

# THE GREY MATTERS

ISSUE 25 WINTER 2021

THE  
BRAIN  
TUMOUR  
CHARITY

COMING TOGETHER TO GO  
FURTHER, FASTER  
FOR A CURE





## HELLO

Welcome to issue 25 of *The Grey Matters*.

We're delighted to bring you your new issue themed around 'Voices for Change'. This is one of the four programmes in our charity strategy for 2021-22, 'Defeating Brain Tumours – Leaning In'.

Though it's been another difficult year, we remain as dedicated as ever to doubling survival and halving the harm brain tumours have on quality of life. You can read more about our strategy, and how we're leaning in to the community's needs in the wake of the COVID-19 crisis, at [thebraintumourcharity.org/our-strategy](https://thebraintumourcharity.org/our-strategy)

Those affected by brain tumours are at the heart of our strategy and you'll find many of their voices amplified in this issue – from explaining what being a voice for change means to them (page 16), to talking about BRIAN, our ground-breaking app (page 12), to offering their tips on coping as a carer (page 20).

We've been so inspired by your involvement this year. Just some highlights include the 350 of you who took part in Conquer the Challenge – running, cycling and walking to help us pick up the pace of progress. And at the time of press, we've now reached over 5,200 sign-ups to BRIAN, a monumental step forward in getting researchers the brain tumour data they need, faster. Thank you! We hope you enjoy reading this issue and that you'll continue to stand with us this year as we step up, take action and unite our voices in calling for a world where brain tumours are defeated. Why not start by ordering from our Christmas shop this season? Our brain-tumour-beating range of cards and gifts is featured inside (page 24) – every purchase will help us accelerate change.

Thank you,

Dr David Jenkinson  
Interim CEO and Chief Scientific Officer

**When you've finished with this magazine,**

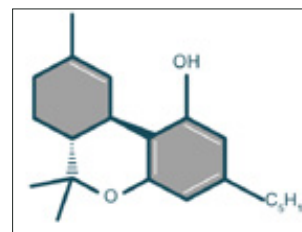
**Please share it!**

It will show others the difference we make, together. We rely 100% on voluntary donations to help us drive change.

If you receive this magazine and would like to join our movement, you can make a donation in the following ways:

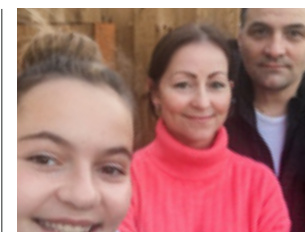
Online:  
[thebraintumourcharity.org/donate](https://thebraintumourcharity.org/donate)  
Phone: **01252 237792**  
Post: **The Brain Tumour Charity, Fleet 27, Rye Close, Fleet, Hampshire GU51 2UH.**

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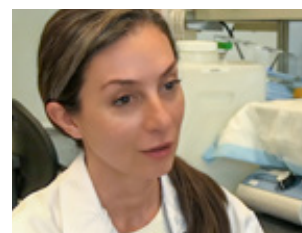
See how Peter and Nicola are going above and beyond to drive much-needed change – and find out how you can get involved.



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Buying your Christmas cards and gifts from us is an easy and inspiring way to support our mission to defeat brain tumours.

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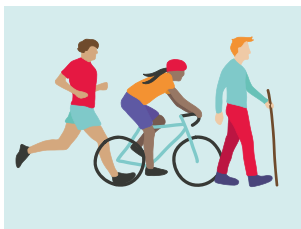
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All information correct at time of print



## YOU WENT THE DISTANCE

We want to say a huge thank you and congratulations to everyone who took part in #ConquertheChallenge 2021 earlier this year.

We're thrilled to announce that over 350 intrepid challengers took part, completing an epic 34,456 miles in total and helping us move further, faster for everyone affected by brain tumours.

The community has raised an incredible £275,000 together - that's enough to fund over two years of one of our world-class research projects to find new and safer treatments!

Thank you again - we're incredibly grateful for all your support.



## ADVANCING A CURE FOR DMG

In July, one of our recently completed research projects published new data showing that a genetic mutation, called H3K27M, drives the formation of diffuse midline glioma (DMG), a group of devastating and incurable childhood brain cancers that includes the tumour formerly known as DIPG. Dr Adrian Bracken, from Trinity College Dublin, has also found a drug that can slow the cancer's unchecked cell growth in lab tests.

Finding the cause and a potential treatment for this often inoperable brain tumour within one project is an amazing achievement and brings new hope to families of children with a DMG. This research is also a great example of how collaborating with another funder, Worldwide Cancer Research, has paid dividends for our community.



## BETTER CARE CAN'T WAIT!

The 'Tessa Jowell Centre of Excellence' status recognises delivery of outstanding care and treatment for people diagnosed with a brain tumour - and patient insight is absolutely key to awarding this designation to centres. By sharing your experiences in our six Improving Brain Tumour Care Surveys, you'll help us get a better picture of the care you're receiving, help as many hospitals as possible achieve 'Excellence' status in the future and make sure best practice is shared around the country. We'll work closely with clinicians and at a national level to close the gaps in care and drive urgent change. Each survey only takes 10 minutes to complete and you can fill out as many as are relevant to your own experiences.

Visit [thebraintumourcharity.org/care-surveys](https://thebraintumourcharity.org/care-surveys) to take part



## JOHN'S MAD SWIM

More people have walked on the moon than have solo swum the 42.8-mile length of Lake Geneva. In memory of his sister Emma, who died of a brain tumour, John Royden aimed to be the eighth person to complete this epic challenge. On 28 July, John set off - but unfortunately, after 22 hours' continuous swimming and 26 miles covered, medics made the difficult decision to pull him from the water for safety reasons.

