

THE GREY MATTERS

ISSUE 21 WINTER 2019

THE
BRAIN
TUMOUR
CHARITY

| Groundbreaking
research

| Sherrie Hewson
on her most
important role

| Living well when you
have a brain tumour





HELLO

I'm delighted to welcome you to issue 21 of *The Grey Matters*.

As you can see, we've made some updates to the format and content of the magazine, having listened to your thoughtful feedback. That's why you'll now see sections focused wholly on research and dedicated to the experience of living with a brain tumour. We really hope you enjoy reading it!

In these politically and economically uncertain times, it's more important than ever that we unite as a community to achieve our goals: doubling survival and halving the harm of brain tumours. Only together can we accelerate a change.

In the following pages, you can read about just some of the transformative projects we're developing and funding. From BRIAN, our innovative brain tumour databank (pages 6-7) to our latest round of research grant awards (pages 12-13), we're determined to keep driving progress until we create the step change needed to find a cure for this disease.

There's also a range of people's stories and experiences of living with a brain tumour, and their tips on coping with common symptoms and issues, such as fatigue (page 15).

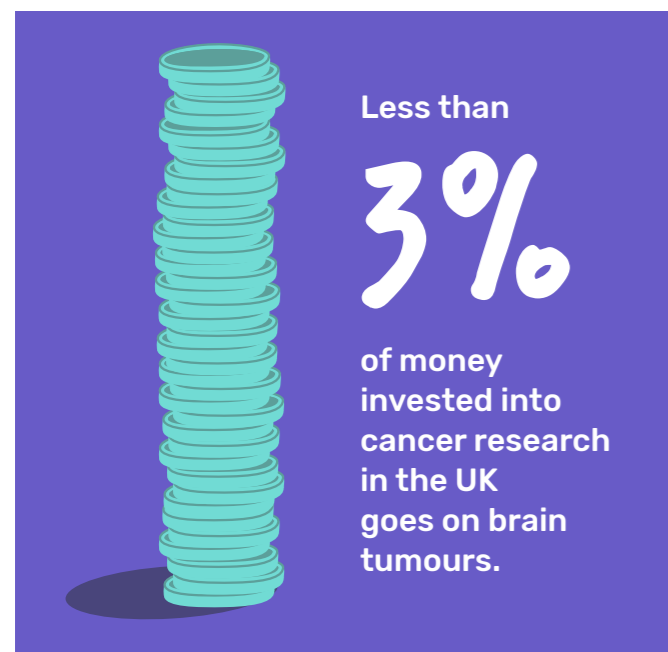
You'll find our 2019 Christmas brochure enclosed with this issue too, packed with an inspiring selection of cards and gifts that will help us move faster towards a cure. Last year, we raised an outstanding £70,000 – that's enough to fund more than nine months of pioneering research!

Finally, we all know how easy it can be to put things off. Making or updating your Will can often be one of them. Why not make today the day you take advantage of our free guide? It has information on making a Will, our free Will-writing services and how you can leave a gift. Just visit: thebraintumourcharity.org/gift-in-will

We're going further every day in the fight against brain tumours. A cure can't wait – together, we know we can get there.

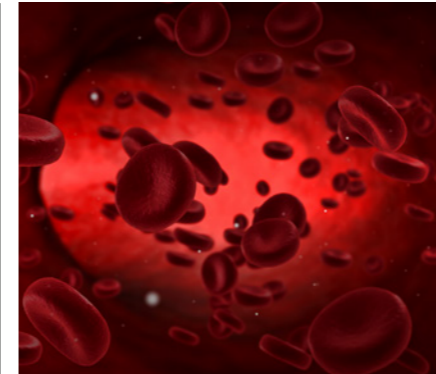
Thank you,

Sarah Lindsell
CEO



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THE TWILIGHT WALK IS BACK!

Want to help us propel progress and make a life-changing difference to people affected by a brain tumour? Join us for The Twilight Walk this autumn!

This inspiring event sees our community unite for one common goal: to help accelerate a cure and ensure no one has to face this diagnosis alone.

Sign up to one of our 10km walks in Warwick (29 September), Windsor (6 October) or Edinburgh (13 October), or hold your own walk of any length in a location that's best or most meaningful to you.

Side by side and stride by stride, your footsteps will help lead our search for a cure!

Visit: thebraintumourcharity.org/thetwilightwalk to sign up.

TRANSFORMING OUR BENEFITS CLINIC

One way we're striving to halve the harm brain tumours have on quality of life is by ensuring our community has access to the financial help they're entitled to.

In 2017, we launched our benefits clinic to do just that, partnering with Citizens Advice Rushmoor to provide a weekly phone clinic giving specialist guidance to the benefits system.

We're thrilled to announce - thanks to our generous donor, the AOK Trust - that we're now offering this service two days a week, with appointments available on Tuesdays and Thursdays from 9.30am to 4.00pm. And our advisors can also now offer their expert guidance on a wide range of strategies to help you save money.

Visit: thebraintumourcharity.org/benefits-clinic to find out more and book an appointment.

CAMPAIGNING FOR CHANGE

Our Campaigns and Policy team have been driving change across the UK for the brain tumour community.

After campaigning alongside Dame Tessa Jowell to call for the rollout of the surgical aid 5-ALA (the 'pink drink'), we were thrilled to hear in January that it would be made available in Wales. All adult patients with a high grade glioma in the UK should now be able to access it if appropriate.

In Scotland, we've been working with Cllr Ryan Smart to ensure our HeadSmart campaign is launched in Fife. This follows a unanimous council motion earlier this year.

In Northern Ireland, we've joined forces with the Department of Health, alongside other cancer charities, to develop a cancer strategy. As the only UK nation without one, it's vital we get the voices of our community heard while this strategy is written.

And finally, we've met with important political stakeholders to emphasise the vital needs of brain tumour patients in discussions around Brexit.

CELEBRATING YOU 2020

Celebrating You, our community awards event, returns in May 2020. And nominations are now open!

Celebrating You is all about celebrating and recognising you: our inspirational and dedicated community. It's our chance to say a heartfelt thank you for going above and beyond to move us closer to a cure.

We know there are so many people out there who deserve special recognition for their outstanding contribution to the cause. But we need your help! If you know someone who's been tireless or relentless in their efforts, nominate them in one of our award categories today.

You can nominate someone for Volunteer of the Year, Influencer of the Year, Fundraiser of the Year, Young Fundraiser of the Year or Partnership of the Year.

Visit: thebraintumourcharity.org/celebrating-you to submit your nomination.



