The Nerve



National support for all neurological conditions

July/August 2022



Our adorable new dog bandanas are now available

Stand out from the crowd and help spread awareness of The Brain Charity when you take your pooch for walkies!

Details:

- Pet bandana branded with The Brain Charity logo
- Made from polyester, so it's machine washable
- Full-colour dye sublimation print, which stays fresh even after washing







- Large 4cm loops to fit all collars easily
- Suitable for any collared pet, including cats and dogs
- · One size fits all

Our dog bandana also makes the *pawfect* dog owner's gift for a friend with a new puppy or rescue dog. They cost £5.99 each and are available now from our web store: www.bit.ly/TBCpets

Ladies Day Race Night

They're under starter's orders – and they're off...To The Brain Charity's first Ladies Day Race Night on **Friday 12th August.**

Yes, it's the glorious twelfth for our runners and riders as we present a full racing programme on our big screen starting at 7pm.

It's a chance to put on your Ladies Day finery

Ladies Day Race Night!
Friday 12th August

and have some wine and canapés on a summer's evening – where the going is guaranteed to be good! Tickets are priced at £7.50. Ask at reception, or get yours online here now: www.bit.ly/TBCRN22

We're joining the food revolution!

The Brain Charity now has its very own edible wall. Thanks to Farm Urban's Greens for Good programme, this 2m by 1.8m structure will be keeping The Brain Food Café stocked with free and delicious leafy greens, herbs and salad.

We'll also be using the wall to teach people how to grow healthy, sustainable food using hydroponics. Hydroponics is a farming method which is soilless and pesticide-free (food is grown indoors using LED lights and circulating water).

Courses begin this autumn and we hope they will improve participants' mental health (after all, taking care of plants is a known mood booster), help them learn new skills and empower people to make healthier choices for their diet and for the planet.

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



Making sure **your voice** is heard:

The Brain Charity calls for specialist neurological mental health support for people with brain injuries

The Brain Charity has called upon the Government to provide specialist neurological mental health support for people with acquired brain injuries within 10 weeks of a referral.

Our CEO Nanette Mellor made the request as part of a response to the Department for Health and Social Care's call for evidence around acquired brain injuries (ABIs) in order to develop a new ABI strategy.

We are calling for focus on the following areas:

- Specialist neurological mental health support for people with ABIs.
- A focus on the prevalence of ABIs within the prison population.
- Neurological conditions related to ABIs to be diagnosed by medical professionals as early as possible.

Nanette said: "This is an important opportunity to ensure that the needs of people with ABI are pushed to the top of agenda.

"We know from our own experience that there are vast numbers of people within the criminal justice system who are there simply because they did not receive the help and support they needed for their condition.

"We also know that there is a huge problem when it comes to specialist mental health provision - across the UK, just 1% of practising psychiatrists are neuro psychiatrists - that's less than 45 specialists for the whole country."

Read more at www.bit.ly/Nerve2271

If you'd like to share your story as part of The Brain Charity's campaign, email communications@thebraincharity.org.uk

Learn your rights: carer information day

Learn your rights as a carer at The Brain Charity's carers rights information day.

Anyone who cares for someone else is welcome to attend this free event, held at The Brain Charity's centre on Norton Street on Wednesday, September 7th between 10am and 4pm.

You will be able to find out from legal professionals and academics how to put an appropriate care plan in place, what support options are available and how to challenge inadequate or reduced care packages.



Professor Luke Clements, Chair in Law and Social Justice at the University of Leeds, will lead the event. Professor Clements is a former practising solicitor and human rights lawyer who was involved in drafting and scrutinising care legislation including the 2014 Care Act. He specialises in using the law to combat the social exclusion experienced by disabled people and their carers, and how to break down the barriers people often face in accessing what they are entitled to.

Lunch will be provided, and there will also be talks from Irwin Mitchell Solicitors, Liverpool City Council and The Brain Charity's Peace of Mind Project.

To register your attendance head to www.bit.ly/Nerve2272 or email peaceofmind@thebraincharity.org.uk Please also email us if you have specific dietary requirements for lunch.

WILLIAM'S DOWN'S SYNDROME STORY:

"We feel so lucky we discovered The Brain Changer Arts Project during the COVID-19 lockdowns"

William, 17, was diagnosed with Down's syndrome shortly after birth. This means the teenager, from Surrey, has low muscle tone, poor fine motor control and coordination, severe learning disabilities and is non-verbal.