Despite being initially disappointed, John has been inspired by the enormous amount of support received, and has already booked the boat for next year to "finish what he started". Well done John - you're an inspiration to us all!

You can support John at [justgiving.com/fundraising/johnsmadswim](https://justgiving.com/fundraising/johnsmadswim)



## WALK IT YOUR WAY

The Twilight Walk is back! Join us remotely this October to help us pick up the pace towards a cure. You can opt for our traditional 10km, go further with our more challenging distances: 40km or 130km, or choose your very own special distance.

You can take part however works best for you, striding out on your own or coming together as a team. You might choose to complete your distance in a day, across multiple days or even split it across your team and tackle it as a relay!

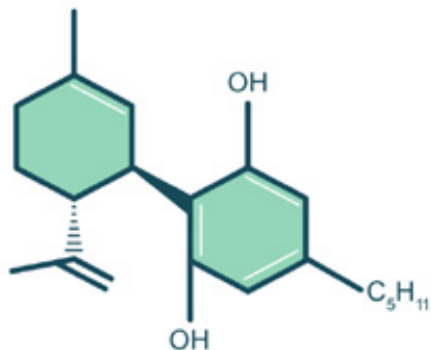
So limber up, plan your route and be part of our movement - though we're walking apart, we'll beat brain tumours together.

Visit [thetwilightwalk.com](https://thetwilightwalk.com) to sign up

# CANNABINOIDS

## WHAT AND WHY?

**CANNABINOIDS HAVE WELL-DESCRIBED EFFECTS IN THE BRAIN – AND PRELIMINARY RESEARCH IS SHOWING THAT BRAIN TUMOURS MAY RESPOND TO THEM.**



### What are cannabinoids?

Cannabis is the dried preparation, or resinous extract, of the flowers or leaves of the cannabis plant, a member of the hemp family. It's an illegal drug in many countries, including the UK.

Cannabinoids are the parts of cannabis that are considered important for medical reasons – the complex chemicals that are responsible for the effect cannabis has on the body. Two cannabinoids are of particular interest:

- **THC – Responsible for the psycho-active and addictive effects of cannabis. Cannabis and cannabis oil are classified as class B drugs in the UK because they contain THC. However, from 1 November 2018, cannabis-based products for medicinal use became available in the UK in some circumstances only.**

- **CBD – CBD oil is different from cannabis oil because it does not contain THC. It's currently legal in the UK – as long as it has been produced from an EU-approved strain of hemp and as long as it is marketed as a food supplement without any medicinal claims. You can buy it in many high street health food shops.**

### Cannabinoids and brain tumours

Although there's good evidence for the benefits of cannabis-derived products in, for example, relieving pain and treating chemotherapy-induced nausea and vomiting, there's currently limited proof that these products can treat brain tumours themselves.

There have been some early positive results using a drug called Sativex (a combination of THC and CBD) alongside the chemotherapy drug temozolomide. Though this was a small study, it found that in people with recurrent glioblastoma, those treated with Sativex had a higher chance of longer survival time compared to those who didn't have the drug.

The next stage (see opposite) is a larger study to see whether Sativex really does work better than standard treatment and whether it produces fewer side-effects.



Professor Susan Short

## ARISTOCRAT: OUR CANNABINOID CLINICAL TRIAL

**We're driving progress in investigating whether cannabinoid treatments can improve survival in people diagnosed with recurrent glioblastoma (GBM).**

For years we've heard, anecdotally, that cannabis-derived products help people with brain tumours. And we've been asked repeatedly to prioritise research into this area. To answer this call we created an opportunity for our researchers to design an appropriate clinical trial. Professor Susan Short, based at the University of Leeds, has done just that.

Professor Short has a wealth of experience in clinical trials, including a 25-person pilot study using the cannabinoid/cannabis derivative drug, Sativex – an oral spray containing two extracts from the cannabis plant: delta9-tetrahydrocannabinol (THC) and cannabidiol (CBD).

With the support of the team at the University of Birmingham Clinical Trials Unit, and using the resources provided by our BRAIN MATRIX platform study, we want to fund Professor Short's trial into the effects of Sativex on survival as well as quality of life.

Known as ARISTOCRAT, this will be a randomised trial – a trial where people are put into treatment groups by chance. Everyone in the trial will receive the current standard of care (temozolomide chemotherapy) in addition to an oral spray, which will be placebo-controlled, meaning some people will receive a placebo instead of Sativex in the oral spray they're given. This means the trial results won't be influenced by what the doctors or participants think they should be feeling or seeing.

### THANK YOU!

In August, we launched a one-week fundraising campaign to raise the money needed to kick-start this ground-breaking clinical trial.

We're thrilled to share that the community rallied to support it – donations were doubled through The Big Give match funding platform and an amazing £127,000 was raised in total!

We're so grateful to all of you who donated – this is a crucial step towards being able to press the 'go' button on this pioneering trial.

You can find out more and support the trial here: [thebraintumourcharity.org/get-involved/cannabinoid-clinical-trial-appeal](https://thebraintumourcharity.org/get-involved/cannabinoid-clinical-trial-appeal)



# DRIVING PROGRESS IN RESEARCH

## HOW COVID-19 HAS AFFECTED RESEARCH

COVID-19 has dramatically transformed the landscape of research into brain tumours, with all experimental labs closed for at least a few months after the start of the pandemic. When these did re-open, it was – and largely still is – at reduced capacity, with numbers in the lab limited due to social distancing. The pandemic has also delayed clinical trials, as clinical priorities and personnel have had to be diverted towards COVID-19 care.