USING AI TO DIAGNOSE BRAIN TUMOURS

Stories about artificial intelligence (AI) have started to appear regularly in the news, so it's exciting to report on one of our funded researchers using it to help defeat brain tumours.

Dr Phedias Diamandis and his Toronto-based team have shown that AI can be used to diagnose different types of brain tumours, as well as specific features and patterns within them.

To achieve this, the team showed the AI program 838,644 images of brain tumour samples, across 1,027 patients.

Normally, a pathologist will make a diagnosis by looking down a microscope at a small tumour sample. But this means that diagnosis is quite subjective and could easily be different, depending on who looks at the sample.

The advantage of AI is that diagnoses will be more consistent and it can also recognise patterns that aren't visible to the human eye.

BRIAN IS COMING SOON!

You may have seen previous updates from us on BRIAN (Brain tumouR Information and Analysis Network), our pioneering brain tumour databank. BRIAN is a free, global web-app enabling patients to make better-informed decisions about their care and accelerate research to find a cure. Now, we're absolutely thrilled to announce that it's launching very soon!

WHAT IS BRIAN?

We've worked hand-in-hand with people living with a brain tumour and their carers to build BRIAN. It will allow those affected to share their healthcare records with researchers, upload information about their treatments and quality of life, and view aggregated data and reports on others' experiences, all through a secure web-app accessible on laptops, tablets and smartphones.

The web-app is what people see, but that's just the tip of the iceberg. The real power of BRIAN comes from the databank sitting behind the scenes.

WHERE DOES BRIAN'S DATA COME FROM?

BRIAN's data will be drawn from three main sources:

1. From patients and carers via the BRIAN web-app.
2. From NHS Digital. This dataset currently consists of 8.2 million records stretching back over 10 years and covering 140,000 brain tumour patients! This data offers a comprehensive record of inpatient admissions, outpatient appointments and A&E attendance records at NHS hospitals in England.
3. From Public Health England (PHE). PHE data is collected with the primary purpose of creating a registry about cancer patients. We've been getting to grips with a sample dataset from PHE – loading this into BRIAN will allow for analysis and data visualisation.

THREE THINGS THE DATA WILL TELL US

1. Patients and carers will be able to view their data combined with the anonymised clinical data from national datasets. BRIAN will allow you to share your experiences, learn from others and make choices about your treatment and care that are right for you.
2. BRIAN will let healthcare professionals compare their performance against other centres, highlighting differences in service provision. This will allow clinicians to share best practice and promote better delivery and improved effectiveness within the healthcare system.
3. Finally, BRIAN will provide timely access to patient data for researchers, which will drive forward new research into brain tumours and accelerate progress towards a cure.

WHY SIGN UP TO BRIAN?

BRIAN is designed and led by people living with a brain tumour and their carers who want to make better-informed decisions and propel much-needed research. The key to its success is your willingness to share information for mutual benefit – so we need you to sign up and give consent to share your healthcare records.

For more information about how we'll use your data and what you'll need to sign up, visit: thebraintumourcharity.org/BRIAN

THE JOURNEY TO BRIAN

JUN 2017
The project begins! We hold our first Patient Mandate Group.

JAN 2018
Patient recruitment starts – we have 640 consents to date.

AUG 2018
BRIAN gets Research Ethics Committee approval.

OCT 2018
We receive 8.2 million NHS Digital records.

DEC 2018
We receive sample Public Health England (PHE) data.

MAY 2019
The team starts to build the BRIAN web-app.

JUN 2019
The Patient Mandate Group previews the BRIAN web-app.

AUG 2019
Young Ambassadors begin BRIAN web-app testing.

AUTUMN 2019
BRIAN launches.

“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, The University of Edinburgh

