# The Nerve

National support for all neurological conditions

September/October 2022



We need to hear from you: share your views on neurological delays and misdiagnoses

Find the Value of You with new confidence-boosting sessions

Mum who fell asleep next to baby and woke up in hospital shares recovery story

### LCFA's first County Cup finals for 3 years bring in £1,000 funding boost for The Brain Charity

LCFA recently held 17 County Cup finals, with the competition returning after a three year break due to COVID-19. Following the competition, LCFA were able to make a generous £1,000 donation to The Brain Charity, their current charity of the season.

Tui Benjamin Thorp, Head of Fundraising at The Brain Charity, said: "We are delighted to receive this generous donation from LCFA thanks to County Cup final matchday programme sales. This funding will allow us to bolster our front-line services at a time demand is higher than ever due to the cost of living crisis."



## We need to hear from you: share your views on neurological delays and misdiagnoses

We know that for far too many people with neurological conditions, getting a diagnosis can be a lengthy and deeply frustrating process.

That's not good enough and we're determined to change it. To do that, The Brain Charity is launching a brand new survey, to help us get a better understanding of the difficulties people are facing and to try and understand how and where improvements can be made.

#### Who can take the survey?

The 10-minute survey is designed for people with neurological conditions and their family members and is completely confidential.

If you or a loved one has been through a diagnosis or has experienced a neurological condition, we want to hear from you.

#### How can I take the survey?

On the right is a QR code. If you have one, you can use the camera on your phone to take you straight to an online version of the survey.

Alternatively, you can head to

www.bit.ly/TBCSurvey22 or complete a paper copy in The Brain Charity's centre.

Please email **campaigns@thebraincharity.org.uk** if you need any support with filling out the survey or require it in a different format.

#### Is there any other way I can help?

As part of our report, we are looking for people to be interviewed about the challenges they have faced with delayed or misdiagnosis.

If you are happy to share your story as part of the report, please let us know by emailing **campaigns@thebraincharity.org.uk** 





### **Find the Value of You:** The Brain Charity launches free confidence coaching

We have recently launched our Value of You confidence coaching project thanks to £60,000 of funding from The Life Rooms.

The Brain Charity's tailored confidence coaching sessions are designed to remove self-limiting beliefs using a range of techniques. These include grounding, breathwork and positive affirmations, so clients feel more independent and empowered to help themselves.

Rhian Beckett, Head of Employment and Welfare Projects at The Brain Charity, said: "We are really excited to have been awarded funding from The Life Rooms to launch a service we recognise is so sought after across our community.

"Our service users often report feelings of low confidence and self-esteem in part due to their neurological condition or disability. Our coaches will work holistically with participants to deliver client-led, person-centred coaching which is tailored to the person seeking support."

Anyone who lives within the boundaries of Liverpool City Council and is affected by a neurological condition (whether they have one themselves or care for someone who does) is eligible to receive coaching. Particular support is available for parents who have neurological conditions or care for children affected.

Fill out the form on this page to self-refer for free confidence coaching from The Brain Charity: www.bit.ly/Nerve2291

Alternatively, email confidence@thebraincharity.org.uk or call Mandy on 07888 301735

## The Brain Charity is launching new group counselling sessions to support our clients' mental health.



We will be providing 8-week courses of group therapy in which you'll be able to speak openly about your emotional health and receive support for any issues that you're facing in a safe, secure and social space.

Delivered by two trained counsellors, the sessions will cover techniques and topics such as:

- Mindfulness
- Managing mental health alongside a health condition
- Coping with stress
- Improving confidence

If you would like to take part, please email counselling@thebraincharity.org.uk

## Workplace neurodiversity training from The Brain Charity

The Brain Charity has now launched neurodiversity training to teach businesses about the benefits of neurodiversity in the workplace. Diversity is key to the development and progression of any organisation.

#### What is neurodiversity?

Some people's brains simply work in a different way. For at least 20% of the UK's adult population, these differences mean they are not seen as 'neurotypical' and may be diagnosed with neurological conditions such as autism spectrum disorder (ASD), dyslexia and attention deficit hyperactivity disorder (ADHD).

## Hiring a neurodiverse workforce comes with huge benefits, and allows companies to access a wider talent pool.

Neurodiversity can empower the workplace and encourage creativity, new ideas and fresh perspectives. As well as their individual strengths, neurodivergent employees often possess highly desirable skills and attributes.

