



## 30 FOR 30 CHALLENGE

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The Brain Charity

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**RAISING £30,000 IN 2023  
TO MARK 30 YEARS  
OF THE BRAIN CHARITY**

Also find inside...

**Love your brain at Head Matters 2023**  
**Functional neurological disorder explained**  
**Learn real world maths and money skills**



The  
Brain  
Charity

# Annual Report

2021/22



It has been a year of huge change and growth at The Brain Charity, and it was an honour to share the stories of some of the people The Brain Charity has helped over the last 12 months in our annual report for 21-22.

We have chosen to make this year's report film-based to improve accessibility and maximise impact. Watch the videos on the link below to find out more about how The Brain Charity has supported people affected by neurological conditions over the past year.

A huge thank you to Rupak, Dominick, Pammy and John for telling their stories to illustrate the human impact of The Brain Charity's work.

You can read our full annual report here: [www.bit.ly/TBCAR23](http://www.bit.ly/TBCAR23)

## We're celebrating a **BIG BIRTHDAY!**

### This year is The Brain Charity's 30th birthday.



The  
Brain  
Charity

**RAISING £30,000 IN 2023 TO MARK  
30 YEARS OF THE BRAIN CHARITY**

Our charity was founded 30 years ago by consultants at The Walton Centre, who knew better community support was needed for people with neurological diagnoses. To mark 30 years of helping people with all forms of neurological conditions, we've launched the 30 for 30 challenge.

Throughout 2023, we're inviting our supporters to create their own challenge involving the number 30.

If you're feeling sporty, you could run 30 miles a month for a year, swim 30 lengths every day for a month or complete 30 10km runs!

Or why not climb 30 mountains, take on a Tough Mudder as part of a team of 30, or organise a pub quiz with 30 friends?

You could also bungee jump from 300ft, bake 30 cakes for an office bake off, watch 30 films in a month or take part in a 30-hour sponsored silence?

All fundraisers who take part in the challenge and help us head towards our £30,000 target will receive a commemorative 30th anniversary pin badge.

To sign up, head to [www.thebraincharity.org.uk/30-for-30](http://www.thebraincharity.org.uk/30-for-30)

# Learn how to love your brain at Head Matters 2023

FEED - PROTECT - MAXIMISE POTENTIAL

**Head Matters is The Brain Charity's annual open day, where you can find out all about how we can support you - no matter whether you are completely new to The Brain Charity or are a regular visitor.**

If you're able to travel to our centre in Merseyside, we hope you can join us on Wednesday, 15th March, 2023. The free event will open at 10.30am and close at around 3.30pm.

This year's theme is 'Love your brain: feed - protect - maximise potential'. There'll be a range of talks throughout the day on how we can look after our brains, so save the date! Expert guest lectures include:

- **Brain injury rehabilitation by Professor Gus Baker.**
- **Beating brain fog by Dr Sabina Brennan, neuroscientist, health psychologist, author and host of the Super Brain podcast.**
- **An exploration of sleep issues with Specialist Sleep Practitioner Helen Rutherford, from The Sleep Charity.**

As usual, you will have the chance to ask questions of the experts afterwards.

You'll also be able to head inside an inflatable brain to learn more about the six parts of the brain, and find out how to look after your mental health and wellbeing with Healthy Mind UK.

Other charities, groups and partner organisations will also have stalls in our building offering advice, support and interactive activities.

Please go to the link below and RSVP to let us know you're coming.

**[www.bit.ly/HeadM23](http://www.bit.ly/HeadM23)**



Gus Baker



Dr Sabina Brennan



Helen Rutherford



The inflatable brain

## Paul defied the odds to walk a mile for The Brain Charity - raising nearly £2,000

Paul Ives, 54, was paralysed down his left side after suffering a subarachnoid haemorrhage in January 2020 while completing a 5km fun run.

Last October, the dad-of-two walked the Liverpool Rock 'n' Roll mile to raise nearly £2,000 for The Brain Charity.

Paul said: "It's difficult when you have a brain injury, as you find it harder to process your emotions and talk to others. "That's why I'm supporting The Brain Charity, as they help people recovering with the practical things but emotional support too."

Paul's wife Toni and son Liam also ran the Cambridge Half Marathon and Liverpool Half Marathon in aid of The Brain Charity. Together, the determined family have raised nearly £2,000.

Read more: [www.bit.ly/Nerve1233](http://www.bit.ly/Nerve1233)



## If you go down to The Brain Charity, you're sure of a big surprise!

### Meet Bearsac - an extraordinary teddy bear

We were most flattered to welcome Bearsac, a famous teddy bear, to The Brain Charity when he and his human, Debra, made a visit to Liverpool recently.