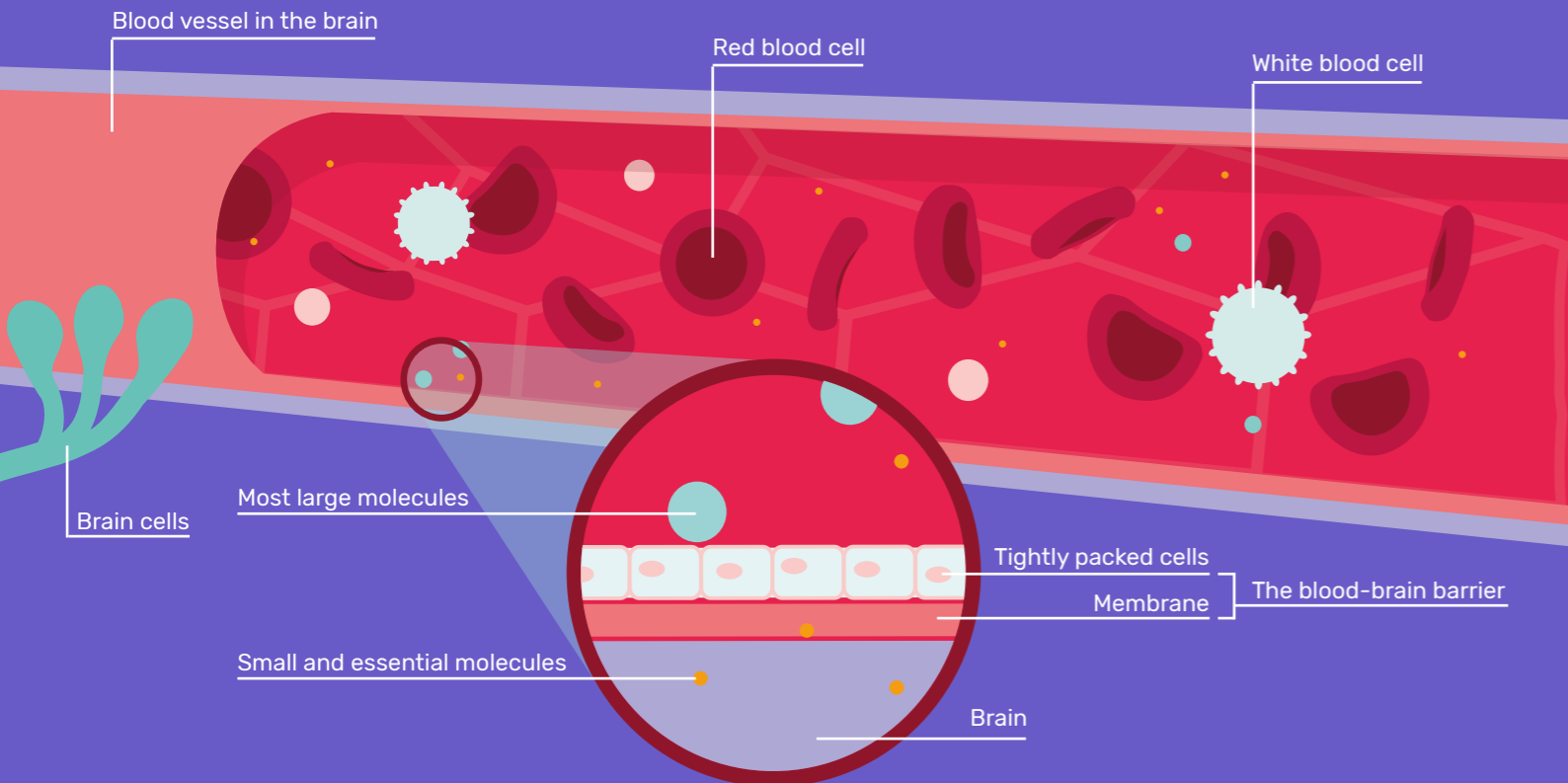


**RESEARCH
IN FOCUS**

One of the biggest challenges for scientists working to cure brain tumours is getting life-saving drugs to pass through the blood-brain barrier and reach the tumour.

CROSSING THE BLOOD-BRAIN BARRIER

HOW THE BLOOD-BRAIN BARRIER WORKS



The blood-brain barrier is a layer of tightly-packed cells that helps protect the brain from harmful substances in the blood, like bacteria or viruses. These cells surround the walls of the blood vessels in the brain.

The blood-brain barrier (BBB) is a great security system for the brain, but it also prevents many drugs from crossing it and can stop life-saving medicines reaching the brain.

This can be a major reason for certain treatments not working for patients, and also presents researchers with a significant challenge when developing drugs to target brain tumours.

SPOTLIGHT ON RESEARCH

BYPASSING THE BBB USING DRUGS AND GELS

Lead researcher: Professor Colin Watts, University of Birmingham

Professor Watts' research focuses on glioblastoma (GBM). His team is researching 'hydrogels' as a technique to deliver drugs across the BBB.

These are highly absorbent materials with similar properties and structures to human tissue, making them effective platforms for the loading and release of drugs in the body.

- The team are determining the most effective treatment combinations to target genetically different cells in GBMs.
- They're also testing the safety of the delivery method (the hydrogels).
- Finally, the team are loading the drug combinations onto the gels and injecting them into models of surgical cavities. This tests how well the drug delivery platform works.

Overall, this is an important project, determining whether hydrogel drug delivery is a feasible treatment option for GBM patients. If successful, it'll then be tested in a clinical trial, with the potential to move quickly into clinical practice.



OVERCOMING THE BBB WITH NANOTUBES

Lead researcher: Dr Khuloud Al-Jamal, King's College London

With our funding, Dr Al-Jamal researched 'nanotubes' as a method of overcoming the BBB to treat glioblastoma (GBM). These nanotubes are tiny, needle-shaped carbon structures that are thought to be able to carry therapies.

Dr Al-Jamal's project made use of CRISPR/Cas9, a gene-editing tool that's been hailed as a revolution in genetic engineering. This tool looks for pieces of tumour-causing DNA and cuts them to cause cell death.

But one of the big challenges in delivering this tool to the brain is overcoming the BBB.

The team successfully tested CRISPR/Cas9's activity on GBM cells growing in the lab. They also managed to load Cas9 protein onto the nanotubes and showed that the tubes can deliver the protein to the cells.

The team plan to carry out further work on the gene-editing technique, and, ultimately, the ability of the nanotubes to cross a representative lab model of the BBB.



HELP US FUND MORE WORLD-CLASS RESEARCH

A donation of £20 could buy the specialist liquid nutrients used to grow glioblastoma cells in the lab, so researchers can assess responses to different drugs. Make a donation: thebraintumourcharity.org/donate

BREAKING NEW GROUND OUR NEW £6.7M GRANTS

As we head into the final year of our five-year strategy, **Defeating Brain Tumours**, we're as committed as ever to our twin goals of **doubling survival and halving the harm brain tumours have on quality of life.**

As part of this, we fund pioneering research across the globe to drive new discoveries, find better treatments and propel progress towards a cure. We're thrilled to report that we recently committed **£6.7 million** to seven brand new projects, spanning childhood and adult brain tumours, development of new treatments and quality of life improvements.

Here's an overview of three of the recently-funded projects.



IMPROVING QUALITY OF LIFE FOR YOUNG SURVIVORS

Lead researcher: Dr Sophie Thomas, Queen's Medical Centre, Nottingham

We've awarded Dr Thomas more than £220,000 to look at whether a therapy called Acceptance and Commitment Therapy (ACT) can be adapted to improve quality of life for young brain tumour survivors.

Childhood brain tumour survivors have the poorest quality of life of all cancer survivors. Long-term effects can include learning difficulties, problems with motor control and symptoms of post-traumatic stress, among others.

ACT incorporates aspects of other therapies such as cognitive behaviour therapy and mindfulness, and aims to help participants build a rich and meaningful life despite their ongoing difficulties. It also encourages them to engage with their painful experiences and move towards acceptance.

The results could have a big impact, extending the options for supporting childhood brain tumour survivors.

“Psychologically, there was little time to comprehend the life-defining diagnosis I'd received just hours before being rushed to hospital.

If something like ACT had been available, it would have provided a healthy and more personal approach to process what was an extreme and very surreal life event to experience at a young age.

Sabrina, 24, who's living with a meningioma



TARGETING AND TREATING GBM

Lead researcher: Professor Neil Carragher, The University of Edinburgh

With £3 million of our funding, Professor Carragher and his team will adopt a systematic approach to finding new drug targets and new drug combinations to treat glioblastomas (GBMs).

Glioblastoma is the most common, and least survivable, high grade (cancerous) brain tumour in adults, for which more effective treatments are urgently needed. In addition to investigating new combinations of drugs, the researchers will also continue previous work by testing drug combinations already discovered by their team.

This grant will allow the researchers to suggest the treatment combinations that have both the greatest chance of working and of being well-tolerated by patients.

We hope these new combinations will help create a step change for people living with a glioblastoma, improving quality of life and length of survival.

A LASTING LEGACY

Leaving a gift in your Will, no matter how small, can help us change the course of how brain tumours are diagnosed and treated. Help us move further, faster towards a cure.



