THEGREY MATTERS

ISSUE 22 SPRING 2020





Nicki Chapman on dealing with her diagnosis

Managing relationships



WELCOME



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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:

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HELLO

Welcome to issue 22 of *The Grey Matters* and your first instalment of 2020!

The new year is often a time of new beginnings, or at least a new type of normal, as we reflect on the year just gone and make resolutions for the months ahead. That theme runs throughout this issue.

In this edition, we're shining a light on biomarker testing and molecular diagnoses, an emerging field of research that promises new hope for better treatments and improved quality of life for people diagnosed with a brain tumour.

The new discoveries happening in this field are incredibly exciting, and we hope this will lead to adults and children with high or low grade tumours benefitting from better-planned and more personalised therapies in the future. We're proud to have awarded funding to several world-class projects that involve biomarkers (see page 13). We couldn't do this without you.

We also spoke to a range of people living with a brain tumour about their experiences. On page 24 you can read about how three of our supporters have moved forward and regained their self-esteem after the effects of their brain tumour or its treatment knocked their confidence. And on page 28 another supporter, Gemma, talks about how she began a new chapter of her life post-diagnosis when she had her baby son, Hudson.

It's because of your previous support that we've been able to make strides towards our goals of doubling survival and halving the harm that brain tumours have on quality of life – so, from all of us, a big thank you. Now, we're heading into 2020 more determined than ever to achieve our vision of a world where brain tumours are defeated, which means funding more of the best research and supporting more people than ever before.

It's only with your continued support that we'll be able to drive forward progress and reach a cure quicker, so we'd be incredibly grateful if you'd consider supporting us again this year. And we'd love to hear from you, so please don't hesitate to get in touch!

Thank you,

Sarah Lindsell CEO

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TV presenter and radio broadcaster Nicki Chapman talks about the shock of her diagnosis and how it affected those close to her.



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NEWS NEWS



THE BIG BAKE IS COMING!

On Friday 6 March, people across the country will be donning their aprons and dusting off their cake stands to help us raise money to accelerate a cure for brain tumours.

We'd love you to take part in The Big Bake at home, at work or anywhere you fancy. And it doesn't have to be on 6 March - you can hold your bake on any day during the month.

You don't need to be a whizz in the kitchen to get involved. You can bake it, fake it or get others to donate it.

We'll provide everything else you need, from balloons and bunting to fundraising tips to boost your takings. Order your free pack now at thebraintumourcharity.org/thebigbake – which includes a special packet of coffee, thanks to a generous donation from our partner 200 Degrees Coffee.

OUR WINTER APPEAL

We want to say a huge thank you to those of you who donated to our Winter Appeal over the festive season and new year period, including through The Big Give Christmas Challenge.

Thanks to the unprecedented response from our community, we were thrilled to hit our target. We're delighted to report that we've raised a tremendous £147,000 so far, with £103,519 of this total donated through The Big Give Christmas Challenge (including Gift Aid). That's enough to fund more than one year of a world-class research project at a leading UK institution, to find new and safer treatments.

This money will go a long way towards helping us find a cure faster and bringing hope to everyone affected by a brain tumour, so we're incredibly grateful for your generosity.



INFORMATION PACK REFRESH

We've refreshed our Brain Tumour Information Pack for adults, which includes a wide variety of resources to help our community understand their diagnosis and feel more confident about talking to their medical team.

Based on your feedback, the four updated booklets in the pack - *Brain tumours:* the basics; Tumour types and treatments; Living well with a brain tumour; and A guide for family and friends - are more practical and interactive. The booklets feature tips from our community and healthcare professionals, as well as clear steps on where to go for more information.

We've also included two Deliciously Ella recipes from our high-profile supporters, Ella and Matt Mills.

While our Information Pack is helpful to those of you who've recently been diagnosed, it's also suitable no matter where you are on your journey and however you, as well as your friends and family, have been affected.

Our updated Brain Tumour Information Pack will be available online from the spring, by going to **thebraintumourcharity.org/information-pack**

BREXIT: WHAT HAPPENS NEXT?

December's general election delivered a significant majority for Boris Johnson, meaning that, as we went to press, the UK was set to leave the EU by 31 January. At that point, we'll enter a transition period until 31 December 2020, while the future relationship between the UK and the EU is being negotiated.

However, there are numerous matters still to be addressed, so that the needs of the brain tumour community are met. It's unclear how the UK will collaborate with the EU on scientific research, while a new immigration scheme must enable EU researchers to come to the UK.

Although the Government has previously committed to participation in future multinational EU clinical trials, the UK also needs to align with new EU trial regulations. And, given that the NHS relies on EU staff to help fill some of the vacancies in its workforce, it can't afford for these professionals to leave.

Visit: thebraintumourcharity.org/brexit for more information.



DNA 'FLAGS' COULD CHANGE CHILDREN'S BRAIN TUMOUR TREATMENTS

We recently had some exciting news about how research we fund is improving diagnoses and treatments for children with a high grade brain tumour. Professor Thomas Jacques, at the UCL Great Ormond Street Institute for Child Health, found that a laboratory technique called methylation testing can help make diagnoses more accurate and even change treatments.

Traditionally, childhood brain tumours have been diagnosed and categorised following microscopic examination of cells within the tumour. However, recent developments mean that scientists can analyse methylation – effectively a 'stop-go' flag in parts of the DNA, which says if it should be used or not. Methylation can either help or hinder tumour growth.

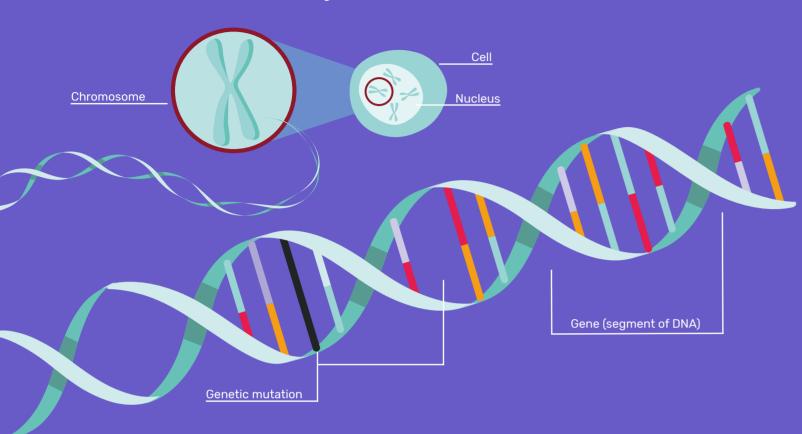
When Prof Jacques matched the new information to clinical trials he and his colleagues are planning, he estimated that in the near future a different treatment may be available for up to 10% of the children diagnosed.