Debra has Asperger's syndrome and she uses the toy as her medium of communication with the world. In turn, he helps her overcome sensory overload.

Bearsac is the star of Debra's book, 'Travels with my Teddy Bear', which is both a travel memoir and an illustration of the highs and lows of living with autism spectrum disorder (ASD) from a female perspective.

The intrepid teddy has met more than 200 famous people and accompanied his owner on trips all over the world.

Find out more about this incredible assistance bear and his owner online here: [www.bearsac.com](http://www.bearsac.com)



# Rupak's MS story

## "I was homeless after my diagnosis - The Brain Charity finding me a home was irreplaceable"

**Dad-of-three Rupak, from Surrey, had just set up his own business when he was diagnosed with primary progressive multiple sclerosis (MS) in 2018.**

**Before then, the businessman had a successful career in media and advertising and a comfortable lifestyle, taking his eldest son on holidays all over the world before his sixth birthday.**

But when he began to fall over a lot, Rupak, who is originally from India, went to hospital - where an MRI scan discovered lesions on his spine which pointed to MS. Over the next few years Rupak's condition got worse, and he was struggling to get up the stairs. He became unable to work and lost the new business he had poured so much energy into.

Rupak's partner and three children, aged 5, 7 and 11, were forced to move in with family in Liverpool to ensure the children had a stable home environment. Rupak was left homeless - living between Travelodge and Premier Inn hotels when the UK's first COVID-19 lockdown hit.

He said: "It felt like my life was basically done at that stage. I had no support, and no one to turn to. Surviving is difficult enough, surviving with no support is impossible."

Rupak was referred to The Brain Charity by The Walton Centre, and initially came to our centre seeking advice from our employment team which would help him return to work.

He then worked with The Brain Charity's Info & Advice Officer Jane, who has a background in working with vulnerable people around housing issues, to apply for a new property.

Now, Rupak has his own wheelchair-accessible flat in Merseyside, and The Brain Charity has assisted him to apply for grants for new carpet and a tumble drier to make it comfortable to live in. He has also benefited from our phone befriending service so he has someone to talk to at times he's felt lonely or isolated.

Rupak said: "My support went from nothing to nothing but support from The Brain Charity, and that was irreplaceable to me.

"I can go around the centre and say hello to everyone, because there's so many people here that have been a major part of me trying to rebuild my life.

"If it wasn't for the support of The Brain Charity, I don't know what situation I'd be in now.

"It is so much more than just a charity - it is part of my life now. They have helped me so much - from what I was, to helping me get where I want to go myself."

**Watch Rupak talking about his story here**  
**[www.bit.ly/Nerve1232](http://www.bit.ly/Nerve1232)**



Rupak getting advice at  
The Brain Charity



Rupak in his new flat before the  
carpet was fitted



Rupak (before his diagnosis)  
and his son at Disneyland



# What is functional neurological disorder (FND)?

Explaining the most common condition you have never heard of...

**Functional neurological disorder (FND) is a problem with the functioning of the nervous system and how the brain and body send and receive signals.**

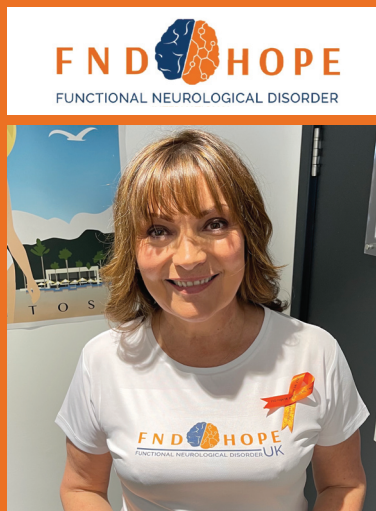
It has multiple causes and can be triggered by physical injury, psychological factors or other trauma to the brain and/or body. Patients live with life-changing symptoms, which can include a variety of physical, sensory and cognitive issues that have yet to be explained by a recognised disease. **The most important point is that symptoms are real.**

Historically, FND has been viewed as an entirely psychological disorder, resulting in physical symptoms caused by suppressed trauma. Psychological disorders and stressful life events, both recent and in childhood, may be risk factors for developing the condition, but they rarely provide a full explanation for the cause and are absent in many patients.

This has resulted in a great deal of confusion, stigma, and frustration surrounding FND, and lack of information and understanding amongst the general population and medical community. A staggering 81.64% of patients feel they had been treated poorly due to stigma related to their FND diagnosis.