NO BRAIN TUMOUR IGNORED

Lead researcher: Professor Richard Gilbertson, University of Cambridge

Professor Gilbertson's grant is for a large programme of research into two rare childhood brain tumours: choroid plexus carcinoma (CPC) and a subtype of ependymoma called ST-EP-RELA.

No new treatments for these tumours have been developed in the last 30 years, and regardless of how they're treated, most children affected will relapse within five years of diagnosis. Research that accounts for the rarity, resistance and unique biology of these tumours is critical to give these children and their families hope of a cure.

We've awarded Professor Gilbertson and his team £1.5 million to focus on:

- making better models to use in the lab
- discovering and testing new drugs
- trialling the best way to deliver new drugs to these tumours.

We've committed

£32.6M

to transformative research since the start of our strategy in 2015.

We only invest in world-class projects that we believe will have the greatest impact on the brain tumour community.

Thank you for your ongoing support.





“ The treatments in this trial put the person first and looked at the person behind the fatigue.

Dr Alasdair (Ally) Rooney

EMPOWERING PATIENTS TO FIGHT FATIGUE

Fatigue is a common problem for people diagnosed with a brain tumour, but medication for it isn't very effective. With our funding, Dr Ally Rooney at The University of Edinburgh is analysing results from a trial to evaluate ways of managing fatigue that don't involve medicines.

He put together an expert team to find out if person-centred lifestyle changes, including 'health coaching' (see below), are manageable for people living with a brain tumour and can help alleviate their fatigue.

This was a multi-centre study which recruited patients in Edinburgh, Glasgow and Manchester. If results are successful, the study will lay the groundwork for a bigger trial, and could be a key step in discovering new, non-drug treatments for fatigue.

Find out more at: thebraintumourcharity.org/BT-Life

to answer any questions and build rapport. After that, we'd do seven weeks of remote health coaching, consisting of a weekly 30-minute phone call. The patients would fill out as much as they could of a DREEMS diary, send it through, and we'd discuss what had worked, what hadn't, and what they wanted to focus on next.

Q. Tell us more about the 'person-centred' aspect of health coaching.

This is a really important aspect of health coaching. We weren't setting any expectations on the patient of what they needed to do. It was very much just explaining the principles and then allowing the patient to decide what they felt able to do.

Even if they just started with one small thing – like increasing their water intake from two to three glasses per day – that often created momentum and led to them feeling able to do more. It's about the person feeling in control of what they're doing. I was supporting them to help themselves.

Q. What was it like working with the patients?

I definitely think I've benefited just as much from the patients I've worked with – their stories, and the challenges they've gone through – as they have from me. A lot of the patients were parents, a lot of them were working. But these people had also been diagnosed with a brain tumour, so they had all the additional challenges from that. It was inspiring.

I think our model is really a human health model. It's scalable, and could be used not just by the brain tumour community but others too. Hopefully this is just the start – it's exciting!



EMMA'S STORY

In 2015, Emma Mitchell from Warrington was diagnosed with a trigeminal schwannoma – a type of low grade brain tumour – and had two surgeries to debulk it, followed by radiotherapy. She still lives with fatigue on a daily basis.

“When I was diagnosed, I was in the final year of my degree, so I had to take a year out. When I came back to my exams, I found the fatigue quite frustrating.

“I'm a perfectionist, so it was difficult to accept I couldn't do everything – I had to choose between work and

sleep, very often. Fortunately, the university pushed back the deadlines and I was able to graduate from Durham with a degree in psychology.

Day in, day out

“I think the fatigue affects my confidence more than anything. I often doubt my ability to do things. On a day-to-day basis, just regular activity is quite draining. If I decide to go shopping during the day, I'm always conscious of how easy it'll be to get home.

“I have to be aware of my limits. For example, I recently met up with some old uni friends in London. It was great to see them, but just walking around was quite tiring.

“I felt as if I was being anti-social, but I was so tired, I just couldn't contribute to the conversation.

Coping strategies

“Doing any form of exercise can help, but it's like lots of things in life, getting the motivation to do it is tough.

“What I've learned is that, if I have to walk to the shop to do something then taking a little detour via the park gives me a little boost.

“I have a small to-do list and ticking things off gives you a focus. It's all about setting realistic goals, such as doing some baking, or going for a short 5-10 minute walk.

“I've realised that regardless of what I do, I'm going to feel tired, so it's the little achievements that help.”

MAKE A DIFFERENCE

A donation of just £25 could pay for one hour with a specialist nurse ensuring brain tumour patients have access to the best care possible. Help us pick up the pace of progress today. Make a donation: thebraintumourcharity.org/donate

Q&A

with Garry Anderson,
Lead Health Coach
for BT-Life



Q. What's your background?

I became a personal trainer in 2004 after leaving the Royal Marines. Very quickly, I realised health isn't just about exercise – nutrition's involved as well. If you're putting something in your body, that's going to have an effect just like any medication can. So there was a definite switch, for me, to wanting to help people be healthier rather than just fitter. I worked on a list of the key fundamentals for human health, and that was the birth of the DREEMS model – drink, rest, eat, exercise, movement and stress.

Q. How did you get involved in the trial?

When I moved to Edinburgh in 2009, one of my first clients was

an inspirational lady who's now a 27-year brain tumour survivor. Through her, I met Robin Grant, a senior neurologist who's also involved in BT-LIFE, and Ally Rooney.

I became the lead health coach on the study, and held my final coaching session just a few weeks ago. The team are now finishing up collating all the data.

Q. What does health coaching involve?

Some patients were randomised to receive health coaching and others weren't – I was responsible for delivering coaching to those in Glasgow and Edinburgh, as well as supporting our NHS physio to deliver coaching at our third site in Manchester. We'd begin with an initial 60-minute face-to-face consultation

YOU NEVER THINK IT'S GOING TO HAPPEN TO YOUR FAMILY

Loose Women and Benidorm star, Sherrie Hewson, reveals her heartbreak about "wonderful" brother, Brett Hutchinson, being diagnosed with a glioblastoma.

Now Sherrie has become a charity ambassador to raise awareness as Brett's "legacy" to help save other families their heartache. We spent a day with them, Brett's partner of 40 years, Annie, and their daughter Chloe.

As Sherrie Hewson and her brother Brett sit chatting in his quirky tea shop, Characters, in Llandudno, north Wales, it's clear they adore each other and enjoy that unique teasing relationship and shared history siblings have.