Before the pandemic, William had been enrolled in full-time education at a special needs school. But when the UK went into lockdown in March 2020, all that changed and his parents, Chris and Helen, had to try and pick up providing this vital education from home.

Chris said: "During covid, everything stopped abruptly. William needs one-to-one support and while his teachers were doing what they could, they couldn't be there.

"He didn't have many years left of education, these were vital years and time that he couldn't get back, and we were worried he was going backwards."

When Helen was searching for options, she discovered The Brain Changer Arts Project.







These free workshops, run by The Brain Charity, provide physiotherapy through dance and occupational therapy through art and crafts and are open to all children with neurological conditions.

During the pandemic, they ran as online video sessions and were open to young people from anywhere in the UK. As the workshops went on, William began to look forward to taking part in the sessions.

Chris said: "The sessions gave William a chance to keep practicing his fine motor skills, using scissors and drawing and painting with different techniques we wouldn't have come up with, like using cotton buds to dab the paint on.

"The regular workshops helped him maintain a good level, he was using his skills so he didn't forget them."

Chris also said the impact of having a regular activity in the diary for William was huge. The sessions helped give them new ideas as parents for activities they could do with William while he was off school.

He said: "There was an absolutely huge emotional impact. We could get him back into a routine, which is vital for Down's syndrome. In the mornings, he was up and doing something. It was really good to have that structure to the day, which we were missing.

"We're so grateful The Brain Changer Arts Project was opened to the whole of the UK via Zoom during the pandemic, so we could take part despite not being based in Merseyside. There was nothing for us locally, so we feel very lucky we discovered the programme during lockdown."

The Brain Changer Arts Project team are hosting free art and occupational therapy sessions at The Brain Charity this summer. Sign up here: www.bit.ly/brainchangerarts

The incredible ways





After brain injury and stroke, many people report feeling more creative. But did you know embracing your creative side can actually improve your brain's health?

That's why we run a range of services and activities at The Brain Charity which encourage people to get their creative juices flowing - from our Music Makes Us! project for people living with dementia (pictured) to The Brain Changer Arts Project for children and our regular workshops such as art and crafts, knitting and choir.

Nurturing the innate creativity we all have within us encourages neuroplasticity - the brain's amazing ability to rewire itself by creating new pathways. Creative activities like drawing and playing a musical instrument are also known to improve connectivity between the left and right sides of the brain, improving cognitive function.

A report released by the National Alliance for Arts, Health and Wellbeing in 2020 revealed creative hobbies can also be beneficial for mental health. They can help people manage negative emotions and anxiety and stress, or express trauma. Completing a task such as finishing a creative project also floods the brain with the feel-good chemical dopamine.

If you've been persuaded, check out our activities on page 11.

A hug in a box, when you need it most

If you or someone you love has been suddenly rushed to hospital due to a neurological condition, life may suddenly feel very frightening.

The Brain Charity's Information & Advice Officers are based in hospitals across Merseyside to provide support to patients when they need it most. Now, our new hospital care boxes have arrived and we look forward to distributing these to parents and their families. The boxes are packed with all the toiletries and other essentials people may need to manage an unexpected hospital stay.

Find out more about the support The Brain Charity gives to hospital patients here: www.bit.lv/Nerve2273



Have you written your will yet?

At The Brain Charity, we recognise the importance of writing a will, which is why we have partnered with Kwil to make will-writing easier.

Why use Kwil?

- It's free with the code BRAINCHARITY
- Write your will in 30 minutes
- Free lifetime edits
- Speak to will-writing experts to guide you through the process if needed
- Have the option to ensure your legacy has a lasting impact by leaving a donation to The Brain Charity

Start writing your will today by scanning the QR code, or go to www.bit.ly/Nerve2274 / call 0800 061 4934.



Mum bereaved by glioblastoma calls for awareness of similarities between brain tumour and mental illness symptoms

A mum bereaved by a brain tumour is campaigning for more awareness of possible similarities between some psychiatric and brain tumour symptoms. Retired teacher Barbara Everard's son Gareth was 38 when he passed away due to a glioblastoma brain tumour in January 2019 - just 14 months after he was diagnosed.

Gareth had received mental health treatment since the age of 17, following a diagnosis of schizophrenia and psychosis. He was diagnosed with the stage four tumour on his left frontal lobe in November 2017, having spent much of his life in psychiatric hospitals.