But many of our funded researchers have been able to continue projects where much of the work is computational and can therefore be done from home. Many have also been using this time to analyse existing results, publish scientific papers to share their findings and plan new experiments and collaborations.

Most of our researchers have told us that they are now making good progress, though some are still feeling the impact of reduced capacity. During this time, due to the delays caused by COVID-19, we've awarded over 20 no-cost extensions to timeframes so that project leaders have the time they need to complete their work.

## UPDATES ON OUR GRANTS



### BEATING TREATMENT RESISTANCE IN HIGH GRADE GLIOMAS

Lead researcher: Professor Terrance Johns, Telethon Kids Institute Cancer Centre, Australia

We're excited to share the great progress made by Professor Johns and his team during the two-year term of their grant (2018-2020). The team gained valuable insights into how high grade glioma cells change and may be resisting treatments. This enabled the team to identify new drug combinations that could be more effective and improve survival for children and adults with high grade gliomas. To achieve all this, the team studied 'ion channels', small holes in the cell membrane that control the flow of substances in and out. These are thought to be key to why glioma cells change.

This work could pave the way for ion channel drugs to form new treatments for these aggressive tumours. The team have already secured more funding that they hope will propel their discoveries into clinical trials – and from there into meaningful treatment benefits.



### A BRIGHTER FUTURE FOR CHILDREN WITH LOW GRADE TUMOURS

Lead researcher: Dr David Jones, German Cancer Research Centre, Germany

The team at the Everest Centre for Paediatric Low Grade Brain Tumours are now over halfway into their landmark grant with us and have made huge strides towards a brighter future for children with these often debilitating conditions.

The team have identified a previously misdiagnosed subtype of childhood low grade brain tumour, which will improve diagnosis and ensure children get the best possible treatment options. They have also generated a new cell model of pilocytic astrocytoma and are now using this model to test how effective new drugs are at attacking tumour cells, which could lead to better treatments.

Additionally, the team have launched the LOGGIC Core (Low Grade Glioma In Children) study which is building a library of low grade gliomas to form the foundation of future clinical trials. And they have also been investigating a brand new class of drugs called 'senolytics', which have shown early positive results in the lab. They now hope to begin a clinical trial to test their effectiveness.



### BLOOD TESTS AND BIOMARKERS FOR MENINGIOMAS

Lead researcher: Dr Gelareh Zadeh, University Health Network, Canada

Meningiomas fall into two categories during clinical care: indolent (less aggressive) and clinically aggressive. It's important to treat the more aggressive tumours with more aggressive treatments, but it can be hard to tell them apart.

Our research, in collaboration with a major UK-led clinical trial and using advanced artificial intelligence, is striving towards tomorrow's clinical care.

Dr Gelareh Zadeh and her team of experts are developing a blood test to identify the more aggressive meningiomas. They're also searching for biomarkers in the blood to predict how the tumours will respond to radiotherapy.

This vital insight could spare people unnecessary treatments and their side-effects. Together, we're working to achieve our goal of halving the harm of brain tumours and their treatments.

# MEET FUTURE LEADER SPENCER WATSON

**We established the step-changing Future Leaders scheme in 2017 to support and encourage the future leaders of research into brain tumours.**

**The scheme identifies excellent early-stage non-clinical researchers and provides financial and personal support so they can establish themselves as leading researchers in the field.**



Dr Spencer Watson

**DR SPENCER WATSON**  
University of Lausanne, Switzerland

Dr Watson is a Postdoctoral Researcher in the Department of Oncology at the University of Lausanne, Switzerland. His research in the lab of Professor Johanna Joyce focuses on how the brain tumour microenvironment responds to current therapies and how this can lead to tumour recurrence.

We're incredibly grateful to The Brian Cross Memorial Trust for committing £180,000 to fund Dr Watson's three-year project as part of our Future Leaders programme.

## **Q. Tell us about your project**

We're investigating how the tumour microenvironment around glioblastomas (GBMs) may be encouraging growth – and importantly how to stop it. We've discovered in preclinical models of GBMs that tumour recurrence always occurs right next to so-called 'glial

scars' that form during treatment, so we're testing the idea that glial scars may create a protective area for surviving tumour cells that also reprograms the microenvironment to drive rapid tumour recurrence. It's our hope that by repurposing currently approved drugs to target the microenvironment of brain tumours, we can improve how patients respond to standard treatments now – and not ten years from now.

## **Q. What does this funding mean to you and your research?**

As a researcher, having your work validated by the support of a prominent charity is hugely encouraging and incredibly motivating. Being part of the Future Leaders programme is vital to my goal of making a meaningful contribution to improving outcomes for GBM patients. Not only does the generous support scheme allow me to attempt highly ambitious projects, but the connections and communication with other Future Leaders creates a collaborative network that helps all of us reach our goals.

## **Q. What motivated you to get into this field?**

I was very fortunate to discover science at an early age and find that I had some talent for it. I have also been lucky enough to have some amazing scientific mentors during my career who inspired me to take on big ambitious goals, and taught me that the point of science was to make a difference.

I was always motivated by the idea that if you were good at something, you had a responsibility to use it to help people. Teachers, nurses, aid workers, first-responders; where would we be if people like this didn't use their talents to make life better for the rest of us?

So I wanted to focus on problems that needed the most urgent help. And beyond a doubt, that field was brain cancer research. There has been so little improvement in treatment for patients for so long, and I hoped that I could change that. I don't believe that any problem is insurmountable, and by working with charities, fundraisers and patient advocates I think we can make a real difference to patients' lives.