Squeezing gently-spoken Brett's hand, at 71 her senior by three years, Sherrie says, "Ever since I was a little girl, I have idolised my wonderful big brother. Everyone loves Brett and everything he touched turned to gold."

But life was turned upside down in March when he was diagnosed with a grade 4 glioblastoma – the most common aggressive brain tumour in adults.



Sherrie and Brett. Photo credit: Julian Hamilton Sunday People

Brett's main symptom was being "engulfed" by a pungent, floral smell – like Parma Violet sweets – coupled with feeling he was in an "alternative universe."

His daughter Chloe took him to A&E as instinct told her something was seriously wrong. Scans revealed he had a golfball-sized tumour. That instinct saved her dad's life as doctors said Brett was days away from death due to swelling on his brain.

Surgeons at Liverpool's Walton Centre removed the whole tumour during a nine-hour operation on April 4.

Three days later, Brett suffered a massive bleed on the brain and had another operation to remove a blood clot from the cavity where the tumour had been.

He underwent radiotherapy and chemotherapy and had a stable scan at the end of July.

MY MOST IMPORTANT ROLE YET

Now Sherrie has become a High Profile Supporter of The Charity, as Brett dearly wants it to be his "legacy" to help raise awareness about brain tumours.

"You never think it's going to happen to you or your family, but this devastating disease can affect anyone at any time," says Sherrie.

"At first, there was a sense of sheer disbelief – I just couldn't take it in. More than all my roles in hundreds of years in show business, becoming an ambassador for The Brain Tumour Charity is my most important role."

Tears glistening in her gentle blue eyes, Sherrie says she thinks about Brett's prognosis 'every minute' – but they have vowed to 'live in the moment.'

"Fear permeates everything – it's always there overshadowing everything we do.

"I don't allow myself to look too far into the future – it's too frightening. We all try to focus on the 'now' because Brett is here now."

Earlier this year, Brett was overcome by the Parma Violets smell and also suffered fatigue and anxiety. He went to a GP, who said he was depressed and referred him to a counsellor.

But then Chloe noticed the left side of Brett's mouth was slightly pinched and his tongue wasn't moving properly when he talked.

She took him to A&E at Glan Clwyd Hospital in Rhyl on March 21, where a CT scan revealed the 5cm tumour. During surgery, the tumour was removed from his right temporal lobe – which is the part of the brain that controls the sense of smell, explaining the Parma Violets symptom.

When Brett had emergency surgery to remove the blood clot, Sherrie flew to Liverpool from Belfast where she was on tour with Benidorm – Live! the spin-off of ITV show Benidorm.

"Chloe phoned me and said, 'You need to get here now,'" says Sherrie. "I had no idea if my brother was still going to be alive when I got there. We all sat in the family room crying and praying he was going to make it through surgery."

Brett was in critical care for 11 days and in hospital for four weeks. The family are now researching clinical trials in hopes of extending Brett's life beyond his 12-18 months prognosis.



Brett and daughter, Chloe

RAISING AWARENESS

Now Sherrie and Brett feel "driven" to help raise awareness.

"Sherrie will always be my Shez," says Brett. "People think there must be a 'side' to her because she's an actress, but she's the same lovely, down-to-earth girl she's always been.

"I've always told my family I love them. Now I hug them that bit closer. We're all doing our best to live in the moment, but I haven't got a bucket list. I have all I want or need – my family.

"Now it's about living the best life I can in the time I've got left. What I do to help others matters more than ever.

"It means the world to me to work with The Charity and if sharing my story helps to save one life, it's worth it."



Sherrie and Brett as children

HOW BRETT COPES WITH HIS PROGNOSIS

1. One step at a time

"I am facing my own mortality – you can't take everything in at once or be strong all the time."

2. My family's love

"I'm blessed with an amazing family. Chloe saved my life, Annie is my rock and Sherrie and I are bound together by love and humour."

3. Focus on the positive

"I feel blessed I've lived a rich, full life until my 70s. It makes me so sad to see younger people and children with brain tumours."

4. Let your emotions out

"If you want to cry, cry. If you want to shout, shout. You can't bottle it up all the time – you need a release."

5. Live in the moment

"We all do our best to live in the moment and cherish every second with each other."

A CURE CAN'T WAIT

Help us move further, faster towards a cure. A gift of just £20 per month could pay for a day's world-class research every year. Make your donation today: thebraintumourcharity.org/donate

**LIVING WELL
IN FOCUS**

NEW BEGINNINGS

Our supporters refuse to be defined by their brain tumours and have rebooted their lives.

NEW BEGINNINGS AFTER DIAGNOSIS

Starting something new after a brain tumour diagnosis can be especially daunting, but these inspiring people show that the rewards can be life-changing.



“ I could reinvent myself.

STARTING UNI

Hannah Kinsell

Starting university felt like I was reinventing myself. Previously, I was always ‘the girl with the brain tumour’ - now I could choose who to tell and when.

When I was 15, I was diagnosed with a grade 4 (high grade) glioma and had two brain surgeries and chemotherapy.

That was four years ago: I couldn’t take it in - I had brain cancer and feared I wouldn’t realise my dream of going to university.

But I got good grades in my GCSEs and A-levels and - encouraged by my family - I was thrilled when I got a place at Goldsmiths University, London to study history and archaeology. In September 2017, I started my university course.

My first day was nerve-wracking but exciting - overcoming those nerves

was a challenge, especially as I suffer from anxiety, but I told myself every new student feels jittery - I wasn’t so different after all.

It took me about a term to adjust to living away from my family - I had to phone my mum a lot during the first few weeks, but I soon made friends.

Living with a brain tumour affects my studies due to short-term memory loss and fatigue - but I can sit exams in smaller rooms and have extra time.

I try to focus on the positive - I’m in remission, I love my course and have become more comfortable telling people I have a brain tumour.

My advice to other young people living with a brain tumour, nervous about starting university, is to be proud of how far you’ve come and just be yourself.

Now I’m about to start my third year and being a student has increased my confidence and independence.

“ Cancer stole my childhood, but I won’t let it steal my future.



“ Before my diagnosis, I couldn’t run for the bus - now I’m like Forrest Gump!

NEW HOBBY

Adam Carroll

Running helps me to process my thoughts and dilutes the stress of living with a brain tumour. When I get in the zone, nothing matters but putting one foot in front of the other, striving to run further and faster.

Everything changed during a work trip to New York in June 2017 - one minute I was joking with someone, the next I collapsed and came round with paramedics surrounding me.

I was blue-lighted to hospital where an MRI scan showed I had a brain tumour.