Visit: thebraintumourcharity.org/dnaflags for more information.

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The last few decades have seen growing understanding among scientists of the role genes play in brain tumour behaviour. **RESEARCH IN FOCUS** THE POWER O BIOMARKERS

WHAT ARE BIOMARKERS?



A biomarker is a biological marker. It's any substance in your body that can be measured and used as a sign of the presence or severity of disease. It could be a molecule, a gene or some other biological substance.

ABOUT BIOMARKER TESTING

If doctors think you have a brain tumour, they may test you for biomarkers in order to:

- diagnose your specific tumour type
- work out how severe the disease is likely to be
- find out how the tumour is likely to respond to different treatments.

For brain tumours, it's usually your genes (parts of your DNA code) that will be tested. The test is carried out on a sample of your tumour, which is removed during a craniotomy or biopsy operation and then analysed

At the moment, biomarkers are only known for certain types of tumour, but research is continually discovering new biomarkers.

Find out more at: thebraintumourcharity.org/biomarkers

COMMON BRAIN TUMOUR BIOMARKERS

BRAF

BRAF testing can be done on tumours in children and adults to help confirm some diagnoses and to predict how fast the tumour is likely to grow.

In children, BRAF testing (for the mutation KIAA1549-BRAF, or V600E) can help determine whether their tumour is a pilocytic astrocytoma (a type of grade 1 tumour) rather than another type of astrocytoma, if there's uncertainty.

In adults, researchers think the BRAF V600E test can reveal the likelihood of the faster growth and spread of tumour cells.

The BRAF V600E mutation is currently being investigated as a target for various drugs.

IDH1/IDH2

IDH1/IDH2 testing is suitable for people with gliomas, including diffuse astrocytomas, anaplastic astrocytomas, oligodendrogliomas and secondary glioblastomas.

IDH1 and IDH2 are genes. A mutation in these genes (called an IDH mutation) has been found in about 80% of people with the above tumour types.

For people with high grade gliomas, those whose tumours have the IDH mutation tend to have better longterm survival rates than those who don't have it. Work is ongoing to find out what effect the mutation has for people with low grade brain tumours.

1p/19q CO-DELETION

The 1p/19q test is suitable for people with an oligodendroglioma brain tumour. It looks at genetic changes to your chromosomes.

Each cell in your body has 23 pairs of chromosomes, which carry your genes (DNA). One chromosome of each pair is inherited from your mother, and the other from your father. The pairs of chromosomes are numbered 1 to 22 and then XX or XY.

The 1p/19q test looks at chromosomes 1 and 19 to see if they have sections missing. If the 'p' section of chromosome 1 and the 'q' section of chromosome 19 are missing, this means the genes carried in those sections are also missing.

These genes seem to be involved in resistance to chemotherapy. So, if the test finds that these genes are missing, it means you're more likely to respond better to chemotherapy and have longer overall survival.

MGMT METHYLATION

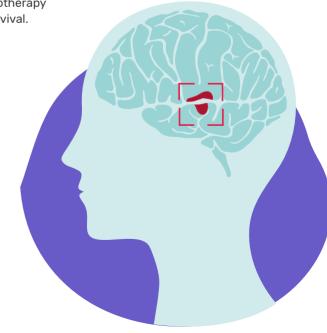
Testing for MGMT methylation helps to predict how effective chemotherapy is likely to be for people with high grade gliomas (including glioblastomas and anaplastic gliomas).

The test looks at whether a gene in your tumour, called MGMT, is 'methylated' or 'unmethylated'.

If the tumour is methylated, it means the gene that controls repair to the tumour (the MGMT gene) is turned off.

If this gene is turned off, the tumour cells are repaired more slowly and so chemotherapy is more effective at damaging the cells. This means that if your tumour is methylated, vou're more likely to respond better to chemotherapy.

We're funding two groundbreaking new grants that involve measuring methylation in tumours - see page 13.



RESEARCH

HOW DO BIOMARKERS AFFECT THE CLINIC?

Biomarker testing can give your medical team a more accurate diagnosis and help them identify the most appropriate treatment. The results may also indicate which clinical trials might be suitable for you.

But it's important to note that biomarker research is still evolving and that biomarkers only indicate likely outcomes – they don't give quaranteed answers.

We fund research that involves biomarker testing, as well as projects aiming to find new biomarkers.

This research has the potential to improve patients' quality of life by allowing clinicians to better plan their treatment. It could also lead to the discovery of new treatments that can target tumours more effectively.

See page 13 to find out about just some of these projects.



THE TESSA JOWELL BRAIN-MATRIX

We're investing £2.8 million into the Tessa Jowell BRAIN-MATRIX. This is a study that will enable children and adults living with a glioma to have treatments specific to them, with the aim of reducing side-effects and increasing survival. Ultimately, this study means more people will have a treatment that the researchers think will work better than the current 'gold standard' treatment.

The study is an innovative platform trial because, at the time it opens, the researchers won't know all the treatments that'll be included. But it will enable speedy testing when new treatments are identified.

In the first phase of the study, everyone who takes part will have biomarker testing and receive a molecular diagnosis. By default, they'll be enrolled onto 'Arm 0' (the control arm), which will deliver the current gold standard treatment.

As new, and possibly better, treatments become available, these can be added to new 'arms' of the study and patients can access them straight away. These will then be compared to Arm 0.

This investment by The Brain Tumour Charity will catalyse transformational change in the UK, by creating the infrastructure to support innovative clinical trials that will improve clinical outcomes for patients of all ages with brain cancer.

-Professor Colin Watts

A&P

We asked Andy
Partridge, a civil servant
for the Foreign and
Commonwealth Office,
about his biomarker
testing for his brain
tumour.

Q. How and when were you diagnosed with a brain tumour?

At the time of my original diagnosis, in 2017, I was working at the British High Commission in Delhi, India. I had a seizure and was taken to A&E at a Delhi hospital. An initial MRI showed that there was something going on in my brain, so I was flown back to the UK for further tests and had another MRI at University College London Hospitals (UCLH).