## **A CURE CAN'T WAIT**

Help us move further, faster towards a cure. A monthly gift of £30 could help improve treatments by covering the cost of a day's world-class research. Set up your monthly gift today: [thebraintumourcharity.org/donate](https://thebraintumourcharity.org/donate)

# BE PART OF THE CURE WITH BRIAN

**As part of our strategy, we're committed to harnessing the power of people's data to drive change. And we know you're with us on this – in a survey we conducted, 97% of respondents said they'd be happy to share their medical and health data to help improve brain tumour treatment and care.**

Unfortunately, data availability and outcome measurements for brain tumours are sorely lacking and this is hampering researchers in their quest for a cure. We need to give them the anonymised data they need, faster – and BRIAN is the key that will help us get there together.

Read on to find out what BRIAN is all about, see the progress we've made since we last updated you, and meet Donald, a BRIAN user who was diagnosed with an oligodendroglioma brain tumour.

## YOUR EXPERIENCES ARE THE KEY TO A CURE

BRIAN is our ground-breaking app and databank that's revolutionising the way we tackle brain tumours. It's the biggest data collection project in the history of

research into this disease, and it's powered by those who are personally affected.

BRIAN's been designed to support and mobilise everyone, whether you're living with a brain tumour, caring for someone who is, or you work in healthcare or research.

BRIAN not only helps people take more control of their diagnosis but will help shape the future of research into brain tumours. The anonymised data in BRIAN will go to world-leading scientists, who'll use it to kick-start vital research into brain tumours. Every single experience logged adds hope for the future and will accelerate progress towards a cure. BRIAN also supports people affected by letting them track symptoms, appointments, moods and more, quickly and easily logging their experiences and getting the knowledge they need to make more informed decisions.

BRIAN is available as an app in the Android and Apple app stores. You can also find out more at [askbrian.org.uk](http://askbrian.org.uk)

**“With this project, researchers will for the first time have access to large amounts of data from lots of patients. This is game-changing for research into brain tumours.**

– Dr Paul Brennan, Senior Clinical Lecturer in Neurosurgery at the University of Edinburgh

## GOING MOBILE AND MORE!

We were thrilled to launch BRIAN as a mobile app in December 2020 – and since then it's gone from strength to strength. We now have over 5,200 sign ups, a fantastic stride forward in our drive for better data availability, better care and improved quality of life for people diagnosed with a brain tumour.

During Brain Tumour Awareness Month in March, we encouraged the community to make their voices heard and share their experiences to help raise awareness of brain tumours. In turn, we shared the benefits of BRIAN with the community and gained over 570 sign ups – thank you!

We were also proud to see BRIAN receive a 91% score from ORCHA – a leading independent evaluator of digital health apps. ORCHA curates a high-quality app library used by local authorities and NHS trusts around the country, and BRIAN's score makes it their top-ranking cancer-related app!

Furthermore, NHS Digital audited BRIAN in January and deemed BRIAN's approach to data security and protection to be low risk (the best outcome possible). The project was also commended for its good practices. This confirms that BRIAN is a safe custodian for our community's data.

Finally, we made great progress this year in obtaining brain tumour data from devolved nations. We also obtained more data from Public Health England and NHS Digital and published eight new insights in BRIAN using this data.

**“I have used the BRIAN app to improve patient experience and outcomes for glioblastoma patients. Thank you for what you have built – this is an amazing resource for brain tumour patients, families, and care providers.**

– Paolo Jose De Luna, Clinical Research Nurse at St. Bartholomew's Hospital

## BRIAN IN NUMBERS

**OVER 5,200**  
people signed up

**OVER 24,000**  
quality-of-life  
check-ins added

**OVER 1,200**  
instances of  
treatment logged

**OVER 2,400**  
appointments recorded

**OVER 4,300**  
tumour logs added

**OVER 2,400**  
questionnaires filled in

**OVER 8,900**  
memory, stability, speech  
and selfie challenges taken

## BE PART OF BRIAN

BRIAN can benefit you, whether you're living with a brain tumour or supporting someone who is. To sign up, visit [thebraintumourcharity.org/brian](http://thebraintumourcharity.org/brian)



# DONALD'S STORY

**We spoke to Donald about his brain tumour diagnosis, how BRIAN has helped him and why he recommends BRIAN to others who've been diagnosed.**

**“The BRIAN app gives you hope and opportunity, no matter where you are in your journey with a brain tumour.**



**Q. Tell us about your brain tumour diagnosis**

I was diagnosed with a grade 2 oligodendroglioma sixteen years ago. Before my diagnosis, I was fit and healthy. Completely out of the blue, I suffered an epileptic seizure and my life completely changed. I was on the phone to my manager at the time. I had no idea what had happened and when I came to, I was totally bewildered,

My wife took me to A&E where I was assessed, but no diagnosis was provided and I was sent home to await a scan appointment. I didn't know what to think and obviously feared the worst. I had an MRI scan the following week and waiting for the results was truly awful. The way I was told I had a brain tumour

was equally horrendous – over the phone, when I was on my own, with little information.

My world had been shattered. My clinician said my options were to do nothing, to watch and wait, or to speak to the surgeon. As you can imagine, we were in total shock and really had no idea what to do. We had a four-year-old daughter at the time and had to ensure she was unaffected by the whole situation.

I was tempted to start looking into the scientific research myself as I had a scientific background, but I thought I would find a lot of negativity, so decided not to.

My wife and I met the surgeon and he was truly

remarkable, positive, realistic and supportive. Fortunately, my tumour was low grade and operable. I count myself so fortunate – so many others aren't so lucky. With help, I decided on surgery, and they successfully removed more than 95% of the tumour.