After biopsy tests revealed it was a grade 3 (high grade) glioma, I had another operation five days later to remove 95% of the tumour. I started running out of sheer

boredom while I was off work for six months having treatment. At first, I was nervous, but doctors said it was fine as long as I didn’t overdo it.

Before my diagnosis, I couldn’t run for a bus - on my first attempt I barely made it to the end of my road, but I’ve gradually built it up and now I’m like Forrest Gump!

I’ve had great support from The Charity, have raised about £4,500 in half-marathons and I’m running for them in next year’s London Marathon.

Running helps to safeguard my mental health - sometimes it feels like a stigma having a brain tumour as people can be afraid of how it will affect your relationships and work.

Doing something new - it doesn’t have to be running - makes you feel less of a ‘patient’, so my advice is to go for it.



“ Work has given me my sense of identity back.

NEW JOB

Akua Appiah-Ampofo

After diagnosis with a meningioma in 2016 and surgery, I wanted to go back to work in HR, but suffered a crisis of confidence.

I found myself either not telling potential employers I’d had a brain tumour or being defensive about it. Luckily, a company I’d done work for before got in touch and offered me part-time work as an HR consultant. Right from the start, I decided to be open and honest about my brain tumour and the challenges I still face - if I overdo it, I suffer from fatigue and a buzzing at the back of my head.

I told myself that if they didn’t value me and realise that having a brain tumour was only part of who I am, then I didn’t want to work for them.

But the company has been supportive and I gained confidence quickly, it was more about learning to pace myself.

I don’t believe employers want to discriminate against people with brain tumours - they’re just worried it will have a negative impact on business.

It’s all about raising awareness, educating them and working together.

My advice to job seekers is to be honest about your brain tumour and needs - give employers a chance to be supportive.

Now I’ve been in my job for a year and it has boosted my self-esteem.

I know I can never be exactly the same person I was before diagnosis, but it was important to me to resume my career - I feel like ‘me’ again.

If you’re going through a difficult time following a diagnosis, did you know you can get in touch with our free Information & Support Line? We’re here to answer your questions, provide support, or just listen. You can call our team Monday to Friday, on **0808 800 0004**, or email: support@thebraintumourcharity.org

WHAT TO EAT DURING TREATMENT

It can be hard to eat well when you're going through chemotherapy or radiotherapy treatment. We asked an expert for advice on how to get the nutrients that you need.

One way or another, chemotherapy and radiotherapy play havoc with your appetite. Favourite foods won't seem appealing if you're suffering from a painful mouth or throat, have a metallic taste in your mouth or feel nauseous.

Or, if you've been prescribed steroids, you might struggle to control your appetite and experience dramatic weight gain as a result.

According to Monika Siemicka, dietitian at Guy's Hospital in London, the most important thing that you can do to support your recovery is eat a balanced diet.

"There isn't one specific 'superfood' that's most important, and chemotherapy won't cause you to be deficient in any particular vitamin," she explains.

"If you've lost your appetite, don't force yourself to eat as you used to, it's fine to eat little and often instead."

TRICKS TO TRY

Monika admits that eating a balanced diet isn't always as easy as it sounds, especially if you're not feeling well. But there are a few tricks you can try to make meals more appealing.

"Try to eat protein-rich foods 2-3 times per day as this helps to maintain muscle mass," says Monika. "If you're struggling, choose scrambled eggs, fish pie, shepherd's pie and mince instead of steak, as these are easier to eat."

Carbohydrates are an important source of energy, but you might prefer white bread and pasta to wholegrain varieties. "Opt for fluffy white rice or mashed potato – both are nice and soft," says Monika.

Can't face a full meal? Try nourishing snacks like cheese on toast, yoghurt or a milky drink.

It's best to avoid spicy or acidic foods, like lemon, vinegar or pineapple, as these can be painful to eat if you have a sore mouth.

However, if your main problem is taste, you might find that adding herbs and spices or choosing sharper-tasting foods helps your food to taste better.

"Eating meat can be difficult if you have that metallic taste in your mouth," says Monika. "So think about preparing a marinade, or eating cold meats with chutney. Some people also find it helps to use plastic cutlery."

We all know that fruit and vegetables are important. If you're struggling with

steroid-related weight gain, snacking on fruit and veg sticks is a low-calorie way to fill up.

But if you're not eating much, Monika recommends thinking about what you can add, whether that's butter on your vegetables or a creamy dressing on your salad. "This is a great way to get the goodness of the vegetables, while adding some extra calories," she says.

When you can't stomach solid food, soups and smoothies can be helpful. "Try adding milk, cream, beans or cheese to soups," advises Monika. "Smoothies are really popular, so add nuts, peanut butter and whole milk to increase the calories and provide some good fats."

"If you're really struggling to eat, talk to your doctor who can prescribe nutritionally complete shakes like Fortisip or Foodlink."

THE KETO DIET

Many people believe that the ketogenic diet (a very low-carb, high-fat diet) can help treat brain tumours and related seizures. But Monika says there's no evidence that it works.

"The keto diet is extremely restrictive and difficult to follow. When people are going through treatment, a balanced diet is very important, and maintaining weight is beneficial – the keto diet works against these goals. There's nowhere near enough evidence to support it, so it isn't something I can recommend."

For more information on diet, visit: thebraintumourcharity.org/diet

FIVE WAYS TO CONTROL YOUR SYMPTOMS

If your symptoms are making it painful to eat, Monika recommends talking to your doctor about the following options:

01

If you have a sore mouth, or you're suffering from ulcers, your doctor can prescribe a soothing mouthwash.

02

If you're having radiotherapy, ask your doctor about solutions that you can rinse around your mouth (and swallow) to help with the pain.

03

Take soluble paracetamol four times per day to ease a sore mouth and throat.

04

Mix up a salt solution to rinse your mouth with after you eat.

05

Check your mouth and tongue for white patches. These can indicate thrush, which can make food taste different. It's easily treated.



SEASONS TO BE CHEERFUL

Everyone reacts differently to the changing of the seasons. At this time of year, the chill in the air and the crunch of leaves underfoot is comforting and cosy for some, full of the promise of Christmas.

But we also know that for others, the colder weather and lack of sunlight as the days grow shorter can be challenging. Many people speak of the 'seasonal blues'. Some might even be affected by the more serious S.A.D. (seasonal affective disorder), a type of depression that often arrives with winter.