After that, they gave me a diagnosis of a grade 2 (low grade) diffuse astrocytoma. Because I had very few symptoms before the seizure, they had no idea how long I'd had my tumour – I could've had it for years. Until I was told I had one, I'd never really read much about brain tumours, so it was a lot to take in.

Q. How did the biomarker testing come about?

I was originally told that I would probably have surgery to remove the tumour. But a few days later, I had a call to say that my case had been reviewed and that the risks of surgery were too high due to its location in the brain and the tumour being diffuse.

At that point, they suggested doing a biopsy to confirm the tumour type and, at the same time, offered to do biomarker testing to find out the tumour's molecular profile.



Q. What were you told about the molecular profile of your tumour?

I had the biopsy surgery in December 2017 and got the results in early January 2018. They confirmed that, histologically (under a microscope), my tumour looked like a WHO grade 2 diffuse astrocytoma, but its molecular profile indicated it was an IDH-wildtype glioblastoma.

Q. How did this affect your treatment?

The biomarker testing was quite a new thing at the time – I was told that if I'd presented just six months earlier, they would've done the standard six weeks of radiotherapy and then put me on 'watch and wait'. But the molecular profile enabled them to come up with a different treatment plan better suited to my tumour.

Based on the molecular profile, they decided to do six weeks of radiotherapy and chemotherapy together, followed by six cycles of chemotherapy on its own.

I completed my treatment in August 2018 and have been on 'watch and wait' since then, with quarterly MRIs.

Q. For you, what were the advantages of having this testing?

Everyone is different of course, but personally I like to have as much information as possible. One of the most difficult things for me, in terms of dealing with my condition, is the not knowing. So if I was offered it again, I wouldn't hesitate.

It helped my medical team make better-informed decisions on what to do next – and who knows, the changes made to my treatment following the testing might have led to the tumour being kept in check for a longer period of time. I think if you can tailor someone's treatment so that the effects are maximised, then that's got to be a good thing.

A LASTING LEGACY

Leaving a gift in your Will, even a small percentage, can help us change the course of how brain tumours are diagnosed and treated. Help us move further, faster towards a cure: thebraintumourcharity.org/ gift-in-will

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RESEARCH

PICKING UP THE PACE A PROGRESS UPDATE



NEW THERAPIES FOR ACP

Lead researcher:Dr Todd Hankinson,
University of Colorado, USA

Adamantinomatous craniopharyngioma (ACP) is a rare childhood brain tumour that causes very poor quality of life. Most children diagnosed with ACP will develop life-changing disabilities.

In 2018, we awarded Dr Hankinson and his team over £1 million to look for better treatments for children living with ACP. The team aim to find out how the tumour cells communicate, so they can stop

them 'talking' to each other and so stop them growing.

We're excited to report that the team have made great progress. They have now refined the technique they'll use to separate out cells from the tumour so they can study them. They're also working with innovative imaging tools to gain a clearer picture of the communication within the tumour.

So far, their first drug candidate has been tested in pre-clinical models and the results are being analysed. Additionally, the proposal for the team's Phase II clinical trial has been reviewed and accepted, pushing them closer to the project's ultimate aim of getting new treatments into the clinic.



EXPLORING BRAIN NETWORKS

Lead researcher: Mr Michael Hart, University of Cambridge and Addenbrooke's Hospital, Cambridge

Treatment for diffuse low grade gliomas involves removing as much of the tumour as possible. But this is influenced by how much the tumour has spread and the need to avoid removing parts of the brain that have essential functions.

In 2016, we awarded Mr Michael Hart £50,000 to investigate networks in the brain. While doing this, he developed a method of locating, during surgery, parts of the brain

that house these important hubs so they can be avoided. This technique allows Mr Hart and his colleagues to remove as much of the low grade glioma as possible.

The team focused on identifying areas of the brain responsible for 'executive function' (which includes multitasking and switching between tasks), as well as how these abilities change after surgery. They were able to test executive function at the bedside, as well as during awake brain surgery.

As a result of this research, in Mr Hart's institution, surgeons have more information to help them plan procedures and can give their patients a better idea of potential outcomes of surgery. They hope to share their technique with other surgical teams soon.

PUSHING BOUNDARIES A TRIO OF NEW GRANTS



A 3D MODEL TO UNDERSTAND GLIOBLASTOMA

Lead researcher: Mr Ola Rominiyi, Sheffield Teaching Hospitals NHS Foundation Trust

Mr Rominiyi and his team have pioneered a method of growing cells in a 3D way that more reliably predicts clinical response compared to 2D models.

Researchers have long suspected that glioblastoma (GBM) cells left behind after surgery (residual cells) behave differently to cells removed with the bulk of the tumour (resected cells). For the first time, this 3D model will be used to grow both resected and residual cells and test drugs in a more accurate way.

This will allow the researchers to prioritise some of the best potential drugs to target GBM cells more effectively. GBM is the most common cancerous primary brain tumour in adults and has poor survival rates, so new techniques to assess potential treatments are urgently needed.



FINDING A BIOMARKER FOR LOW GRADE GLIOMAS

Lead researcher: Professor Monika Hegi, Lausanne University Hospital, Switzerland

The aim of Professor Hegi's project is to improve quality of life for people with IDH-mutated (see page 9) low grade gliomas.

The team want to find a biomarker that can predict which people will get the most, and the least, benefit from TMZ chemotherapy. With this knowledge, treatments like radiotherapy could be reduced or delayed, meaning side-effects are avoided.

In a European trial, some people treated with TMZ did significantly better if their tumour showed high MGMT-methylation (see page 9) compared to those whose tumours had no or low MGMT-methylation.

Professor Hegi's team hope to use the information and samples from this trial to propose a level of MGMTmethylation that can be used to predict how well TMZ will work.



TARGETING TREATMENT RESISTANCE IN GBM

Lead researcher:Dr Stuart Smith, University of Nottingham

Dr Smith and his team are taking a new approach to the problem of drug resistance in GBM. They're exploring the idea that a fast-acting process, called RNA methylation, is responsible for this resistance.

Like DNA, RNA is a code that tells cells what to do. Specifically, RNA provides information to make all the proteins within a cell.