Our training packages are competitively priced and income from the workshops funds our vital front-line work helping people with all forms of neurological conditions to lead longer, healthier, happier lives.

For more information call Jane Cullen, Training Manager at The Brain Charity, on 0151 298 3288.

Alternatively, email training@thebraincharity.org.uk or complete this online form:

www.bit.ly/Nerve2293

## ICE BALL SPONSORSHIP OPPORTUNITIES

We are looking for companies to sponsor our Ice Ball on Friday 2nd December at Crowne Plaza Liverpool City Centre.

Be an 'Ice Guy' and sponsor a table to enable a group of our volunteers and service users to attend who might otherwise not be able to afford to come.

## The 'What an Ice Guy' package includes:

- A table of 10 at The Brain Charity's Ice Ball
- A second table of 10 for The Brain Charity's volunteers and service users
- Your logo on both table numbers on the night
- Mentioned as an official attendee organisation on social media and on the evening



Find out more about the 'What an Ice Guy' package or discover our other packages here: www.bit.ly/SponsorIceBall or email events@thebraincharity.org.uk

## Sam's ADHD story:

### "I was lurching from crisis to crisis; The Brain Charity put my mind at ease"

Sam was diagnosed with ADHD in August 2020 after years of struggling with keeping a regular sleeping pattern, forgetting to eat and take medication and becoming easily obsessive.

ADHD (attention deficit hyperactivity disorder) is a behavioural condition. As with many neurological conditions, the cause is still not known, but it is thought to be influenced by genetics.

Sam has a 'combined type' diagnosis, which means she has issues with both attention and hyperactivity.

The 47-year-old, from the Wirral, said: "Before my diagnosis I was the same as everyone else; I just thought ADHD was something little boys got diagnosed with. Getting diagnosed was a bizarre mixture of feelings. It was a relief, but I also felt sad as well because I imagined what my life would have been like if I'd been diagnosed 20 years ago. There was a bit of hope too - I could be me properly, I wouldn't have to hide anything."

Due to the impulsive nature of ADHD, Sam, who also has anxiety and depression, has struggled with money issues over the years, managing bills, accruing debt and being unable to pay it back.

She applied for PIP herself in spring 2020, but was given the standard allowance, having previously been awarded the enhanced payment. Appealing the decision was causing Sam anxiety, and she sought help from The Brain Charity's welfare benefits team.

Sam said: "I wasn't comfortable asking for help, because it was in the middle of the pandemic and I felt people wouldn't have time for me.



"Also, I had used other services in the past that weren't great or fobbed me off, or didn't have the money to help. I've always had a problem with self-advocacy and seeing myself as a massive burden."

When Sam spoke to The Brain Charity's welfare benefits team in late December 2020, she thought she'd left it too late to get any assistance. But our Information & Advice officer Janet was quick to help Sam reword her application to highlight the severity of her situation, and could anticipate conclusions an assessor might make.

At the end of February 2021, Sam was not only awarded enhanced daily living allowance, but was also given standard mobility allowance as well to help her cover travel costs.

Sam said: "It has made a big difference to me to me psychologically and financially for my needs to be recognised by an organisation like The Brain Charity. I consider myself really lucky to have got this financial support when so many folk are struggling, but I couldn't have done it without Janet's experience and help."



Sam getting the DWP letter telling her she'd won her appeal

## Neurodivergence, ADHD and dance music

Recently, The Brain Charity's CEO Nanette Mellor was interviewed for a feature in DJ Mag on the prevalence of neurodivergent conditions such as ADHD in the dance music scene.

Here, she shares her views on how the ADHD brain is affected by music and why neurodivergent people are often drawn to creative industries. For people with ADHD, there are real additional benefits to the stimulation music provides. Music can be used in the same way as 'fidget spinners' to help individuals with ADHD to occupy parts of the brain. This allows their executive functioning to be able to focus on the task they want to complete.

Individuals with ADHD have naturally lower levels of this chemical within their brains. This means they will often seek out dopamine -inducing activities. Brain scans have demonstrated music increases dopamine neurotransmission within the brain, while dance



Nanette Mellor

music's regular beat and repetitive nature stimulates the body into dancing, which can itself induce euphoria.

It is still early days in our understanding of the brain, but it appears true creative genius is often born out of neurodiversity and conditions like ADHD, ASD and dyslexia.