Barbara and her family believe Gareth may have survived if any possible symptoms of his brain tumour had been picked up earlier. They are calling for more awareness of how brain tumours can cause problems like personality changes, communication difficulties and psychiatric symptoms such as depression and anxiety.

Barbara, from West Sussex, said: "Gareth didn't want this to happen to anyone else. It is absolutely agonizing for me to think he could have been around for at least for another 5 years, and his quality of life could have been much higher."

Gareth's family say he first felt something was wrong in 2014. The symptoms of his mental illness included verbal outbursts, trembling, dribbling, numbness, pins and needles and difficulties communicating.

Gareth was discharged from hospital in October 2017 but experienced a seizure and collapsed the following month. He was taken to A&E, where he was given an MRI scan and the glioblastoma was discovered. Gareth underwent a three-hour operation in November 2017 to remove part of the tumour but was readmitted to hospital in December 2018 and died five weeks later.

Barbara said: "Although Gareth's health improved for a while after the operation, I find it difficult that his original diagnosis was never reviewed or the possibility of anything other than a mental health issue considered.





"I want to raise awareness of the potentially overlapping symptoms between mental health issues and brain tumours."

Gareth's hospital apologised to Barbara, and told her Gareth's case will influence the training their staff receive.

Pioneering new treatment leads to improved recovery from brain trauma

Scientists say a pioneering new treatment which harnesses the body's immune system can help the brain recover from traumatic injury.

One major cause of cognitive impairment following brain injury is inflammation, as the swelling of the brain causes secondary injuries which can lead to permanent damage. Researchers have designed a targeted therapy which reduces brain inflammation and could therefore be effective at treating brain injury, stroke and multiple sclerosis (MS).

When healing from an injury, the body usually sends natural anti-inflammatories known as regulatory T cells to the site of the trauma. But very few numbers of these cells live in the brain as a molecule they need to survive, IL2, cannot pass the blood-brain barrier which protects the nervous system.

The new treatment could work by allowing more IL2 to be made in the brain, increasing the number of regulatory T cells there by up to 10 times. By boosting these cells, the Babraham Institute scientists believe they can prevent the death of brain tissue following brain injury and they now hope the treatment can enter clinical trials.

Dr Lidia Yshii, lead author of the report and Associate Professor at KU Leuven, said: "The first experiment was a 'eureka moment' – we could immediately see that the treatment reduced the size of the injury lesion."

Co-author Professor Liston added: "With tens of millions of people affected every year, and few treatment options, this has real potential to help people in need."

Music Makes Us! goes viral on





music makes us sina

The Brain Charity's Music Makes Us! project was recently featured on a viral TikTok video, racking up an incredible 857,600 views and counting.

The project brings physiotherapy through dance and speech and language people through song to people living with dementia.

Park View Nursing Home's video shows the different types of dementia therapies residents take part in, also including doll therapy, reminiscence therapy and art therapy. The viral clip was put together to mark Dementia Action Week.

Watch the video at www.bit.ly/Nerve2279

Three cheers...

for another cohort of fabulous fundraisers

It's time for another fundraiser round-up. We're celebrating some incredible people who've dedicated themselves to supporting The Brain Charity over the last few months.

Sarah threw herself out of a plane to take on a daredevil skydive in honour of her dad, who experienced a brain injury caused by a car accident before he passed away last year.



The sun shone on the Portsdown Group Practice staff when they pounded the pavements for a sponsored walk. They chose to support us as one of their team has chiari malformation and because they regularly come across neurological conditions. These superstars raised £1,417.04 across 6 GP surgeries.

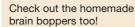
Tim completed the Brighton Marathon - his first ever.
He said: "This was the most unforgettable moment of my life. I am really proud of myself that I didn't give up.
The volunteers, adults and kids who gave high fives and cheers all along the way were so amazing."



Libby raised more than £200 when she walked 12,000 steps a day throughout March - 372,000 total - for her dad, who died from a subarachnoid haemorrhage in 2016 aged 44. She said: "It has been a wonderful experience. What The Brain Charity do is just amazing. They change lives."



Claire and Laura took on the Wirral Coastal Walk last month in memory of Claire's dad, who passed away from a brain tumour. They smashed 12.5 miles in 4.5 hours, raising nearly £400.





Roisin raised £300 by taking part in our Stroll & Roll challenge to travel 60km in May. She said: "Completing it was hard but rewarding. I have a neurological condition so it made me more determined to do this."