RNA methylation acts like a switch that turns protein manufacture off. Dr Smith's team will investigate the levels of RNA methylation in GBM cells and compare them to levels in low grade tumours. They'll then test the theory that RNA methylation is responsible for some GBM tumours becoming resistant to current treatments.

With this knowledge, the team can look at how to stop or even prevent such resistance.

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RESEARCH

BRIAN IS MAKING AN IMPACT

BRIAN (Brain tumouR Information and Analysis Network), our online app to help people cope with a brain tumour, allows you to track your entire journey in one place, from appointments, treatments and side-effects to your moods and much more.

You can also share your data with anyone you trust – such as family, carers and your healthcare team – helping them to better understand your situation.

BRIAN has been designed for everyone, whether you're living with a brain tumour, caring for someone who is, or you work in healthcare or research. Here, three users explain how BRIAN has helped them.



Peter lost his wife Wendy to a glioblastoma almost nine years ago. He signed up to BRIAN and entered Wendy's data posthumously.

I've learnt an awful lot about brain tumours since Wendy died, but it would've been better if that knowledge had been available while she was ill. Having information about side effects through BRIAN, from carers who have been there with their loved ones at 4am, could have an incredible impact on easing part of the burden and distress of the disease.

BRIAN can make this information easily accessible and simple to add to. It can become such a helpful and supportive community and give some comfort to those who dread waking up each morning to find out what this disease will throw at them. It helps to know you're not the only one and to be able to share coping mechanisms.

BRIAN also contains an enormous volume of data that can cut down the time and cost of research projects which will be of great benefit.

It was simple and quick to sign-up to BRIAN and for me, as an ex-carer, it's therapeutic. I have a unique perspective and it channels my indignation at having lost my wife 30 years too early. Personally, being able to help others to avoid some aspects of this awful disease is satisfying and motivating.

66 Being able to help others is satisfying and motivating.



Molly was 18 when she was diagnosed with a grade 1 pilocytic astrocytoma. She found out about BRIAN from The Charity's young adults' Facebook group.

I felt using BRIAN was a good way to keep track of things, as I've suffered with memory issues since starting treatment. I've entered medication, symptoms, side-effects and mood tracking information. This has been really useful for me as I've just had to fill in a Personal Independence Payment reassessment form and found it helpful to look back, as my memory isn't great. It really helps people with memory loss (most people I know with a brain tumour experience this) to keep all of their information in one usable and trackable place. I hope that I can continue to use BRIAN to store and track how I've been doing, and

that it will help people in the future by showing how brain tumours affect individuals, and finding what most people struggle with, so that accessing specific help will be easier.

I'm now keen to start using the feature where my healthcare professionals can access my information to see how I'm doing.

66 BRIAN helps people with memory loss to keep all of their information in one place.



Mike's daughter Elsie is two years old. She was diagnosed with a pilomyxoid astrocytoma last May.

We signed up to BRIAN so we could organise Elsie's treatment and her medication regime, which is complicated. Elsie's diagnosis has been life changing. She's now six months into 18 months of chemotherapy and we've had to change our working patterns to accommodate her treatment and all the challenges this brings. The process is emotionally exhausting but we draw strength from Elsie who battles through each hurdle with a smile, a giggle and a cuddle.

BRIAN has been useful to keep a check on Elsie's side-effects from treatment and we've also been completing the quality of life questionnaires. Keeping a record of appointments and treatments has reminded us of her progress so far. It helps to keep track of the burden of treatment and puts things into perspective when things are difficult. We also wanted to share Elsie's information so researchers can better understand what's important to families. BRIAN is a great tool to track your child's treatment and it's good to know the information will help support other families and improve quality of life for other children with brain tumours going through treatment.

66 BRIAN has been useful to keep a check on Elsie's side-effects.

However you're affected by a brain tumour, BRIAN is for you. By signing up as a user, you can better understand your or your loved one's experience and make more informed choices about treatment and care. Sign up to BRIAN at **askbrian.org.uk**

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IN A WAY, IT'S HARDER **FOR THOSE CLOSE TO YOU**

Our high-profile supporter, TV presenter and radio **broadcaster Nicki** Chapman talks to us about the shock of her brain tumour diagnosis, how it affected those close to her and holding on to inner strength to get through the darker days.

It's a sunny winter's morning when we sit down to talk in Nicki's London home and, for someone who's been up since 4.30am to cover for Zoe Ball's Radio 2 morning slot, she radiates energy with her infectious smile.

Nicki has had a long career in the music industry. She's worked alongside artists such as Kylie Minogue, Take That and the Spice Girls, and as a judge on *Popstars* and *Pop* Idol with Simon Cowell, Pete Waterman and Dr Fox. Recently, Nicki's presented RHS Chelsea Flower Show and Escape to The Country.

Life is now hectic and all-consuming again but last year it took a dramatic turn in May. In recovery from a knee operation, Nicki experienced a loss of vision and slurred speech. "My symptoms were very sudden, over 24 hours. Initially doctors thought I'd had a stroke but scans revealed a golf-ball sized meningioma," remembers Nicki.

"It's the initial shock of diagnosis and then the shock when you tell people that's even more distressing. It's like a slap. When you have to ring people - your family - and tell them; it's just

Nicki only told close family and a few friends at first, partly as a coping mechanism for herself and husband Dave Shackleton, affectionately known as 'Shacky'. "When I was diagnosed, it was the hardest week. When we got home, I said, 'Let's go and pack a bag in case I collapse suddenly." and he said, 'You're going to be fine.' But inside I was thinking, 'What if I'm not..." she says. "You walk around like you've got a firework in your back pocket - that's how diagnosis feels."



Photo credit: Nicki Chapman

SURGERY

Things then started to move very fast and surgery was scheduled for later that month. Shacky was Nicki's rock throughout. She never doubted he would be.

"I said to Shacky that we needed to do our Will and he said, 'Okay,' and I said, 'No - right now!' That was a major thing. That was hard," Nicki says. "We signed the new Will the day before I went into hospital and that was absolutely vile - sitting across the table with the most lovely person and wiping away a tear, literally as I'm signing and it goes 'plop' on the pages in front of me, and all the while him keeping it together.