It is estimated that between 50,000 and 100,000 adults and up to 20,000 children under the age of 16 live with FND in the UK. **In addition, there are an estimated 10,000 new cases per year.**

Following the COVID-19 pandemic questions have been raised surrounding potential links between 'Long COVID' and FND. At present, there is not enough research surrounding 'Long COVID' to comment with any authority.



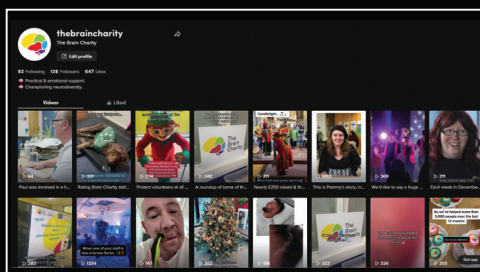
*Lorraine Kelly is patron of FND Hope UK*

*This guest article has been written by FND Hope UK, a patient-led charity for people with the condition. Their mission is to promote awareness, support affected individuals, and advance research for the prevention, treatment and recovery of FND.*

For further information on FND and the support they can provide, go to [www.fndhope.org.uk](http://www.fndhope.org.uk)

## Find us on TikTok

The Brain Charity currently has over 25,000 Followers on social media, and we have recently expanded our reach into TikTok. We hope this move will introduce the charity to new generation of supporters and awareness raisers - and allow us to support younger people who might need our help. We'll be sharing bite-sized videos about activities at The Brain Charity and behind the scenes exclusives on our new account [@thebraincharity](https://www.tiktok.com/@thebraincharity).



So if you're young, or young at heart, check out our clips and follow us here:

[www.tiktok.com/@thebraincharity](https://www.tiktok.com/@thebraincharity)

# What are reasonable adjustments, and how to ask for them

Being diagnosed with a neurological condition often means so much more than a change in your health. You may feel you can no longer work in the ways you used to, or worry about workplace discrimination.

Here, The Brain Charity's Employment Law and Welfare Officer Aneeta Bibi (pictured below) shares how to ask your employer for reasonable adjustments.



## When should I disclose my disability?

Disclosing a disability to a current or potential employer can be a stressful but necessary step. The fear of discrimination, unconscious bias and other negative consequences leads many to withhold information about their physical or mental health. However, telling an employer about a disability - be it visible, like cerebral palsy, or invisible, like chronic migraine - may be necessary to receive adequate accommodations to perform your job.

Disclosing in a cover letter is the most common way, but you may need to disclose before an interview or assessment for adjustments to be made.

## How can I request reasonable adjustments?

It is important your employer knows about your disability before you request reasonable adjustments. An employee who needs a reasonable adjustment should talk with their manager or employer. It's a good idea to meet first to discuss the situation, but anything agreed should be put in writing.

## Who pays for reasonable adjustments?

The employer is responsible for paying for any reasonable adjustments. Government Access to Work grants may help fund reasonable adjustments.

To find out more and download a reasonable adjustments template letter, head to [www.bit.ly/Nerve1231](http://www.bit.ly/Nerve1231) or if you need help, email [employmentservices@thebraincharity.org.uk](mailto:employmentservices@thebraincharity.org.uk)

## What are reasonable adjustments?

A 'reasonable adjustment' is a 'practical, effective and significant' change that must be made to remove or reduce a disadvantage related to:

- An employee's disability
- A job applicant's disability

A reasonable adjustment could involve making changes to:

- The workplace
- Equipment provided
- The ways things are done
- An individual's working pattern

## The law behind disability and reasonable adjustments

Under the Equality Act 2010, there is a legal duty on employers to make reasonable adjustments for disabled employees. Failure to do this is classed as discrimination.

## How you can prevent disease today - and find out about your own health

How can we help prevent diseases and detect them earlier? Do you want to be part of the answer, while also learning about your own health?

An ambitious new health research programme is inviting The Brain Charity's clients and supporters to do just that.

**Our Future Health** is designed to help researchers discover new ways to prevent, detect and treat common diseases like cancer, diabetes and dementia. The programme is bringing together up to five million volunteers aged 18 and over from across the country - making it the UK's largest ever health research programme.

To take part, you must complete an online questionnaire, give consent to disclose your existing health records, provide a small sample of blood and have some physical measurements taken.

**Our Future Health** also offers the opportunity to get feedback on your health.

To join **Our Future Health** today, head to: [www.bit.ly/FH2023](http://www.bit.ly/FH2023)

# LGBTQIA+ and neurodiversity

John Anderson is The Brain Charity's LGBTQ+ representative. Here, he shares his thoughts on LGBTQ+ and neurodiversity.