I always knew there would be a chance the tumour would regrow, and in 2015, I had a second awake craniotomy, reducing the tumour by 70%. The medical professionals at the Western General Neurosciences Centre and Edinburgh Cancer Research Centre have been so supportive and helpful through some of the most difficult times.

**Q. Why did you start using BRIAN?**

I came across BRIAN on The Brain Tumour Charity's website. I have a scientific background and found it really useful. It had all the relevant information I required and it really saved me looking for information on the internet, which may not have been suitable.

I really wish I'd had such an informative resource available when I was first diagnosed – and now

that we have the mobile version, it's so easy to have at hand all the time as the app is now on my phone.

**Q. What's your favourite feature of BRIAN?**

The features I find most helpful are the ones that help me with my memory. That's one of the things that's really been affected by my brain tumour, so reminders about upcoming appointments and remembering to take my medication are most convenient.

**Q. Has BRIAN helped you feel more connected to others?**

BRIAN is great for connecting with others, whether it be people who've had a brain tumour or are caring for someone. There are some really great chat rooms where you can log in and chat personally with people about things that maybe your family or friends wouldn't understand or appreciate. I think that's a really good part of the BRIAN app.

**Q. Why would you recommend BRIAN to others?**

I'd definitely recommend BRIAN to anybody who's received a diagnosis of a brain tumour. It gives

you all the information you want – and you can use as much or as little of the app as you need or want to. You can use different parts depending on where you are in your journey with a brain tumour. But I think the main thing is, the app gives you hope and opportunity no matter where you are with your brain tumour.

**Q. And finally, what are your hopes for the future of BRIAN?**

My hopes are that BRIAN will be used more widely within the brain tumour community, not only by patients but carers and medical professionals too. Because BRIAN crosses between patients, carers and clinicians, all the data is going into a central pot and can be distributed throughout the scientific community. I think having all the inputs from these areas, all these resources coming together, will push us quicker towards a cure for this truly awful disease.



**Peter and Wendy -  
see Peter's story  
over the page**



# USING OUR VOICES FOR CHANGE!

Brain tumours are the biggest cancer killer of children and adults under 40 and they shorten lives by an average of 27 years - the highest of any cancer. Just 12% of adults survive for five years after diagnosis. That's why we're so passionate about defeating brain tumours and finding a cure for this condition, which 33 people are diagnosed with every single day.

We know that you're passionate about this too and want to drive change just as much as we do. As a charity, we're fortunate to be far from alone in realising the need to tackle injustice, speed up diagnosis times, propel pioneering research and provide support when it's acutely needed.

The COVID-19 pandemic has highlighted just how vital it is to ensure that everyone affected by a brain tumour gets effective medical treatment, practical help and emotional support right from the point of the first known symptom.

That's why, as part of our 2021-22 organisational strategy, we're calling on the community to raise their Voices for Change and help us create a world where brain tumours are defeated. As soon as you're impacted by a brain tumour, you become the expert in what that really means. So, we want you to share that with us to help make a real difference.

You could have experience with brain tumours in a variety of ways. Maybe you've been diagnosed yourself or you've been affected by the diagnosis of a loved one. Clinicians, nurses, researchers and policy-makers also have valuable insights to share. Through Voices for Change, we can bring together everyone's passion, experiences, opinions, stories and evidence to focus on what our top priorities should be.

There are many ways to use your voice for change. For example, you could share your story to support and connect with others. You could join our Involvement Network to discuss policy and research. Or you could sign up to our BRIAN app (see page 12) to help amass much-needed data on the reality of brain tumours. You can contribute as much or as little as you like around your own time commitments, personal interests and views.

People affected by brain tumours must be heard, and we're here to do just that - so, over the next two pages, we've asked two of our supporters why they're supporting Voices for Change.

## BE A VOICE FOR CHANGE

To see the different ways you can use your voice for change and get involved, visit our website at [thebraintumourcharity.org/get-involved](https://thebraintumourcharity.org/get-involved)



## “It’s only by exposing these issues that improvements can be made.

Peter Buckle, 63, from Kenilworth lost his wife of 31 years, Wendy, to a glioblastoma in 2011, just six months after she was diagnosed. Since then, Peter has been an Ambassador for The Brain Tumour Charity and shared his experiences to help inform clinical trials, research, NHS best practice and government policy.

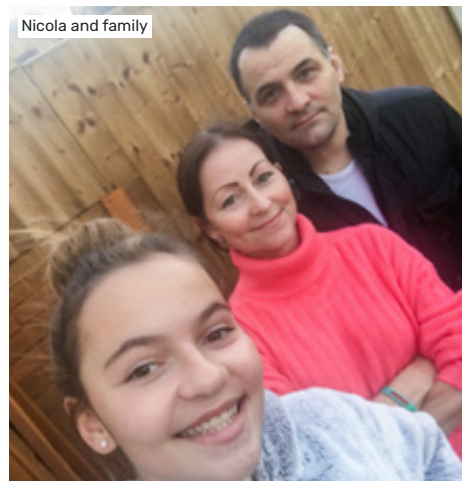
Peter said: “There were many shortcomings in the care and support Wendy received. Even today, people diagnosed with a glioblastoma and their families receive inconsistent and, in some cases, sub-standard care. It is only by exposing these issues that improvements can be made. Those who are diagnosed have little chance to do this themselves either due to the woefully short survival

rates or because the impact of the disease can be swift and brutal. The best source of information is from people like myself – the ex-carers.

“Wendy and I lost probably 30 years of our lives together. Speaking out about what happened to Wendy is unashamedly part of how I cope with this loss. It’s so very rewarding when researchers and doctors say how valuable it is to hear a first-hand account of how this dreadful disease affects people like Wendy and myself.