When you're dealing with a brain tumour diagnosis, these effects can be more pronounced. For example, a lack of vitamin D may make you feel more unwell than you would have otherwise. Or if you've lost weight due to the tumour or its treatment, you may feel the cold more.

Now that the holidays are over, we asked people living with a brain tumour, or caring for someone who is, for their words of wisdom on coping with these changes. Here are just some of their tips.



“I find it enjoyable to go for an evening walk. It can be very refreshing in the cold night air, and quite often everyone else is inside so it can be quite peaceful.

Tasha

“Vitamin D supplements can vastly help with mood changes as the body gets less sunlight. I swear by them and can tell within a few days if I haven't been taking them.”

Alan

“Wear a hat in cold weather. My scar was very sensitive for the first couple of years and felt as though it was being stirred with a wooden spoon, if that makes sense.”

Lorraine

“A little bit of exercise, even if you're feeling really tired, makes a huge difference in your mood. My son came out for a short walk every day while on radiotherapy last winter, it helped his mood massively.”

Karen

“Wrap up warm and have a nap on the sofa in the afternoon.”

Aileen

“Have a hot chocolate, watch films on the sofa or in bed or go to the cinema. Put up fairy lights and candle decorations.”

Alma

“Take up a new hobby like knitting, reading or playing board games with family and friends for an hour.”

Amanda

“Meeting up with friends and family for a coffee and a good old catch up is the perfect remedy for me when feeling down in the winter months!”

Belinda

“My golden retriever makes me smile every day.”

Rhonda

“I just think of three positive thoughts or three things I can do every day. Doesn't matter how small or big they are. Just keeps me positive and happy that we are here.”

Lynn

“If people want to visit, ask them to come when it's later so you can enjoy the daytime and have company when it turns dark.”

Amanda

“Notice the little changes in woods and gardens as autumn turns into winter.”

Lisa

IF YOU NEED A GUIDING HAND, OR SIMPLY HAVE A QUESTION, YOU CAN GET SUPPORT FROM US IN A NUMBER OF WAYS

- Visit our website for information on almost every aspect of living with a brain tumour diagnosis.
- Use our LiveChat function via the website - you don't even need to talk to anyone.
- We run a free weekday Information and Support line, between the hours of 9-5.
- Email us on: support@thebraintumourcharity.org

TO MYSELF BEFORE THE DIAGNOSIS



Vicki Browne



Vicki before diagnosis

Dear Vicki,

It feels surreal talking to the 'old' you. I don't want to frighten you, but soon you'll be diagnosed with a brain tumour.

From that freeze-frame moment you hear a doctor break the news, "I'm sorry..." the 'new' you will choose to live in the moment.

Part of me wants to urge you not to take your health for granted or moan about silly little things, like we all do, but a bigger part wants to hold you close and tell you you'll be scared. But I want to tell you that you'll emerge a stronger person who believes in the power of hope.

Rewind to 2009 and you were happily married to Tony, adored your son Louis and loved your job as a presenter on The Jewellery Channel.

Then Tony died suddenly from a heart attack at 42, and you were left a widow bringing up a heartbroken boy.

Oh my, I know you're reading this now, thinking; 'Haven't we been through enough?', but you'll be live on TV when suddenly you won't be able to get your words out properly.

You'll be convinced you're 'just tired' but go to the doctors to 'be safe.'

Scans will reveal you have a low grade astrocytoma in the part of your brain that controls speech.

After surgery in 2011, you'll have MRI scans every three months, relieved each time when they're clear.

Then in July 2013, a scan will reveal another astrocytoma. Six months later, you'll have surgery to remove it and a rare cancerous tumour inside your low grade tumour.

You'll then have seven weeks of chemotherapy and radiotherapy, followed by six months of chemotherapy.

After a year of being off work, you'll go back on screen bald because you'll want to show you're still you; and you'll talk about The Brain Tumour Charity live on air to raise awareness. Besides, you'll hate wearing wigs and head scarves, and ask yourself, "Who am I doing this for?"

You'll decide if it makes other people uncomfortable, it's their perspective that needs to change.

Take a deep breath, it's going to be tough but you'll have more grit than you ever thought possible.

Your strength will be fuelled by love and utter protectiveness for Louis, who'll be 16 when you're diagnosed. 'He's lost his dad, he can't lose me,' will become your mantra.

As Louis gets older, you'll be enveloped by his love and support. When you lose your long, dark hair – a huge part of your heritage and personality – he'll give you a hug and say, "You rock bald, Mum!"

Gratitude will be tinged with guilt – you're his mother, it should be you looking after him. As you get stronger, though, you'll be there for him, as he

forges a career in film making. Your diagnosis will show all that truly matters is your family and friends. Being ill will highlight who your real friends are and you'll feel blessed to have a close circle of friends who'll go to appointments with you.

And you'll be grateful for the 'outstanding' care of the NHS.

In October 2018, a scan will reveal an inoperable part of the tumour is feathering into your brain, and you'll be on chemotherapy tablets for a year. Now you'll learn exactly who you are and want to be.

Before diagnosis, you were frivolous and confident and, after living with a brain tumour for eight years, you'll feel blessed to be alive.

You'll say yes to everything and embrace new experiences like setting up a Salsa class – why wait?

Despite everything you'll go through – or because of it – you'll live life to the full and cherish every moment. Most of all, you'll be so very proud of the person you'll become.



Vicki in 2019



Vicki with her son, Louis

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

ASK THE EXPERTS

Got a nagging question that's bothering you? Do you need some reassurance about something you've been told? Look no further! Just ask us the question and we'll find the right person to answer it for you.



IS IT COMMON FOR MOST BRAIN TUMOUR PATIENTS TO HAVE COGNITIVE PROBLEMS IN EDUCATION?

Michelle Smalley, Clinical Psychologist (Paediatric Neuro-oncology), University Hospital of Wales

Every child and tumour type is different and there are many factors which impact on the long-term outcomes in children who have had a brain tumour.

These include the direct effects of having a tumour on the delicate structures of the brain and the pressure inside the skull caused by the tumour, the length of time the tumour has been growing in the brain, the child's age, how aggressive the tumour is, its symptoms, and the treatments required to combat it.

Some children may struggle with cognitive and communication difficulties, including their IQ, visual-perceptual skills, attention, memory, vocabulary, grammar, social skills or problem-solving skills.

Their treatment may also cause lasting fatigue, so full-time education may be a challenge and therefore keeping up with classwork and their peers may be difficult due to their fatigue.

Children diagnosed with a brain tumour at a younger age are more at risk of long-term cognition or communication difficulties. This is because the developing brain is particularly vulnerable.

