

# THE GREY MATTERS

ISSUE 23 SUMMER 2020

THE  
BRAIN  
TUMOUR  
CHARITY

Brain tumour  
microenvironments

Author Adam Blain  
on coping through  
humour

Looking after mental  
health and emotional  
well-being







HELLO

Welcome to issue 23 of *The Grey Matters*.

When we began to plan this edition of our magazine and decided to theme it around mental health and emotional well-being, we had no idea just how relevant and crucial these topics would soon become. The last three months have been extremely challenging for the brain tumour community and the country as a whole, but throughout this crisis, we've been as determined as ever to support our community and ensure everyone has the information they need.

We've packed this issue with stories, tips and advice for looking after your mental health and well-being when you've been affected by a brain tumour, which you may find especially helpful at this difficult time. We've also included an update on our recent research grant awards, as well as a feature explaining the brain tumour microenvironment – an important area of study that researchers believe could be key to understanding tumour growth.

In this uncertain and ever-changing situation, as we work tirelessly to support all those affected by a brain tumour, your monthly donations are more important than ever and are making such a difference – so, from all of us, a huge thank you.

Despite the difficulties the coronavirus has thrown at the charity sector, we remain committed to halving the harm brain tumours have on quality of life, and your support has helped us respond to this crisis rapidly and in innovative ways – such as rolling out a coronavirus (COVID-19) information hub on our website and holding virtual meet ups to allow people to connect.

Better treatments and care for those affected by this disease can't wait and, with you beside us, we know we can get through the challenging months ahead and continue to drive progress towards our goals, now and in the future.

Thank you,

**Sarah Lindsell**  
CEO



We will spend at least 80p of every pound spent on our charitable objectives.

WHEN YOU'VE FINISHED WITH THIS MAGAZINE, PLEASE SHARE IT!

It will show others the difference we make, together. We rely 100% on voluntary donations to help us drive change. If you receive this magazine and would like to join our movement, you can make a donation in the following ways:

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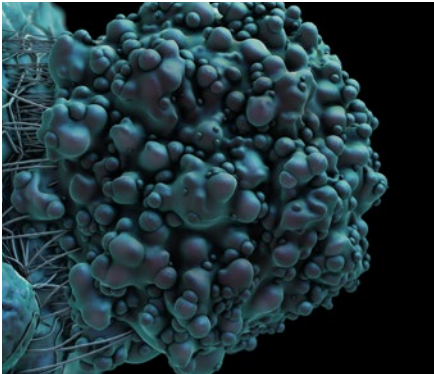
Phone: 01252 237792

Post: The Brain Tumour Charity,  
Hartshead House, 61-65 Victoria Road,  
Farnborough, Hampshire GU14 7PA.

If you'd like to receive a digital copy of this magazine next time, please email us at: [donations@thebraintumourcharity.org](mailto:donations@thebraintumourcharity.org)

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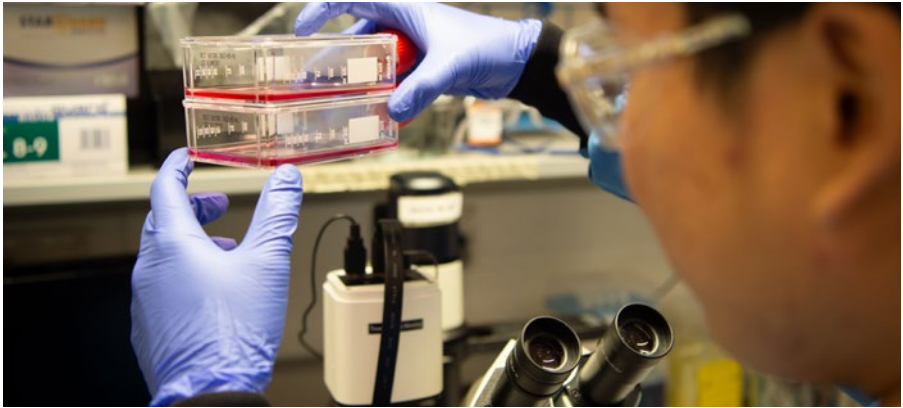
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# NEWS



## WE WON'T STOP FUNDING NEW RESEARCH!

We're living in extraordinary times, and the impact of coronavirus has been felt by us all. In spite of this, we remain committed to funding world-class researchers to accelerate the discovery of new treatments and improve our understanding of brain tumours.