"He's been amazing. He's much stronger than I thought he was going to be. In a way, it's harder for those close to you. I could just think about me and how I was going to get through this, but for others it was just as hard. They're trying to do the right thing and say the right thing and they want to be your emotional support, but what's going on for them? They're not allowed to say, 'I don't know whether you're going to come through this tomorrow,' or 'What am I going to do if it goes wrong?' They can't say that

The last few days before my surgery were so very dark. I just wanted to get the damn thing over with. I was literally on my hands and knees and Shacky was picking me up.

to me - they've got to be strong,

I'd have been in pieces."

to be positive. If it had been the other

way round and it had been Shacky,

FEATURE

As the surgery date moved closer, the reality of what Nicki was about to face hit home. "The last few days before my surgery were so very dark. I just wanted to get the damn thing over with. I was literally on my hands and knees and Shacky was picking me up."



RECOVERY

Thankfully, Nicki's surgery was successful and, after a brief hospital stay, the recovery process began. Nicki started to take tentative, but regular, walks outside in the spring air to help get herself back on track, but there were other, more surprising, effects.

"When I first saw one of my friends, her nose would be growing in and out and moving around, in a really comical, cartoon-like way. I was thinking, 'This isn't right - this is really strange.' I was obviously still feeling the effects of the medication I was on. I didn't tell my friend at the time!" she says.

"I'd also be in the hospital and I'd look out of the window and see this black shape jumping around the car park. Then I realised one of my get-well cards had a rabbit on it, so I think I was taking it from there. I hadn't expected these effects. Luckily, they didn't last long." Nicki now wants to share her story and to show people that if they reach out, people will reach back to help them. "Every person's story is so different. A big conversation I often have with people is whether this sort of diagnosis and treatment has changed them – it's the biggest concern how it affects people's personalities and impacts them mentally.

"It petrified me when I was told of my own diagnosis and the risks the surgery may have. It's important for people to know that although I've put on a very brave face, I was working my way through it in my own personal way. But I have, and have had, very dark days. A dear friend of mine, going through a similar life-changing experience, called it a 'dark gift'. It's not the gift you want but it's the gift you have. You have to see it like that..." Nicki trails off and it's clear the rollercoaster that was 2019 continues for her. She's still processing her experience on her journey of recovery.

"I'm definitely more vulnerable now but I have to balance that with whatever else may be going on. Is it the menopause as well as my recovery? We now live in a world where we know more about the menopause and how it affects us. Thankfully, it's becoming more recognised and talked about," she says. "I can cry at anything. Is that the menopause or is it what I've been through? Who knows?"

Nicki noticed how much her everyday life, work, family and those around her were impacted by her diagnosis. "From a work point of view, I didn't quite expect everybody to be so kind and supportive. I knew people would be shocked, like I was, but I thought once I'd explained they'd have more of a 'come back and see us when you're ready' type of attitude. Luckily for me, they've been the opposite. People are much more supportive than you realise when you go through something like this. You need to take comfort from their genuine concern and friendship."

ADJUSTING

Since May, life for Nicki has been a series of adjustments, both large and small. The surgery, treatment and subsequent recovery have had more of a profound effect than she could ever have imagined. "It's made me a lot more grateful and hopefully a lot more patient with what's going on in my world. When you walk down the street and maybe bump into people you often think, 'You have no idea what I'm going through." Now I look at other people and think, 'I don't know what you might be going through.' They could be walking down the street looking great but carrying the biggest burden on their shoulders."

As 2020 begins, Nicki's positive and enthusiastic personality is stronger than ever. She still has a hectic work schedule, but also a determination to reach out to others affected and acknowledge those who helped her get through last year, from healthcare workers, to family and friends, to the thousands of public messages of support. "When I look back, 2019 isn't a year I'd want to repeat, but that's life, there's nothing I could have done about it. I've been amazed at people's reactions, both those close to me and people on the street who want to say hello and maybe share a personal story but without ever infringing on my space. People have been so kind and wanted to share their genuine warmth with me," she savs.

"It's important for me to work with The Brain Tumour Charity and share my experience to help others know that they're not alone in this."

Nicki's latest scan was stable and she's continuing to support our 2020 campaigns, including Brain Tumour Awareness Month this March, as well as championing BRIAN, the pioneering free online app we've developed to help people cope with a brain tumour.



NICKI'S TOP TIPS FOR COPING

1. Get outside

"Everyone who came round to see me had to take me out for a walk. That was the deal. You can come round but you've got to walk me. It was like having a dog! It's winter now but spring is just round the corner. If you can, get out into the sunshine; get out into the open."

2. Only 30 seconds of crying

"I have a 30-second rule of crying. If you're going to cry when I tell you I've got a brain tumour; you've got 30 seconds and I will only cry for 30 seconds. Does it work? Most of the time!"

3. Give yourself permission to have bad days

"If you're having bad days, let yourself have bad days. It's like giving yourself permission; don't fight against yourself. Tomorrow might still be a bad day and you've still got this condition, but you're going to find one thing in that day that is good; one thing that you can hold on to."



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

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LIVING WELL

MANAGING RELATIONSHIPS

A brain tumour diagnosis doesn't just affect the person living with the tumour, it can have a massive impact on their family, friends and carers too.

Processing emotions, dealing with practicalities and the personality changes that brain tumours can sometimes cause, can all put a strain on relationships for everyone affected.

Dr Katherine Carpenter, Consultant Clinical Neuropsychologist and Chair of The British Psychological Society's Division of Neuropsychology, explains how a brain tumour diagnosis can affect relationships and offers some tips on how to cope. Dr Katherine Carpenter

Our relationships with partners, family and friends can be an incredible source of support in the face of a brain tumour diagnosis. But they can also be a source of frustration and confusion – just when we need them most.

We all use subconscious defence mechanisms to protect ourselves from unpleasant or painful thoughts and feelings. These include:

- denial when you refuse to accept the reality of a situation to avoid painful feelings
- repression when you subconsciously try to suppress unpleasant thoughts, memories or experiences
- projection when we attribute difficult feelings away from ourselves; for example, you may be convinced someone you find difficult doesn't like you
- regression when we become more childlike and slip back into more immature ways of thinking and behaving
- rationalisation when we use logic and reason, however false, to distance ourselves.

These psychological defences can be very useful at times – if you're facing a difficult operation or therapy it can help to not think about it or temporarily pretend it isn't happening. But it's easy to see how these defence mechanisms can get in the way of openness and intimacy in our relationships.