It can often take years for subtle deficits to become noticeable in survivors of a brain tumour. They can show up when children start school, make new friends, transition to high school, or go for their first job. Ideally all children should be monitored throughout development, with early, ongoing intervention and support.

Many children learn to overcome these sometimes subtle cognitive difficulties, others may require additional support in school, but I have had a number of patients get fantastic results in their GCSEs or A levels and go on to university.

If you or your child has been affected by a brain tumour, you can find more education resources on our website: thebraintumourcharity.org/education-resources

WHAT ARE THE SIDE-EFFECTS OF CHEMOTHERAPY?

Toni Sidwell, Information Development Officer, The Brain Tumour Charity

As chemotherapy works on healthy cells and tumour cells, it often causes some unpleasant side-effects. Some of the more common ones are:

- Increased risk of bleeding due to a low platelet count (platelets are cells that help the blood to clot)
- Anaemia
- Tiredness (fatigue is very common – see p14 for more information)
- Nausea (but some people don't feel sick at all)
- Hair loss
- Sore mouth
- Change in taste / appetite.

You may find that you experience all or very few of these – all side-effects vary from person to person and from drug to drug.

Side-effects tend to disappear gradually over time after treatment, but if you're concerned about any of your side-effects, speak to your healthcare team.

For more in-depth information, have a look at the 'Diagnosis and treatment' section on our website.

HOW 'LONG' ARE LONG-TERM EFFECTS?

Ingela Oberg, Macmillan Lead Neuro-Oncology Nurse, Addenbrooke's Hospital, Cambridge

Long-term side-effects depend on what treatment (if any) you have had. Some side-effects from surgery for example are temporary and most will recover within 6-12 months (e.g. nerve regeneration, tender scalp, hair regrowth).

If you are on a watch-and-wait programme and haven't had surgery, some of your side-effects may be from the tumour itself (depending on size and location) and can sometimes be managed with medication. Other long-term effects – such as peripheral nerve damage (neuropathy) – normally recover once you stop chemotherapy, but fatigue can be indefinite.

The best advice is to speak to your specialist nurse or key worker who can guide you on the likely length of any side-effects and how to best manage them. Don't be scared to ask us, it really is what we are here for!

IS IT TRUE THAT RADIOTHERAPY AFFECTS YOUR FERTILITY?

Dr Sarah Jeffries, Clinical Director Cancer, Addenbrooke's Hospital, Cambridge

The short answer is sometimes. Patients with primary brain tumours can be at risk of becoming infertile because of the potential long-term side-effects from surgery or radiotherapy.

Occasionally a tumour will also affect the pituitary gland (the gland that produces hormones needed for fertility).

Chemotherapy (temozolomide and PCV) that's commonly used in the treatment of primary brain tumours can also impair sperm production in men, or lower the pool of ovarian oocytes in women, leading to infertility.

SEND YOUR QUESTIONS

Do you have a question? Send it to us via email: comms@thebraintumourcharity.org and we'll try to find the expert for the job. Unfortunately, we can't guarantee we'll answer every question and we're not able to reply to everyone individually.

YOUR LETTERS



We wanted to thank you and the team for the Trafford Family Day. Noah loved it and it was such a great event. All the team were brilliant and so lovely, offering tea and juice constantly.

I've only found The Charity recently and I wished I had met you earlier. It's wonderful what you all do and so reassuring to know you are there. I know in the future, when Noah starts to understand what he actually went through, that you'll all be there for us.

Donna

Pictured: Donna and her son Noah



The leaflets from The Charity were so helpful, I used them to cross reference with medical letters and the discharge report. It is only in the last few weeks I have wanted to read information about Leila's tumour, and I didn't want to go on the internet because I was scared what I would read. The information from The Charity was really helpful because of the clarity of the language used.

Sarah

Pictured: Sarah and her daughter Leila



Working with these incredible Young Ambassadors (and all of the other amazing team members) is one of my favourite things to do. We have managed to turn our darkest times into something incredible... all thanks to The Brain Tumour Charity for giving us this opportunity!

We'll keep working until we get a cure for brain tumours. I love this photo from the Kidderminster meet up with a few members of the Ambassador team! Thank you all for making this journey so amazing!

Shane

Pictured (left to right): Elliott, Sunil, Shane, Chantal, Sabrina and Abigail at the Big Meet



Thank you so much for all your help in the last seven years since my op. Knowing I have you to turn to has kept me as sane as possible and I wouldn't have come as far as this without your help.

Lots of love

Fiona

Pictured: Fiona

KEY DATES EVENTS AND MEET UPS

SEPTEMBER 2019

- Saturday 21 Young Adult Meet Up in Birmingham
- Sunday 29 The Twilight Walk Warwick

OCTOBER 2019

- Check website Virgin Money London Marathon ballot results announced
- Sunday 6 The Twilight Walk Windsor
- Saturday 12 Young Adult Meet Up in Edinburgh
- Sunday 13 The Twilight Walk Edinburgh

NOVEMBER 2019

- Saturday 23 Christmas Family Day at Marwell Zoo, Hampshire

DECEMBER 2019

- Saturday 7 Christmas Family Day at the Snowdome, Tamworth
- Saturday 14 Young Adult Meet Up in Bristol

JANUARY 2020

- Saturday 25 Young Adult Meet Up in Manchester

FEBRUARY 2020

- Saturday 29 Young Adult Meet Up in Southampton

MARCH 2020

- Sunday 15 Bath Half Marathon
- Friday 20 Young Adult Meet Up in Edinburgh
- Sunday 29 London Landmarks Half Marathon

APRIL 2020

- Sunday 5 Greater Manchester Marathon
- Sunday 5 Paris Marathon
- Sunday 19 Brighton Marathon
- Sunday 26 Virgin Money London Marathon

MAY 2020

- Friday 15 Celebrating You Awards
- Sunday 24 Edinburgh Marathon Festival

JUNE 2020

- Saturday 20 Snowdon by Night

FEBRUARY 2021

- Saturday 27 February to Saturday 6 March 2021 Sahara Trek

To find out more about any of these events, visit our website: thebraintumourcharity.org

HELP US MOVE FURTHER, FASTER TOWARDS A CURE!

We rely 100% on voluntary donations to help us drive change.

Please share your copy of this magazine so others can see the difference we make. Or they can help us accelerate progress by donating online: thebraintumourcharity.org/donate

Together we'll beat brain tumours sooner. Thank you!

thebraintumourcharity.org

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