Head to www.bit.ly/Nerve2294 to purchase a digital version of the magazine to read the full article.

## Things to do online for free: fun online activities you can take part in from home

Social Connection Officer Suzanne has found 8 things you can do for free online today - all you need is a smartphone or computer and a data or Wi-Fi connection.

1 Listen to the latest news with Talking Newspapers The Talking News Federation is a free nationwide service. Most are accessible online and even using a home device such as Amazon Alexa.

## 2 Create soul-soothing colouring images with Zentangle

If you've ever coloured in a mindful picture and wondered how they get made, Zentangle shows you how to create your own.

#### 3 Head to your Virtual Village Hall

The Virtual Village Hall allows you to access live online activities via Facebook. There is a lot on offer, from cooking to crochet to Zumba!

#### 4 Browse incredible pictures of the day

For those with an active imagination, 'Picture of the day' websites are very visually appealing. Why not try NASA's Astronomy Picture of the Day, National Geographic's photo of the day page or the Evening Standard's pictures of the day.

#### 5 Reap the benefits of a month of mindfulness

Bupa has provided a monthly mindful calendar that you can print off or use on your device.

#### 6 Use online time to learn something new

Why not do take part in a free online activity with someone else? FutureLearn has hundreds of short online courses available, any marked 'unlimited' are free.

#### 7 Join an online chess club

If you know your check from your checkmate, the English Chess Online website will become your new go-to.

#### 8 Sit back and watch a documentary

At Documentary Heaven (whose tagline is Food For Your Brain), you can enjoy hundreds on such topics as true crime, philosophy, celebrities, and archaeology - for free.

You can already take part in virtual sessions like poetry, cookalongs, coffee mornings and knit and natter. Find our programme of activities on page 11.



# Are you living with long COVID?

## Here's how to manage your symptoms at home



Whilst coronavirus passes quickly for most, some people are still facing the long-term effects of long COVID. Typical symptoms of long COVID include fatigue, breathlessness, anxiety, depression, joint or muscle pain, muscle weakness, memory problems and 'brain fog'. Here are some ways to manage long COVID symptoms.

#### Plan your days

Creating a plan for your days and weeks is useful. Divide up the tasks you find more important and less important so you can prioritise.

#### Rest

Sleep and rest are a big part of the body's natural healing process - aim to get 7 to 8 hours of solid sleep every night.

#### Healthy eating

Some people may experience significant appetite loss. Splitting up your normal meals into smaller snacks spread across the day can make eating seem like less of a task.

#### Gentle to moderate exercise

Staying physically active has so many benefits. Just going on one short walk a day is enough to keep you feeling active.

#### Prioritise your mental health

If you find that you're feeling anxious or depressed, please make sure that you speak to your GP. The Brain Charity also provides free counselling.

#### Explain your situation

Symptoms can impact your close relationships. Let people know what has happened and what you are feeling.

#### Try to avoid over-working

Keep in touch with your employer or school and explain your situation to investigate necessary options such as a flexible return.

#### Keep your GP informed

Let your GP know any symptoms or worsening symptoms you are experiencing from long COVID.

Read the full article at www.bit.ly/Nerve2296

#### Access to life-saving procedure for stroke extended in Salford

## An innovative procedure that is saving the lives of stroke patients by physically removing blood clots is now available around the clock at Salford Royal Hospital.

The mechanical thrombectomy service for treating patients with acute ischaemic stroke is now available 24 hours a day, 7 days a week.

Ischaemic stroke is the most common type of stroke and is caused by a blood clot blocking an artery of the brain. This treatment, when combined with other medical treatments provided within a specialist unit, has been proven to significantly reduce the severity of a disability that a stroke can cause.

Salford Royal is now one of the few centres outside of London to be able to deliver 24/7 thrombectomy. Read more: www.bit.ly/Nerve2295

### Why neurodivergent women are diagnosed with ADHD and autism later in life, and what this means for their careers

## Recently, there has been a lot of discussion in the media around women being diagnosed with neurodivergent conditions such as autism and ADHD as adults.

Conditions like autism and ADHD present differently in girls, and the symptoms can often be much more subtle and easier to miss - particularly if, as is often the case, less behavioural problems are apparent. The lack of childhood diagnosis in women means it is likely thousands remain undiagnosed, and it is only with increased awareness online and amongst peers that many are beginning to self-identify and seek diagnosis in adulthood.