We all use subconscious defence mechanisms to protect ourselves from unpleasant or painful thoughts and feelings.



KATHERINE'S FIVE RELATIONSHIP TIPS

There's no 'one size fits all' when it comes to relationships, but the following may help:

01

Acknowledge what's happening.

Be aware that what's happening affects both you and others around you. It's okay not to be okay.

02

Talk things through.

Talking to someone neutral can be helpful to process what's going on and your feelings about it.

03

Don't jump to judge.

Share your own feelings rather than jumping to judge others. You could say, "You probably aren't aware, but when you do X it makes me feel Y."

04

Give yourselves time.Everyone having time to get used to the idea of the diagnosis and

its implications is vital.

05

Ask about professional help you can get from your clinical team.

Our community also shared some advice on how to cope with changes to relationships with a partner after a brain tumour diagnosis. Here's what they said:

"I try to meet my partner where he is. Sometimes that means dropping everything and working on his problem. It also means understanding his memory isn't what it was and arguing with him is pointless. It also means accepting a complete loss of intimacy. And, finally, it means learning to ignore or walk away from the nasty comments he makes, although sometimes it means calling him out on his meanness."

-Lynn

"Accept changes. We still have the same love as before but now I'm the one who needs to look after my husband... I can't rely on him anymore. Before it was sharing, give and take, but now I give much more than I take from him."

-Maria

"It took me a while to realise my diagnosis was affecting my partner too. Once I started to understand exactly HOW things were changing, I slowly started adapting my behaviour by being more empathetic to HER needs and not just my own."

-Nic

"Look after yourself and ask for help if you need it. I'm so grateful to our local hospice for ongoing counselling. My husband was diagnosed with a GBM just over two years ago. I was shocked, then very angry at what the tumour had

done to him. After months of his verbal abuse and weird punishing behaviour, including him wanting a divorce, I needed help. I've worked really hard at looking after my needs and have now learned to detach emotionally. After he recently spent over a week moping around the house, not washing, etc. I didn't row, I was able to calmly say I care but I'm going to live my life and asked what he's going to do with his life. It sounds really tough, but for the next two days he got up, showered, made me a coffee and thanked me for dinner!"

-Karen

"My husband and I made a promise to always be honest. If either of us is having a bad day, we choose a good time to allow each other the opportunity to completely offload with no judgement. This is usually teamed with an outburst of tears, but it's worked. Although there's only one diagnosis, it affects both of us. We now actually feel closer than ever."

-Suzanne

"Talk! It opens so many doors. Laugh and enjoy each other even if it's no longer possible physically. Above all, remind each other that you still love and care for each other regardless of how bad it is."

-Karen

"Make the time to communicate about it in the way you find easiest: text, write a letter or just talk. It's easy to shut it away but makes it all so lonely. Communication is key!"

-Emily

If you need a guiding hand, or simply have a question, we're here to help. You can call our Information and Support Line on **0808 800 0004**, Monday to Friday, or email support@thebraintumourcharity.org

ISSUE 22

LIVING WELL
LIVING WELL

REGAINING CONFIDENCE AFTER DIAGNOSIS

The effects of a brain tumour or its treatment can sometimes knock your confidence. Three of our supporters told us how they bounced back and didn't let their tumour limit them.



66 I didn't want to stop talking and engaging.

LANGUAGE PROBLEMS Oliver Highway

Before my diagnosis, as well as the headaches I'd been having, my wife Sharon and I noticed changes to my language and cognition. For instance, I'd type something, look up and see that what I'd written wasn't proper words. I also found I'd forget the names of people I knew, like colleagues.

At the time, I thought it was stress or tiredness. But after six weeks of these symptoms, I had an MRI and straight away they could see I had a brain tumour. I had surgery to debulk it and a few days later I was told I had a glioblastoma the size of a golf ball.

An assessment with an occupational therapist confirmed I had dysphasia (partial loss of my ability to speak and write) caused by the tumour and the surgery. I was referred to speech therapy, which helped my brain

recover a bit after all that trauma. But it's an ongoing effort to keep it at a good level.

When your communication is affected, it can cause awkwardness and misunderstandings. I've learnt it's important to support the people you're talking to. Some people don't know if it's better to suggest words or if they'll make it worse. So the earlier you can tell them you're happy for their support, the better.

I started pushing myself to keep speaking to my friends and, if I got something wrong and had to ask for help, I didn't feel embarrassed because I knew them well. Then, when I went out to town, that confidence helped me speak to the people there.

I've also found support through helping others. I've done speeches at The Brain Tumour Charity and, initially, I felt pressure to speak perfectly and know what to say. But now, if I forget a word, I ask the group to help instead – I make it into a fun game.

The most important thing I've learnt is to keep looking forward. Things might not go back to how they were before, but the one thing you can do is crack on and be positive.

And keep smiling – I do that with everything!



66 Find ways to make your new look seem purposeful.

HAIR LOSS Emeline Gilhoolev

I was diagnosed with a low grade brain tumour in 2018. It was mentioned that the radiotherapy treatment might make me lose my hair, but not how much, as it's different for everyone.

By session 17, I was half bald. I ended up with what I called a 'reverse monk' hairstyle – an island of hair at the top and back of my head. I was very selfconscious about this, so I decided to take back some control and shave it all off.

My hair is part of my identity, so losing it really affected my confidence. There's no quick fix to get your confidence back but you can learn how to accessorise and style yourself. Treat yourself and find ways to make your new look seem purposeful. I bought

a lot of earrings: dangly ones, colourful ones, tasselled ones – as many colours and styles as I could find!

My friends were also very supportive and if I told them I was having a crisis of confidence they'd help to build me back up.

It's been bizarre to go through and I've had so many emotions, but I've had an opportunity to try new styles I wouldn't have otherwise. Losing your hair will suck, there's no denying it. But you aren't alone and there are people you can talk to who understand what it's like.

Just learn what works for you, trust your instincts and talk to people – that's the best thing you can do for yourself.



66 I'm determined to make the most of my life now.

MEMORY LOSS Carol Rutherford

My low grade meningioma went undiagnosed for years. Despite countless GP appointments, my symptoms were put down to migraines, my optical prescription or tiredness.