“We must continue to remind everyone every day of the horrors of this disease, including the inadequacy of current treatments and their negative impact on quality of life. This relentless focus is needed in order to make the required advances.

“Everything that The Brain Tumour Charity does is focused on the person who has been diagnosed and their families. Ex-carers also have unique – and unwanted – experience in this area. We have seen just how this disease affected our loved ones. No one in the medical community can gain that perspective when they spend maybe 10 minutes a week with someone in an outpatient clinic. I saw Wendy have no less than 30 different symptoms and side-effects of her tumour and neurology teams can only provide comprehensive support if they are aware of the full picture.”



## “I think it’s really important to share what we know through our own experiences about brain tumours.

Nicola Clark, 43, from Essex was diagnosed with a ganglioglioma in 2017, having first had seizures around 10 years ago after several trips to her GP didn’t lead to an accurate diagnosis. Nicola is now a Champion for The Brain Tumour Charity’s Involvement Network and BRIAN app to help inform various aspects of The Charity’s priorities. She also shared her story in the media, on The Charity’s website and social media channels.

Nicola said: “I avoided talking about the side-effects of my brain tumour, or played them down if I had to mention it, as I didn’t want anyone to worry about me. I know so many other people do this

too. But I think it’s really important to share what we know through our own experiences about brain tumours. Brain tumours need so much more awareness so, by talking myself, I hope to encourage others to do the same.

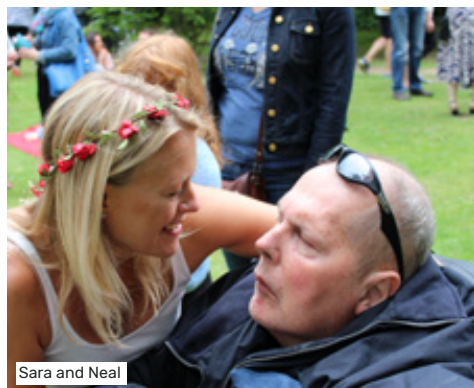
“My family and I didn’t know anything about brain tumours when I first started having symptoms. If I had known then what I know now then maybe I would have been diagnosed sooner. It didn’t happen for me but, by being part of Voices for Change, someone else may be diagnosed quicker instead.

“The Brain Tumour Charity is extremely keen to get real insight into life with a brain tumour both by learning from real-life experience and bringing about change where it is needed. The information we contribute is shared with The Charity’s research partners, the NHS and internationally renowned scientists to help make developments in quality of life, improving diagnosis and finding a cure.

“Anyone can be affected by a brain tumour in any way and at any time. By contributing what we know about it ourselves through campaigning, volunteering or fundraising we can enjoy playing into our strengths and interests and help The Brain Tumour Charity to drive real change.”



# LOOKING AFTER YOURSELF AS A CARER



Sara and Neal

**You may not consider yourself a 'carer'. You might think that what you're doing is just part of your relationship with the person you're looking after. However, if you give unpaid support to a loved one who couldn't manage without your help, you are classed as a carer and it's important to look after yourself too. Here, we look at the support available to carers and some tips on looking after yourself from carers within our community.**

Being a carer is far from easy - it can have a huge effect on you and your life. Caring for someone with a brain tumour can be both physically and emotionally demanding.

Of course, each carer's experience is unique, but it can be easy, often as a result of guilt, to forget that you deserve to be taken care of too. Even if it's something as simple as finding out more about the support available for carers.

**“ For the majority of us who are caring for loved ones, we're so busy giving love and compassion to others that we forget to give ourselves the same love and compassion.**

- Sara Challice, author of 'Who Cares?', who cared for her husband Neal for 13 years

## SUPPORT FOR CARERS

All carers have certain basic rights that can help make life a little easier. Depending on your situation, you may have the right to receive:

- financial support, such as Carer's Allowance, Carer's Credit and Council Tax Support
- help looking after yourself
- assistance from social services.

The best starting point is a carer's assessment to assess your needs and what support, if any, you're entitled to. You can arrange one by calling your local council's social services department. We have further information about the support available to carers on our website at [thebraintumourcharity.org/support-carers](http://thebraintumourcharity.org/support-carers)

We also have a Benefits and Money Clinic, which can help you access the financial support you're entitled to. Find out more at [thebraintumourcharity.org/benefits-clinic](http://thebraintumourcharity.org/benefits-clinic)

## TIPS FROM CARERS IN OUR COMMUNITY

Being a carer is a selfless and difficult thing to do, and likely not something you ever expected or wished to be doing. So do remember to be kind to yourself and that you are worth a short break, a day away from it all or some time sharing with a loved one.

We asked some carers in our community to share their tips on looking after your wellbeing.

**“ Accept help - everyone loves to be a hero and wants to help you out.**

- Shan

**“ Giving people small tasks such as collecting a prescription, doing some shopping or cooking a meal will make them feel useful and be helpful and time-saving for the carer too.**

- Robin

**“ If you are following a specific regime - be specific. In our experience, friends and family love to be given direction.**

- Shan



Sarah (left) and Jade

**“ Take time for yourself to breathe, cry, scream, shout, take a walk, read a book, watch a film, cuddle a pet and laugh out loud as often as possible.**

- Sarah

**“ I would say my most helpful thing is when I write down my thoughts during more positive/stronger moments. When I become overcome with sadness, I can read them. Write anything and everything that helps you stay afloat when those waves crash into you.**

- Lorraine

**“ Although it made me feel guilty, I increasingly found it beneficial to get away to do something I enjoyed. Also, my husband would benefit as I would be more relaxed and probably a more effective carer on my return.**

- Robin



# YOUR MESSAGES



Undertaking my half marathon challenge for The Brain Tumour Charity has had an emotional impact on me. I have been sponsored by people I don't even know; who have been directly or indirectly affected by a loved one suffering from a brain tumour. Because of their stories and generosity I am determined to raise more money in the future to fight this terrible illness that affects so many.'

