

Earlier this year, we launched a nationwide search to find emerging neurodivergent artists who perform their own material.

We approached legendary rock star Jack White's Third Man organisation to stage an exciting live Neurovision final in their hyper cool music venue in the heart of Soho, where the three finalists will battle it out on Wednesday 20th September.

Performing in the Blue Basement at Third Man London will be multi-instrumentalist Murdoch, whose post-rock hardcore takes on mental health, politics, grief and much more; fellow Merseyside-based artist Sandstone Silver, who has overcome his struggles with ADHD and dyscalculia to make relevant and groundbreaking music; and teenager Joshua Thomas-Conn from Hemel Hempstead whose self-penned '500 Words' focuses on dyslexia.

Label owner Jack White, best known for his band The White Stripes, played at the venue himself when it opened in September 2021. Jack's London HQ also houses his own record company offices, and a record store.

All proceeds will go to The Brain Charity, so if you are in the London area on the day, we're hoping to get a Seven Nation Army there to cheer the finalists on!

The show starts at 6pm and tickets are just £5 from the Third Man London website: [www.bit.ly/NVLondon23](http://www.bit.ly/NVLondon23)

The Brain Charity x Third Man London		
	<b>NEUROVISION</b>	
<b>6pm</b>	<b>20/09</b>	
<b>Murdoch</b>	<b>Sandstone Silver</b>	<b>Joshua Conn</b>
		
	<b>£5</b> Proceeds go to The Brain Charity	
The Blue Basement - 1 Marshall St, Soho		

# Social activities September - October 2023

	Monday	Wednesday	Thursday
Mornings	<b>Art for wellbeing</b> 10am - 12.15pm*	<b>Knit and natter</b> 10am - 12 noon <b>Crafters club</b> 10am - 12.15pm	
		<b>Boccia (indoor bowls)</b> 12.30pm - 1.30pm	<b>Ukulele for beginners</b> 11.00am - 12.00 noon
Afternoons	<b>Maths</b> 1.30pm - 3.00pm*	<b>Drawing class</b> 1.30pm - 3.00pm	
	<b>Shared reading</b> 3.00pm - 4.00pm	<b>Aphasia talking table</b> 2.00pm - 3.00pm	<b>New age kurling</b> 2.00pm - 3.00pm
	<b>Shared reading plus</b> 4.00pm - 5.00pm	<b>Sing and social</b> 4.00pm - 5.00pm	

\*waiting list only - Check our website what's on calendar for October pop-up sessions!

**Coffee morning** Takes place monthly at The Brain Charity from 10.30am on 4th September and 2nd October (first Monday of each month).

## Shared reading plus

Starts 4th September at The Brain Charity, weekly

Shared reading plus is aimed at those who have dementia or support someone who lives with it. Our lovely volunteer Barbara, who is also trained in the methodology of Shared Reading from The Reader Organisation, will host this session.

## Essential tips and tricks to stay safe online

Tuesday, 5th September, 11am - 12:30pm via Zoom

Join The Brain Charity's expert for this free webinar and gain valuable practical knowledge on how to protect yourself and your loved ones from online dangers.

## Making the transition to adult services

Thursday September 14th 9.30am - 2.30 pm at The Brain Charity, lunch provided.

A free information event for parents, carers and young people who are moving on to adult support systems.

## Boogie for a cause

28th October, 1-3pm, at Wavertree Lifestyles Aquatics Centre. A Halloween themed dance event in aid of The Brain Charity.

# Ways you can support us

We are very grateful for any support during these challenging times. Here are some of the ways you can help:

## DONATE ONLINE

Making a regular or a one-off donation will help The Brain Charity continue to do the amazing work it does on a daily basis.

Donating couldn't be simpler. Just visit: [www.thebraincharity.org.uk/donate](http://www.thebraincharity.org.uk/donate) to give an amount of your choice today!

## GIVE AS YOU LIVE



Give as you Live is a simple way for you to support The Brain Charity every time you shop with any of the major brands - at no extra cost to yourself. Getting involved is easy - just register at [www.bit.ly/GAYLTBC](http://www.bit.ly/GAYLTBC)

## DONATE BY TEXT

Give just £3 now by texting **BRAIN** to **70460**. Texts cost £3 plus one standard rate message. If you'd like to give £3 but do not wish to receive any marketing communications, text **BRAINNOINFO** to **70460**.

## WEBSITE SHOP

We offer all our charity-branded items for sale, from t-shirts to teas, through our online store: [www.thebraincharity.org.uk/shop](http://www.thebraincharity.org.uk/shop)

## DONATE VIA QR CODE

Scan the QR code below on your mobile phone camera now to donate:



The  
Brain  
Charity

## ABOUT THE BRAIN CHARITY

The Brain Charity offers emotional support, practical help and social activities to anyone with a neurological condition and to their family, friends and carers.

For more information, contact the centre or visit our website:

[www.thebraincharity.org.uk](http://www.thebraincharity.org.uk)

Connect with us:



[thebraincharity](https://www.facebook.com/thebraincharity)



[thebraincharity](https://twitter.com/thebraincharity)



[thebraincharity](https://www.instagram.com/thebraincharity)

You can also find us on:



by searching for The Brain Charity

If you wish to be added to our mailing list, to receive news and fundraising updates including The Nerve, please go to [www.bit.ly/signupTBC](http://www.bit.ly/signupTBC) or ask our information team (on the numbers and email addresses below) to add you to the list.

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The Nerve is available in large text on request and as a PDF on The Brain Charity website:  
[www.thebraincharity.org.uk](http://www.thebraincharity.org.uk)

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Responsibly sourced paper