The Brain Charity's  
LGBTQIA+ rep.  
John Anderson



The Brain Charity's  
staff member Jess  
at Liverpool Pride '22

**“ Society is gradually accepting all brains work in different ways-there is no one 'correct' type of brain! A parallel to this is our gradual acceptance of the many identities that fall under the LGBTQIA+ (Lesbian, gay, bisexual, transgender, queer, intersex, asexual) umbrella.**

**Evidence suggests neurodivergent individuals, particularly those with autism, are significantly more likely to identify as LGBTQIA+ than those who are neurotypical.**

**Latest** data from the Office of National Statistics shows around 3% of the UK population identifies as lesbian, gay or bisexual, while between 15 -20% of the population is neurodivergent. However, one recent study found people with autism might be three times more likely to identify as trans, while another found neurodivergent individuals were 8 times as likely to be asexual.

**Being** neurodivergent remains a huge barrier to many people receiving the gender-affirming healthcare they need, and prejudice can lead to under-diagnosis of neurological conditions amongst the LGBTQIA+ community. One-third of respondents to a 2018 study said their gender identity had been repeatedly questioned due to their autism.

**No one** is sure why there is such an overlap between the neurodivergent and queer communities, but the predominant theory is that neurodivergent people tend to be less aware of or inclined to follow societal norms. We live in a society where being heterosexual and cisgender is the default, so neurodivergent people may feel freer to express their gender or sexuality without the need to conform.

**If we** want greater acceptance of the huge value of neurodivergent individuals, then we also need greater acceptance of non-traditional sexualities and gender identities. Both neurodivergent and LGBTQIA+ people have to effectively 'come out' - not just once, but constantly to new people. There also still remains stigma: some people view being autistic or being gay as conditions to be 'cured'. These are some of the reasons why our community has higher than average rates of mental illness.

**There is** joy to be found in pride, whether accepting your neurodivergence as an inherent strength, or coming to terms with your true gender identity. We will continue working towards a society which fully embraces what neurodiversity and the LGBTQIA+ spectrum have to offer.”

John is working to make The Brain Charity more LGBTQ+ friendly. Get in touch with him with any issues or suggestions at [john.anderson@thebraincharity.org.uk](mailto:john.anderson@thebraincharity.org.uk)



# Boost your maths skills to save money



**In January, we will be launching 'money and maths' drop-ins to help you save money by improving your real-world maths skills.**

Our informal twice-weekly sessions (Mondays 4pm - 5pm and Thursdays 10.45am - 11.30am at The Brain Charity's centre) will help you feel more confident understanding numbers in practical ways. We can provide one-to-one support on topics such as:

- Managing and taking control of your finances
- Maths booster skills - adding, subtracting, multiplication, division and percentages
- Using maths to work out your weekly shop
- Household budgeting
- How to use online price comparison sites
- How to understand and save money on your gas and electricity bills
- Credit cards and store cards and how to manage them
- Money news - inflation and interest rates, what does it mean for me?
- Scams and staying safe online
- Understanding bank accounts
- Your credit score and how to improve it

But we can work with you based on any questions you might have.

If you want more continuous learning, you can also join our weekly maths class.

Email [activities@thebraincharity.org.uk](mailto:activities@thebraincharity.org.uk) or call **0151 298 2999** to sign up now.

## Our revamped rooms reopen

The Brain Charity's base in Liverpool has three fully accessible meeting rooms for hire. They've just been newly renovated - as you can see from the photos below.



When businesses book our training and conference spaces, they are directly supporting The Brain Charity's vital work – helping people affected by all forms of neurological condition to lead longer, healthier, happier lives. This makes booking The Brain Charity's rooms the ethical choice to meet any organisation's corporate social responsibility needs. We offer a 40% discount to any registered charities with a turnover of less than £1 million, and a 10% discount to larger registered charities.

Please let any business or charity you feel would benefit know about this. To book & find out more visit [www.thebraincharity.org.uk/room-hire](http://www.thebraincharity.org.uk/room-hire)

If you want more continuous learning, you can also join our weekly maths class.

Email [activities@thebraincharity.org.uk](mailto:activities@thebraincharity.org.uk) or call **0151 298 2999** to sign up now.