I was on holiday with my husband when things took a turn for the worse. I went to get money from a cashpoint while he waited in the car and I had a very frightening experience of complete memory loss. Suddenly, I didn't know where I was or why I was there. Two hours later I remembered enough snippets of information to make my way back to our hotel, where I found my worried husband.

The tumour was discovered after we returned home, when I collapsed and was admitted to A&E. I had an emergency operation which saved my life – initially, we were told the tumour was too large to operate on and, as I lay unconscious, my family had to say a very difficult and emotional goodbye to me.

I was off work for eight months after my diagnosis. The effects of all this did knock my confidence, particularly the episodes of memory loss. It took a long time for me to regain confidence in my own abilities and not be worried about going out alone.

But I've built myself back up using my hobbies as tools for recovery. I love meditation, gentle yoga and reading, and I'm determined to make the most of my life now. My relationships with some of my family have become closer, too.

I've even ticked some things off my bucket list, including returning to Spain to walk the Camino de Santiago Pilgrims' route with three friends.

If you're going through a difficult time, we're here to answer your questions, provide support or just listen. Call our Information and Support Line on **0808 800 0004**, Monday to Friday, or email **support@thebraintumourcharity.org**

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REGULARS

ASK THE EXPERTS

Got a nagging question that's bothering you? Need some reassurance about something you've been told? Ask us the question and we'll find the right person to answer it for you.

WHAT SUPPORT IS OUT THERE FOR YOUNG ADULTS AFTER TREATMENT?

Emma Wood, Young Adults Service Manager, The Brain Tumour Charity

For young adults, who are often approaching key life events such as getting a job and leaving home, a brain tumour diagnosis can bring additional challenges. We know that it's often after treatment that young adults can feel lost, so having the right support can make a big difference. This is why we developed our Young Adults Service for those aged 16-30 with a brain tumour diagnosis.

The service provides dedicated support and information, helping young adults connect with others who are going through similar experiences. Our support includes:

- a closed Facebook Group to help young adults connect
- events where young adults can meet new people
- individual online, live chat and telephone support providing information and emotional support.

If you have any questions or want to know more about the service, email YAS@thebraintumourcharity.org or call 0808 800 0004. We also have information and resources on our website, including blogs and videos. Visit thebraintumourcharity.org/YAS

WHY IS MENINGIOMA NOT CLASSED OR TREATED THE SAME AS CANCER?

Dr Raj Jena, Academic Clinical Oncologist, University of Cambridge

We use the word cancer for a tumour that can spread to another part of the body and form secondary tumours (metastases). In the case of brain tumours, this usually means spreading to another part of the brain or spinal cord.

Meningiomas are tumours that grow from the tough protective layer that surrounds the brain and spine, and they tend to cause symptoms by compressing areas of the brain and spine that carry out important functions.

Over 90% of meningiomas will only grow from the area where the tumour first formed, and they lack the ability to spread to another part of the brain. Therefore, these low-grade meningiomas are not classed as cancerous, so will be treated differently.

A few meningiomas do behave in a more aggressive way and can spread into the neighbouring brain and skull bone, or spread to other parts of the brain and spine. These are rare and are often treated in the same way as cancerous tumours.

HOW CAN OUR COMMUNITY HELP FAMILIES COPE WITH THE IMPACT OF THE DISEASE ON THEIR MENTAL HEALTH?

Eve Kelleher, Head of Services, The Brain Tumour Charity

A brain tumour diagnosis not only affects the individual themselves, but also their loved ones, family and friends. Everyone will be going through a range of emotions. And the impact on mental health can't be underestimated.

Our community brings a wealth of experience to help those dealing with their loved one's diagnosis. Through Facebook support groups, they can share how they're feeling and seek support from others in a similar position in a safe space. And on our website, our community shares their stories.

Our online app BRIAN has been developed to help people cope with a brain tumour. Whether they're living with a brain tumour or caring for someone who is, it's a helpful way to track how they're feeling each day and make better informed decisions.

We also have videos on how brain tumours can affect mental health and strategies to help people cope. Visit thebraintumourcharity.org/mental-health or call our support team on 0808 800 0004.

ARE RESEARCHERS CLOSER TO FINDING TREATMENT OPTIONS TO EXTEND LIFE IN GBM PATIENTS?

Dr Stuart Smith, Clinical Associate Professor in Neurosurgery, University of Nottingham

We certainly understand glioblastoma (GBM) much more deeply than we did even a few years ago. Research, including that funded by The Brain Tumour Charity, has explored many of the problems that make these tumours so difficult to treat.

All aspects of current treatment have been refined based on laboratory and clinical studies. Surgery, across the UK, can now be guided by 5-ALA (also known as the 'pink drink'), which causes tumour cells to glow bright pink under UV light, making it more effective and safer for the patient. Radiotherapy techniques have also become more effective, and approaches such as repeated radiotherapy are being explored.

We now understand that tumour samples, and the genetic information used to develop targeted drug therapies, taken from one area of a GBM, may not be representative of the whole tumour. Laboratory methods need to adjust to take the complexity of this tumour into account, and to increase the number of drugs making it from the laboratory to successful clinical trials.

The problem of actually getting drugs into the brain is also now much better appreciated. Several teams are working on ways of delivering high concentrations of drugs precisely to the brain tumour, making treatments work better, but – at the same time – reducing the dose given so they can decrease side-effects for the patient.

Sadly, promising techniques that get the patient's own immune system to attack the brain tumour have not worked as well in GBM as they have in other cancers. However, exciting research is continuing to make this technique more effective for people who have been diagnosed with a GBM.

Large-scale initiatives, like the Tessa Jowell BRAIN-MATRIX study (see page 10), are needed to gain a clear picture of what may work for GBM, as no two tumours are the same. Small steps have been made in improving things, but there remains a long way to go until we achieve safe and effective treatment for all brain tumours.

SEND IN 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. We'll try our best to answer as many questions as we can but we're not able to reply to everyone individually.

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TO MYSELF BEFORE THE DIAGNOSIS



Dear Gemma,

I'm writing to reassure you because, soon, everything in your life will change.

You'll soon start experiencing severe pain on the left side of your head.
You'll visit your GP a number of times, but you'll be told it's being caused by stress and depression. You'll know that isn't the reason but it will only be in November 2009, when you begin vomiting violently in the mornings and your dad takes you to the hospital, that you'll be given two MRI scans.