Mary smashed the Horwich Triathlon for The Brain Charity, in memory of her sister who sadly passed away from a brain haemorrhage. She has raised more than £900 - far surpassing her £200 target.

Earlier this year Lisa held a quiz night at Sale Sports Club dedicated to the memory of Yasal, a cherished teammate of FC Sporting Sale Tigers Under 15s who died of a brain aneurysm aged just 14. She raised more than £705.

Feeling inspired? The Brain Charity has recently launched exciting new global fundraising treks and challenges.

Fancy trekking to Petra or attempting the Italian Great Lakes Cycle?

Check them out at www.bit.ly/NerveCC or email fundraising@thebraincharity.org.uk

Lyme diśease awarenes grows as celebrities share their stories



Lyme disease is a bacterial infection that is spread to humans from an infected tick bite. Usually, the first symptom is a circular rash around the tick bite; however, in some cases the rash can take up to 3 months to appear.

Despite its relatively large size and changes in colour, the rash is usually not hot or itchy. If initial symptoms go unnoticed for longer than 48 hours, the likelihood of disease transmission is greatly increased.

In some cases, those who are diagnosed and treated for Lyme disease are affected by symptoms like body aches, a loss of energy and tiredness and other neurological conditions that can last for years.

The disease is nicknamed the "great imitator" because its symptoms mimic other conditions such as fibromyalgia, chronic fatigue syndrome and rheumatoid arthritis.

In recent years, many celebrities have opened up about their struggle with Lyme disease, including popstar Justin Bieber, former president George W. Bush, singer Avril Lavigne and actor Ben Stiller. In September 2020, comedian and actress Amy Schumer shared on Instagram that she also has

In 2021, actor Alec Baldwin said he had been dealing with Lyme disease ever since he was first bitten by a tick over 20 years ago. The actor now shares the dangers of Lyme disease to raise awareness of the condition.

Ticks that spread Lyme disease can be found all over the UK, but high-risk areas include woodlands and grassy areas in northern and southern England, and the Scottish Highlands.



Alec Baldwin

Cases have been on the rise in recent years, associated primarily with global climate change. As temperatures increase, precipitation patterns change and sea levels rise, habitat availability and reproduction rates of ticks are affected. Due to global warming their habitat range has grown and there is a longer season for tick activity, leading to increased human exposure.

If you are taking part in outdoor activities for long periods this summer, follow these steps to reduce the chances of being bitten:

- Cover your skin when walking outside and tuck your trousers into your socks.
- · Use insect repellent on your skin and clothes.

Lyme disease and "maybe had it for years".

- · Stay on clear paths when possible.
- Wear light coloured clothing, so you can see ticks easier and brush them off.
- · Check yourself for ticks and rashes after being outside to ensure early treatment.

Visit our A-Z of neurological conditions for more information on Lyme disease and other neurological conditions: www.thebraincharity.org.uk/conditions



Keep an ear out for these 5 great neurology podcasts

Podcasts are an excellent tool for many people with neurological conditions. If you struggle with reading large pieces of text, a podcast can be a convenient way to take in useful information.

Neurology is a constantly developing and complex field of study, but podcasts can help you stay up to date with discoveries and breakthroughs.

Here is The Brain Charity's summary of five neurological podcasts that you may find useful.

All the podcasts featured are free. Podcasts are usually available to stream or download from major sites such as Spotify and Apple Music. Some have their own dedicated website, which can easily be found by typing the name of the podcast into any search engine.

1. Neurology Podcast

This podcast from the American Academy of Neurology is great at covering new, groundbreaking discoveries in neurological research.

Link: www.bit.ly/NeuroPod

2. The Empowering Neurologist Podcast

This is an interview series which introduces listeners to some of the most exciting leaders in the fields of health and wellness. Link: www.bit.lv/ENPod22

3. Neurology Minute

Neurology Minute delivers all the 'need to knows' from leading neurologists and neuroscientists.

Short, daily episodes distinguish this podcast from others, delivering bitesize chunks of excellent information.

Link: www.bit.lv/NeuroMin

4. Lancet Neurology Podcast

This podcast provides the chance to hear from key opinion leaders across medicine and government in relation to neurology.