#### We spoke to Erin, a Business Change Specialist at Matalan, to find out about her diagnosis experience.

Erin was diagnosed with ADHD and autism spectrum disorder aged 39. She is a confident, valued member of the team at Matalan, but her success did not come without challenges.

Like many undiagnosed women, Erin grew up feeling different. She did not seem to fit in and couldn't understand societal rules that everyone else just naturally knew. It puzzled Erin's teachers when she struggled with her schoolwork, and she regularly received the same criticism: "Erin is bright, she just needs to apply herself".

The problem was that Erin felt she was trying her hardest, often seemingly harder than anyone else. This constant stress causing chronic pain and fatigue resulted in Erin being diagnosed with fibromyalgia in 2013.

Erin always felt that this wasn't a correct diagnosis. She was also told she was suffering from anxiety and depression, but she did not agree with this diagnosis either.

She was living a happy life but struggled with things others took for granted.



Erin enjoys a hill walk with her husband James

This is a common problem for women, misdiagnosis as a mental health condition only prolongs misunderstanding and a large proportion of women give up before receiving the correct support.

Post-diagnosis, Erin said she felt relief and clarity on a lot of the unexplained hurdles she faced throughout her life. But this realisation followed a period of grieving.

Erin continues to face challenges in the workplace, but they are more manageable now she is more self-aware.



The Brain Charity's workplace neurodiversity training for employers is based around understanding the innate talents and skills neurodivergent people possess. See page 4 for more information and read more about neurodiversity in women here: www.bit.ly/Nerve2297



New mum who fell asleep next to her baby and woke up in hospital after brain aneurysm ruptured shares recovery story

In April 2018, former lawyer and mum-of-two Juliet, 39, was driving with her two children, aged 5 months and two years, when she experienced a ruptured brain aneurysm.

A brain aneurysm is a bulge in a blood vessel caused by a weakness in the blood vessel wall. In Juliet's case the brain aneurysm burst, causing a subarachnoid haemorrhage, a bleed on the brain from the ruptured aneurysm which can cause serious brain damage.

Juliet, from Yeovil, said *"I don't remember* how I stopped the car, but somehow I did. Fortunately, the car that stopped behind me was being driven by a nurse. They recognised what was happening straight away and called an air ambulance." Once she arrived at hospital, Juliet underwent successful brain clipping surgery. This is where a neurosurgeon removes a section of the skull to access the aneurysm and places a tiny metal clip over the blood vessel that feeds it. After the surgery, Juliet remained in intensive care for 6 weeks before spending 7 months in brain injury rehabilitation centres.

Her haemorrhage, which affected her right posterior lobe, left her with a host of side effects including limited movement in her left-hand side, no sight in her left eye and memory problems. She has also struggled with her mental health and had to leave her job as a partner at a solicitor's firm.

Juliet said: "Although I've had psychological problems during my recovery, I've been told that 'I must keep doing what I'm doing'. It's taken a lot of family support and inner strength to get here."

Juliet's husband Tom, 41, has supported her throughout.

He said: "It has been an absolute rollercoaster. I still go through a multitude of emotions every day. It's a long road, you need people to support you. Sometimes it's ok to acknowledge a really bad situation. It's ok to feel sad, ok to be upset, that's normal."

Many people who experience brain injuries can find they feel more creative following their injury. Juliet now writes poetry and is working on a novel.

She added: "I have a lot to say about this experience, hopefully people can relate to it. If I had found a story like this I would be reassured, I would know I wasn't alone.

"For a long time it felt like we were the only people this had happened to. Forums like healthunlocked.com let me know that there's people of all ages going through very similar situations."

## SPOTLIGHT ON...

### The Everyman - an accessible and disabilityfriendly theatre in Liverpool

The Everyman Theatre has been part of Liverpool's culture for the past 60 years. Completely rebuilt during the early 2010s, the RIBA Stirling prize winning architecture incorporates a level of accessibility that provides a welcoming safe space for its audiences.

Standing on the site of Hope Hall, a former place of worship in the mid-1800s, the Everyman came to life in the early 1960s. It was part of the Beat revolution, as The Beatles climbed the charts and the Liverpool Scene beat poets took to the boards of the Everyman.