# How to regain and improve swallowing

By Krystina Crolla-Barker (Consultant Speech and Language Therapist) and Amy Tighe (Speech and Language Therapy Assistant) from More than Speech Therapy

**Difficulties with swallowing, eating and drinking are also known as dysphagia. Problems with swallowing look different for everyone. They can be caused by a variety of conditions including Parkinson's, dementia, stroke, brain injury, brain aneurysm, cerebral palsy and motor neurone disease (MND).**

**Difficulties with eating, drinking, and swallowing can happen due to:**

- Muscles not coordinating and moving at the right time
- Muscles not getting the right signals from the brain or mouth
- Being distracted and not concentrating on swallowing
- Becoming more tired, which makes it difficult to swallow
- The side effects of medications

**If someone is struggling with swallowing during eating or drinking, signs include:**

- Coughing or choking
- Turning red or blue
- Eye watering
- Gurgly voice
- Feeling tired during or after a meal
- Not being able to chew properly
- Being short of breath

**Over time, people can also experience unexplained weight loss, chest infections and urinary tract infections.**

Here are some tips to help improve swallowing.

- 1 Eat and drink only when you are sitting up straight in a chair with arms, with your feet touching the floor and at a table which is a good height for you.
- 2 Some foods are more difficult to chew and swallow, you might find it easier to avoid these.

Examples include:

- Crunchy foods
- Crumbly and dry foods
- Tough foods



*Krystina Crolla-Barker*



*Amy Tighe*

- Foods with skins on them
  - Hard-boiled sweets
  - Stodgy foods
  - Nuts
- 3 Cut foods up into pieces as small as a 20p coin, and add sauces to moisten them.
  - 4 Have a drink with your food, regular sips will help you swallow.
  - 5 Don't rush, take your time when eating. This will make sure you chew everything properly.
  - 6 Eat smaller amounts more regularly, rather than three big meals per day.
  - 7 If you struggle swallowing medication tablets, ask your GP or pharmacist for liquid alternatives.
  - 8 After eating, clean your mouth, brush your teeth and gums and make sure there isn't any food left in your mouth.

If you feel you or a loved one needs more support, or you have any questions, contact [info@morethanspeechtherapy.co.uk](mailto:info@morethanspeechtherapy.co.uk)

The Brain Charity's **Music Makes Us!** project provides free speech and language therapy through singing for people living with dementia in care homes across Merseyside, and globally via an online video programme.

Click here to find out more about **Music Makes Us!**  
[www.bit.ly/TNdementia](http://www.bit.ly/TNdementia)

# Social activities January-February 2023

	Monday	Tuesday	Wednesday
Mornings	<b>Art for wellbeing</b> 10am - noon <b>Digital drop-in</b> 10am - 1pm <b>Coffee Morning</b> <i>Monday 9th January and Monday 6th February</i> from 10.30am online attendance can be arranged	<b>Confidence Coaching Sessions</b> <i>From 1st November for 4 weeks</i> 10am - 12.30pm	<b>Knit and Natter</b> 10am - noon <b>Crafters club</b> 10.30am - 12.30pm
Afternoons	<b>English &amp; IT</b> Noon - 3.15pm <b>Maths</b> 1.45pm - 3pm <b>Shared Reading</b> 3.30pm - 4.30pm <b>Money and Maths</b> 4pm - 5pm (Also Thursdays 10.45am - 11.30am)	<b>Afternoon social</b> 1.30pm - 3.30pm	<b>Boccia</b> 1pm - 2pm <b>Bat and chat</b> (table tennis) 2pm - 3pm <b>Choir</b> 4pm - 5pm <b>Warm welcome hub</b> 4pm - 6.30pm

**Now moved to Thursdays and accepting new joiners!** Ukulele for beginners 3.30pm - 4.30pm.

## Online:

**Poetry continues** (Wednesdays, fortnightly- 5.30-6.30pm) starting in 6-week blocks from 11th January.

**NEW! Online Book Club** (Wednesdays 5.30-6.30pm) starting in 6-week blocks from 18th January.

## How to sign up

See all our updated activities here: [www.thebraincharity.org.uk/events](http://www.thebraincharity.org.uk/events)

All The Brain Charity's activities are free for anyone affected by a neurological condition - including family, friends and carers. If you would like to take part in any activities, email [activities@thebraincharity.org.uk](mailto:activities@thebraincharity.org.uk) or call **0151 298 2999** and ask for Suzanne.

**Don't forget... Head Matters 2023: love your brain!**  
[www.bit.ly/HeadM23](http://www.bit.ly/HeadM23)

# 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.

**Give as you Live®**

Getting involved is easy - just register at [www.bit.ly/GAYLTBC](http://www.bit.ly/GAYLTBC) to start raising money for The Brain Charity today.

## 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:



## 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



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](http://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](mailto: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](http://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)