Link: www.bit.ly/LNAudio

5. PN Podcast

Practical Neurology (PN) was created for professional neurologists who want to keep up to date on how to safely manage their patients, but there's still plenty for the layperson to learn. Link: www.apple.co/3qTsCc8

A retired army colonel's journey across Africa to raise awareness of Parkinson's

In 2019, retired Colonel Guy Deacon set off from the UK to drive 12,000 miles solo to Cape Town. This journey would have been an extraordinary challenge for anyone, but for Guy, who was diagnosed with Parkinson's 11 years ago, this was an incredible undertaking.

Guy had just reached the halfway point of Sierra Leone in early 2020, having crossed the snowy passes of the Atlas Mountains and the deserts of the Western Sahara, when his journey was abruptly halted by the pandemic. This April, Guy has returned to Sierra Leone to resume his challenge and travel the remaining 7.000 miles to Cape Town.

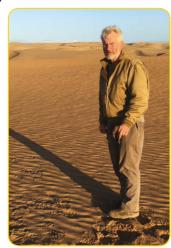
He said: "Living with Parkinson's means there are many things I cannot do as well as I could before. Every day things get a bit worse, and routine matters become more difficult.

"But the worse thing about Parkinson's is not physical, it's the effect it has on your desire to be with other people. It undermines your confidence and you think of yourself as being unworthy of people's attention and care.

"Despite that, I am going to carry on with my plan and not let Parkinson's stop me from living a full life."

Guy is creating a documentary following his travels, to portray the realities of living with Parkinson's in both the UK and Africa.

Find out more at www.bit.ly/Nerve2277



Upcoming activities for July and August

We have lots of free courses and activities happening in this summer, so get involved!

Find out more and sign up at www.thebraincharity.org.uk/events

email activities@thebraincharity.org.uk or call 0151 298 2999.

ACTIVITIES

Mondays

- Virtual coffee morning: 10.30am 11.30pm via Microsoft Teams (monthly: next dates 4th July 4th and 1st August)
- Art for wellbeing: 10am 12pm at The Brain Charity (weekly starting 11th July)
- Shared reading: 12pm 1pm at The Brain Charity (weekly)
- Walking football: 12.30pm 2.30pm at The People's Hub - Everton in the Community (weekly)
- Brain Changer Arts Project summer art and occupational therapy sessions for children & young people: 12pm - 1pm at The Brain Charity (weekly starting 25th July)

Tuesdays

- Afternoon social drop in and chat: 2pm -4pm at The Brain Charity (weekly starting 2nd August)
- Online cookalongs: 4pm 5.30pm via Microsoft Teams (fortnightly restarting 5th July)

Wednesdays

- Knit and natter: 10am 12pm at The Brain Charity and via Microsoft Teams (weekly)
- Neuro-Versity employment course: 11am 1pm at The Brain Charity (six-week course - restrictions apply - weekly restarting September 6th)
- Spinal injury support group: 2pm 4pm at The Brain Charity and virtually via Teams (fortnightly: next dates 6th July, 20th July, 3rd August, 17th August)
- Maths: 2.30pm 4pm at The Brain Charity (weekly)

Thursdays

- English and IT: 10am 12.30pm at The Brain Charity (weekly)
- Afternoon social drop in and chat: 2pm 4pm at The Brain Charity (weekly starting 4th August)

Fridays

- Holistic therapies (aromatherapy, reflexology and reiki): 10am – 2pm at The Brain Charity (15th July, 12th August and 9th September)
- Choir: 4pm 5pm at The Brain Charity (weekly)

SUMMER EVENTS PROGRAMME

We hope you can join in with our summer events! Find out more and sign up or buy tickets at www.thebraincharity.org.uk/events2022 or email events@thebraincharity.org.uk
if you would like to get involved.

- Sunday 3rd July: Liverpool Chester Liverpool Bike Ride - The Brain Charity has free places available for our fundraisers.
- Weekend of 16th 17th July: Tatton Park 300ft Bungee Jump. Sign up for free to join our daredevil team of fundraisers, or come along to cheer them on!
- Saturday 16th July: Come along to support our abseilers as they descend Liverpool Anglican Cathedral.
- Saturday 30th July: Join The Brain Charity contingent on the Liverpool Pride march.
- Friday, 12th August: Ladies Day Race Night from 7pm. Tickets, priced at £7.50, are available from our website shop – www.bit.lv/TBCRN22

Just a reminder that The Brain Charity's Ice Ball will take place on the evening of Friday 2nd December. This is our main annual fundraiser and tickets cost £85 per person. If you can join us, please get yours from our website shop now: www.bit.ly/lceBall22

Ways you can support us

We are very grateful for any support during these challenging times.

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)