Then you'll be dressed ready for work when you're told you have a mass on your brain. Nothing will be able to prepare you for that devastating moment. You'll never have imagined that you could have a brain tumour. In an instant, everything will change.

You'll be admitted to hospital for tests and transferred for brain surgery that will take 10 hours. You'll find out that your tumour is a meningioma, the size of an orange, which is usually low grade but that yours contains cancerous cells. It could have been growing for 20 years, or even for most of your life. Because your symptoms came on gradually, you won't realise the impact they've had. You'll have got so used to the way you felt that when you come round from the surgery everything will be so much clearer. It will feel like someone has switched on a light.

You'll then learn that you need radiotherapy and, knowing you'd like to start a family one day, you'll ask if it will affect your fertility. Doctors will warn you it could, but you have to go ahead with the gruelling six-

week course. It will leave you with permanent partial hair loss, meaning you'll wear a wig almost every day, and a scar from ear to ear. But you'll find a strength you never knew you had and you'll get through it.

You'll be lucky enough to learn that your pituitary gland, the part of your brain that controls fertility, wasn't affected by the radiotherapy, so your dream of being a parent could still become a reality. You'll make a good recovery and regular scans will show no regrowth of your tumour. Nine years later, in 2017, you and your partner will be delighted to learn you're pregnant and you'll give birth to a healthy baby boy who you'll name Hudson. Everything will change again.

Hudson will be the most gorgeous baby and will fill your life with a happiness that you hadn't ever thought possible. You'll feel incredibly lucky that he brings so much love and joy into your life.

Then, in December 2018, one morning your fingers won't work to spray your perfume and you won't be able to put it back in the box. You'll go about your day as usual but when you speak to your partner he'll notice you keep repeating yourself and he'll ring your doctor. You'll say you're okay - you'll know brain tumours can recur and will have worried that something else will happen but you won't think it could happen this soon. You'll be told it's best to be checked and be sent for a CT scan between Christmas and New Year. This will reveal a lump on the other side of your head.

You'll fear the worst as you wait in the hospital to find out what happens next. With Hudson only 15 months old, you'll have so much more to lose now. Last time you were worried for yourself and your future, this time you'll be worried for him and his.

You'll have surgery in February and it will be so much worse than the first time. You'll come round and feel the bandage wrapped too tightly round

your head and you'll struggle to keep pain relief down. Your speech will be affected, you'll have to accept lots of help from your parents and you'll have headaches for months afterwards. There will be days when you'll fear you won't make it and that Hudson might have to grow up without his mummy...

But, you'll find out the lump wasn't another tumour. It was a cavernoma, a cluster of abnormal blood vessels in the brain, likely caused by your previous radiotherapy. Despite not being able to drive for six months, you'll be back at work again two months later. In June, you'll have a scan that's clear and be told no further treatment is needed.

There will never be a day that you won't think about your brain tumour diagnosis. It will never leave you. It will change your perspective on life and so will having a child. But your life is what you make it. You'll be strong and you'll have so much hope for the future.

Love Gemma





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

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REGULARS

Wow! What an experience The Twilight Walk was for me! I'm amazed at the work you all put in to make it look so bloomin' effortless. I loved meeting so many people and I was absolutely buzzing when I got back to the hotel. I'm so looking forward to the next time I can take part in such an event.

Many thanks to everyone – it was just so lovely being with you all.

Mary

Pictured: Walkers at The Twilight Walk Warwick



I don't think I'll ever be able to thank you enough for the help and support! I found your Facebook Carers Support Group the day before my husband got his biopsy results. I posted at 2.00am feeling utterly alone, terrified and desperate. By the time I checked my phone at 7.00am, there were at least 20 messages of love and support. I was blown away by the kindness.

Gill

Pictured: Our Facebook Carers Support Group



Almost a year ago my mum found out she had a large meningioma tumour. She had a 16-hour operation and they managed to remove 98% of it. It was a tough time for us as it all happened so quickly.

We here in the Sales team at Great Rail Journeys chose to raise money for The Brain Tumour Charity through our Dress Down Day. What you guys do is fantastic and to be able to raise money for such a personal charity really meant a lot to us. We managed to raise a total of £1.067!

Thank you and keep up that hard work!

Rhianna

Pictured: Rhianna and her mum



The Young Adults Big Meet was so fun – I haven't had as much fun for a while. It was so nice to meet friends and new people. I wish it was longer as the time went by so quickly. I didn't want the day to end. Thank you and I'll see you in the future.

_ucy

Pictured: Lucy (centre) at the Big Meet

KEY DATES OUR EVENTS AND MEET UPS

FEBRUARY 2020	Saturday 22	Young Adult Meet Up in Southampton
MARCH 2020	Sunday 15 Saturday 21 Sunday 29	Bath Half Marathon Young Adult Meet Up in Leeds London Landmarks Half Marathon
APRIL 2020	Sunday 5 Sunday 5 Sunday 19 Sunday 26	Greater Manchester Marathon Paris Marathon Brighton Marathon Virgin Money London Marathon
MAY 2020	Friday 15 Sunday 24 Monday 25	Celebrating You Awards Edinburgh Marathon Festival Vitality London 10,000

JUNE 2020

JULY 2020

AUGUST 2020

SEPTEMBER 2020

FEBRUARY 2021

Friday 15	Celebrating You Awards
Sunday 24	Edinburgh Marathon Festival
Monday 25	Vitality London 10,000
Saturday 30	Young Adult Meet Up in Birmingham
Saturday 13	Lake District Challenge
Saturday 20	Snowdon by Night
Saturday 20	Young Adult Meet Up in London
Saturday 25	Young Adult Meet Up in Bristol
Sunday 16	Prudential RideLondon-Surrey 100
Saturday 22	Young Adult Meet Up in Manchester

aturday 12 to Sunday 13

Saturday 12 to Sunday 13		
	Thames Path Challenge	
Saturday 12	Young Adult Meet Up in Southampton	
Sunday 13	London to Brighton Cycle	
Sunday 13	Great North Run	
Saturday 19	Marathon Walk London	
Saturday 27	Sahara Trek (one week trek)	

To find out more about our events visit: thebraintumourcharity.org/events
For details of our Family Days visit: thebraintumourcharity.org/family-days

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ONLY TOGETHER CAN WE ACCELERATE A CURE.

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