- Craig, who has so far raised £2,226 in memory of good friend Steve.



I've found you guys incredibly helpful and can't thank you enough for the support. I've recently been diagnosed and will be doing a 50km walk in September - I've raised £1,206 so far and it's not even September yet! All my donations are going to this amazing charity for those who are, like me, going through such a terrible, life-changing battle.'

- Amy, diagnosed with a pituitary tumour.



This is my Mum. Since #ConquerTheChallenge2021 started three days ago she has clocked up the most miles run on our team and has raised over £1,000 for @thebraintumourcharity. #inspirational'

- Dave, who lost his dad to a brain tumour in 2019 just five months after being diagnosed. Their final total raised was £5,964.

## SHARE YOUR STORY

If you'd like to share your story with us, we'd love to hear from you. Visit our website and tell us more: [thebraintumourcharity.org/share](https://thebraintumourcharity.org/share)

## A GIFT IN YOUR WILL ENABLES OUR FULL FOCUS ON A CURE

**Brain tumours are the biggest cancer killer of people under 40, yet only 3% of national cancer research funding is invested into research.**

**Without research, a brighter future is impossible.**

But with your help, we can change this! A gift in your Will, no matter what size, will pave the way for ground-breaking research into brain tumours.

We can accelerate further, faster towards a cure – for every family affected.

Find out how you can make a lasting impact now.

Visit [thebraintumourcharity.org/gift-in-will](https://thebraintumourcharity.org/gift-in-will)  
Call 01252 237804



Registered Charity no. 1150054 (England and Wales) SC045081 (Scotland)

Scan me with your  
phone's camera





# CHRISTMAS CARDS AND GIFTS 2021

As we head towards the festive season, we've got you covered with our wonderful range of Christmas products for 2021!

Buying your cards and gifts from us is an easy and inspiring way to support our mission to defeat brain tumours – each purchase will help us accelerate change for people affected by this disease.

Take a look at some of our beautiful products and either head over to our online shop at [thebraintumourcharity.org/shop](https://thebraintumourcharity.org/shop) or use the enclosed order form to purchase.

## GIVE THE GIFT OF HOPE THIS CHRISTMAS

You can give a life-changing present to a loved one this Christmas by buying one of our Gifts of Hope.

Whichever Gift of Hope you choose – big or small – you'll make a crucial difference to the lives of people affected by a brain tumour through helping us advance research, improve treatments and provide essential support.

### The Gift of Comfort

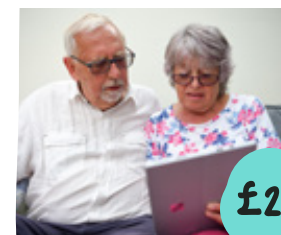
**£10** – Help bring comfort and joy to a child diagnosed with a brain tumour by enabling us to send them a Brainy Bag. These bags are full of fun things to do for the child as well as invaluable resources and information for their parents, providing much-needed support at a difficult time.



£10

### The Gift of Support

**£25** – Help five people facing the upheaval of a brain tumour diagnosis get the support and information they need by enabling us to send out five Brain Tumour Information Packs. These packs have been designed to help people cope, answer their questions and reassure them they're not alone.



£25

### The Gift of Progress

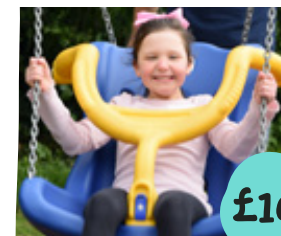
**£50** – Five people giving £50 could cover the cost of an entire day of research! Drive forward progress for people affected by brain tumours by helping us fund one of our leading researchers, to further their understanding of this disease and provide more targeted treatments.



£50

### The Gift of Knowledge

**£100** – Three people giving £100 could pay for a child with a low grade glioma to have a methylation-based diagnosis. Knowing more about the child's specific type of brain tumour can help their medical team give them kinder, more personalised treatments and improve their quality of life.



£100





1



2



3



4



5



6



7. Double Pack



8



9



10



11



12



13



14

# CHRISTMAS CARDS

14 new designs, including six exciting cut out options, for 2021!

## 1. Winter Robin

£3.95 for 10 cards

150 x 150mm [Gloss Board]

Greeting: Merry Christmas and a Happy New Year

## 2. Pacing Through the Snow

£4.25 for 10 cards

150 x 150mm [Glitter finish]

Greeting: Happy Christmas

## 3. Christmas Post

**Cut out shape**

£4.25 for 10 cards

150 x 150mm [Gloss finish]

Greeting: Season's Greetings

## 4. Figgy Pudding

**Cut out shape**

£4.25 for 10 cards

150 x 150mm [Gloss finish]

Greeting: Left blank inside for own message

## 5. 12 Days of Christmas

£3.95 for 10 cards

150 x 150mm [Gloss finish]

Greeting: Happy Christmas

## 6. Beetling Through the Snow

£3.95 for 10 cards

150 x 150mm [Gloss finish]

Greeting: Left blank inside for own message

## 7. Fluffy Hare/Cheerful Donkey

£4.25 for 10 cards 150 x 150mm

[Texture finish]

Double Pack, 5 of each design

Greeting: Merry Christmas

## 8. Snowman Trio

**Cut out shape**

£4.25 for 10 cards

150 x 150mm [Gloss and texture finish]