The Brain Charity's Events and Fundraising Officer Greg spoke to The Everyman's Venue and Events Planner Rachel Elliott-Newton as theatre-goers flocked back after a two-year coronavirus hiatus.

Rachel, who started out in the company's Young Everyman Playhouse and returned to the fold after finishing her degree at Edinburgh University, said: *"The Everyman has been one of the lynchpins of the city.* 

"The model of the bistro within a theatre setting has been taken up by many other creative spaces, and I was fortunate enough to re-join at a very exciting time, when the building was reopened in 2014.

"We always try to engage with any unconscious biases to enable all in the city to feel welcome." The Everyman is not a venue which would simply pay lip service to accessibility, and, while no venue can claim to be fully accessible, Rachel concedes "it's as near as we can possibly get". Staff at The Everyman have undertaken Safe Space training and worked with the Anthony Walker Foundation to ensure they are thinking about accessibility in a wide variety of ways, not just physical and neurodivergence.

There are also chair lifts, a shower room, a disabled access lift and an awareness that each visitor's physical or emotional needs may be different. Rachel explains: "We don't know what people's backgrounds are when they arrive in the theatre, so it's about making it safe for everyone. We always keep the person in mind, not the disability and we minimise any drama surrounding situations."

With national and international traffic regularly coming through its front doors, the Everyman has a genuine desire to fix any issues. Its CEO Mark Da Vanzo took over just as the pandemic struck, and, due to an underlying philosophy of treating everyone with kindness, it seems the Everyman is in good hands.

Rachel said: "As a place to work, it just gets better and better. Our engagement in the community is rooted in our ability to make the theatre accessible to all."



The Everyman Theatre in Liverpool



First floor bar at The Everyman



Rachel and Greg

## Social activities September - December

Come and see what we offer at our activities taster day on Monday 5th September, 1.00pm - 4.00pm at The Brain Charity's centre. You can also find our weekly programme below.

	Monday	Tuesday	Wednesday	Friday
Mornings	Art for wellbeing 10am - 12pm Shared reading 12.30pm - 1.30pm		<b>Crafters club</b> 9.30am - 11.30am	
Afternoons	Maths 1.30pm - 3.00pm Boccia indoor bowls 3.00pm - 4.00pm Bat and chat (table tennis) 4.00pm - 5.00pm	Afternoon social 1.30pm - 3.30pm Gardening group 2.00pm - 4.00pm	English & IT 1.30pm - 3.30pm Drop-in tech support 3.00pm - 5.00pm Ukulele for beginners 3.30pm - 4.30pm	Choir 4.00pm - 5.30pm
Online	Photography club second Monday/ month, starts 12th September 5.00pm - 6.00pm Coffee morning September 5th and October 3rd 10.00am - 12.00pm - also takes place in person in our centre.		Mindfulness podcast second Wednesday/month Poetry starts 14th September fortnightly 5.30pm - 6.30pm	Sit Fit chair-based exercise 10.30am-11.30am Tasty meals for less online cooking 3.30pm - 5.00pm

### More upcoming activities this autumn/winter:

- Monthly online hat making with Denise from The British School of Millinery (limited to 10 participants) starts 20th September. Materials provided.
- Music Mondays, in conjunction with Liverpool Philharmonic, starting 17th October (6 places).
- Pride of Sefton 2 river cruise in Liverpool on 2nd October. 2pm departure (3 hours) (5 places available, free for clients).
- Weekly online socials launching soon contact us to find out more.
- Candle making workshop 21st November. 10am start (10 places available).
- Drama, fine art, holistic therapies & edible wall hydroponics workshops are all starting soon too.

To sign up, email **activities@thebraincharity.org.uk** call us on **0151 298 2999** and ask for Suzanne or head to **www.thebraincharity.org.uk/events** 

## 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.bit.ly/give2TBC** to give an amount of your choice today!

#### 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

#### DONATE VIA QR CODE

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





#### **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

**Connect with us:** 



thebraincharity



thebraincharity



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 or ask our information team (on the numbers and email addresses below) to add you to the list.

The Brain Charity, Norton Street, Liverpool L3 8LR Tel: 0151 298 2999 Helpline: 0800 008 6417 Email: info@thebraincharity.org.uk

The Nerve is available in large text on request and as a PDF on The Brain Charity website: www.thebraincharity.org.uk

The Brain Charity is registered as a charity (No: 1114999) and a company limited by guarantee in England and Wales (No: 05741930)