Greeting: Happy Christmas

## 9. Tree of Presents

**Cut out shape**

£4.25 for 10 cards

120 x 170mm [Gloss finish with gold foil]

Greeting: Blank inside for own message

## 10. Georgian Town Tree

£4.25 for 10 cards

150 x 150mm [Matte finish with red foil]

Greeting: Season's Greetings

## 11. Town Street

£3.95 for 10 cards

150 x 150mm [Gloss board]

Greeting: Happy Christmas

## 12. Nativity

**Cut out shape**

£4.25 for 10 cards

150 x 150mm [Gloss finish]

Greeting: With Best Wishes for Christmas and the New Year

## 13. Bethlehem

**Cut out shape**

£4.25 for 10 cards

150 x 150mm [Gloss finish]

Greeting: Merry Christmas and a Happy New Year

## 14. Dogs Around the Tree

£3.95 for 10 cards

150 x 150mm [Gloss finish]

Greeting: Season's Greetings

**FOR EVEN MORE  
CARDS AND GIFTS**

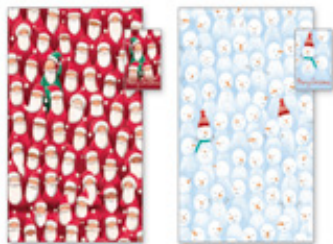
Visit [thebraintumourcharity.org/shop](https://thebraintumourcharity.org/shop)



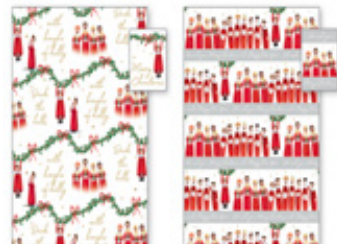
# GIFTS AND WRAP

New designs for 2021

**Christmas Gift Wrap and Tags** [2 designs in each pack]  
Each pack includes 4 sheets 9500 x 700mm] and 4 tags  
£2.99 per pack



15. Santa & Snowman



16. Singing in the Choir



**17. Christmas Greetings Money Wallet**  
When you just don't know what to get, then our money wallet is the perfect gift every time. Comes complete with its own envelope. Size 210 x 100mm  
£1.00 each



a. Champagne Glass



b. Ribbon



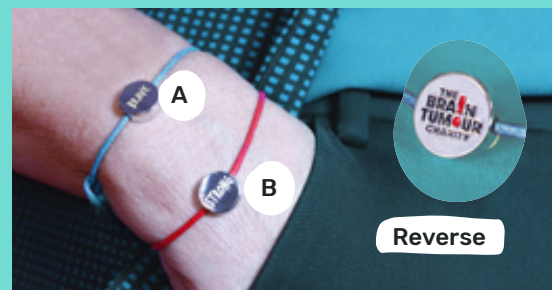
c. Celebration

**18. Festive Favours**  
As popular as ever, these beautiful pin badges will add the finishing touch to your table festivities. With three elegant designs to choose from, they're perfect for Christmas Day or New Year's Eve get-together's.  
a. Champagne Glass  
b. Ribbon  
c. Celebration  
£2.50 each

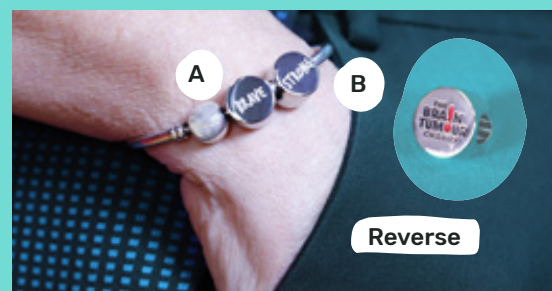
# JEWELLERY



**19. Set of Cufflinks**  
Help us find a cure with these smart cufflinks. Our exclamation mark reflects the urgency of our cause: a cure can't wait. Each set comes in its own presentation case.  
£12.99 pair



**20. Cord Bracelet**  
Show your support for the brain tumour community with our colourful cord bracelets. Choose from 'Brave' or 'Strong', or why not both?  
£2.00 each



**21. Charms**  
With meaningful words, these stylish charms make a perfect addition to a loved one's charm bracelet.  
£4.00 each  
*Bracelet not included*



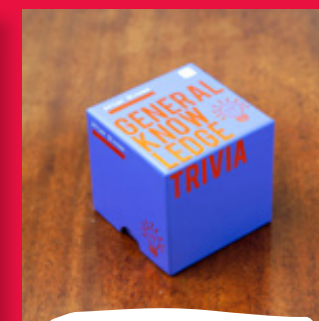
# GO ONLINE FOR MORE GREAT GIFTS



Selection of Puzzles



After Dinner Travel Trivia



After Dinner General Knowledge Trivia



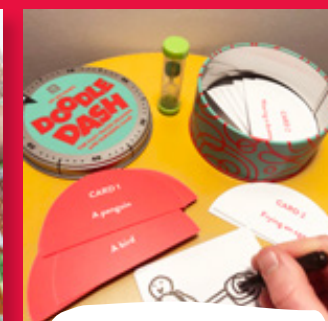
Junior Draw Dipsticks



Dinosaur Facts & Fun Game



Pooch Puzzle 1000 Pieces



Doodle Dash Minute Game in a Tin

FOR MUCH MORE, PLEASE VISIT  
[thebraintumourcharity.org/shop](https://thebraintumourcharity.org/shop)



# CHECK OUT OUR FULL RANGE OF CHRISTMAS PRODUCTS ONLINE



[thebraintumourcharity.org/shop](https://thebraintumourcharity.org/shop)



[thebraintumourcharity.org](https://thebraintumourcharity.org) 01252 749990

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