To date, we've dedicated more than £50 million to forward-thinking research and don't want the current challenges to slow our progress. So we've recently committed to investing a further £4.9 million in research projects to run over the next five years.

We're aware that by maintaining this level of investment in research, we'll have to raise even more funds in the future. But in our commitment to push the boundaries of research to help drive change more quickly, we know that this is the right thing to do for people affected by brain tumours. And thanks to your support we'll continue to fund pioneering researchers – now and in the future, bringing us closer to making our vision of a world without brain tumours a reality.

Find out more at: [thebraintumourcharity.org/funding-new-research](https://thebraintumourcharity.org/funding-new-research)

## NEW CHAT ROOM FEATURE FOR BRIAN

In this uncertain time, healthcare professionals are likely to find it harder to have regular face-to-face contact with their patients. However, it's vital that they're still able to keep them fully informed.

In response to this, we've created some chat rooms in BRIAN, our online app. These chat rooms will be hosted and run by individual NHS Trusts, so that they can hold virtual clinics and Q&A sessions on a range of topics for those affected by a brain tumour.

This feature is now being trialled by two large NHS Trusts, before hopefully being rolled out to further Trusts. BRIAN users will also be able to use some of the chat rooms we're setting up to find others with similar experiences and to share their own experiences.

Although the chat rooms have been set up in response to the current coronavirus (COVID-19) outbreak, we expect them to remain as a permanent feature in BRIAN. If you're not already signed up to BRIAN, you can find out more at [askbrian.org.uk](https://askbrian.org.uk)



## SUPPORTING YOU WITH YOUR RELATIONSHIPS

Sharing a strong, healthy relationship with your partner has numerous proven health benefits. And that's something that's particularly important and relevant in these challenging times, when many of us are spending more time than usual with our partners.

We know that a brain tumour diagnosis, whether it's you or your loved one who's diagnosed, can impact on your relationship in a number of ways. That's why we've partnered with Relate, a leading relationships charity, to deliver a free relationship counselling service for couples and individuals affected by a brain tumour.

It's suitable for people in all sorts of circumstances, even if you just want help to nip any issues in the bud before they get harder to deal with, or you need some extra support at times of challenge or change. And you can access the service as an individual or as a couple – whatever works best for you.

To find out more and get support, visit: [thebraintumourcharity.org/relationships](https://thebraintumourcharity.org/relationships)



## THE TWILIGHT WALK: AN UPDATE

The coronavirus (COVID-19) pandemic has brought a great deal of uncertainty with self-isolation and shielding measures making a big impact on the daily lives of people affected by a brain tumour.

For the safety of our community, we have taken the decision to postpone our flagship annual fundraising event, The Twilight Walk, this autumn.

In spite of the challenges of coronavirus for events like this, we're exploring ways we can bring The Twilight Walk to you, so that you have the opportunity to take part.

We know that The Twilight Walk is a special day for our community to get together to celebrate loved ones and to raise money and awareness, while taking on this challenge.

And although we'll need to wait just that little bit longer before we can all come together to help make a cure for brain tumours a reality, it will be as inspiring an event as ever – whatever form it takes.

Register your interest to be one of the first to receive updates by visiting: [thebraintumourcharity.org/thetwilightwalk](https://thebraintumourcharity.org/thetwilightwalk)

You can read Julie's experience of The Twilight Walk on pages 28-29.



## THE BRAIN RACE WINNERS ANNOUNCED!

Last year, we collaborated with the Center for Advancing Innovation (CAI) and Resonance Philanthropies to launch The Brain Race, a contest to advance innovative inventions and solutions to defeat brain tumours.

We can now report that of the 124 teams that took part, the 15 winners have been selected.

This inspiring initiative will see these winners, 15 start-up companies, advance progress towards a cure. They'll do this by developing new therapies, devices, diagnostics and digital health solutions to bring future improvements for people living with a brain tumour and their carers.

Our Chief Scientific Officer, Dr David Jenkinson, said: "We're inspired by the progress that The Brain Race spin-out companies have made in developing solutions for the brain tumour community.

"The Brain Tumour Charity looks forward to collaborating with these new companies in our fight against brain tumours."

You can find out more about The Brain Race, as well as the winning start-up companies and overviews of their innovations, by visiting: [thebraintumourcharity.org/brain-race](https://thebraintumourcharity.org/brain-race)



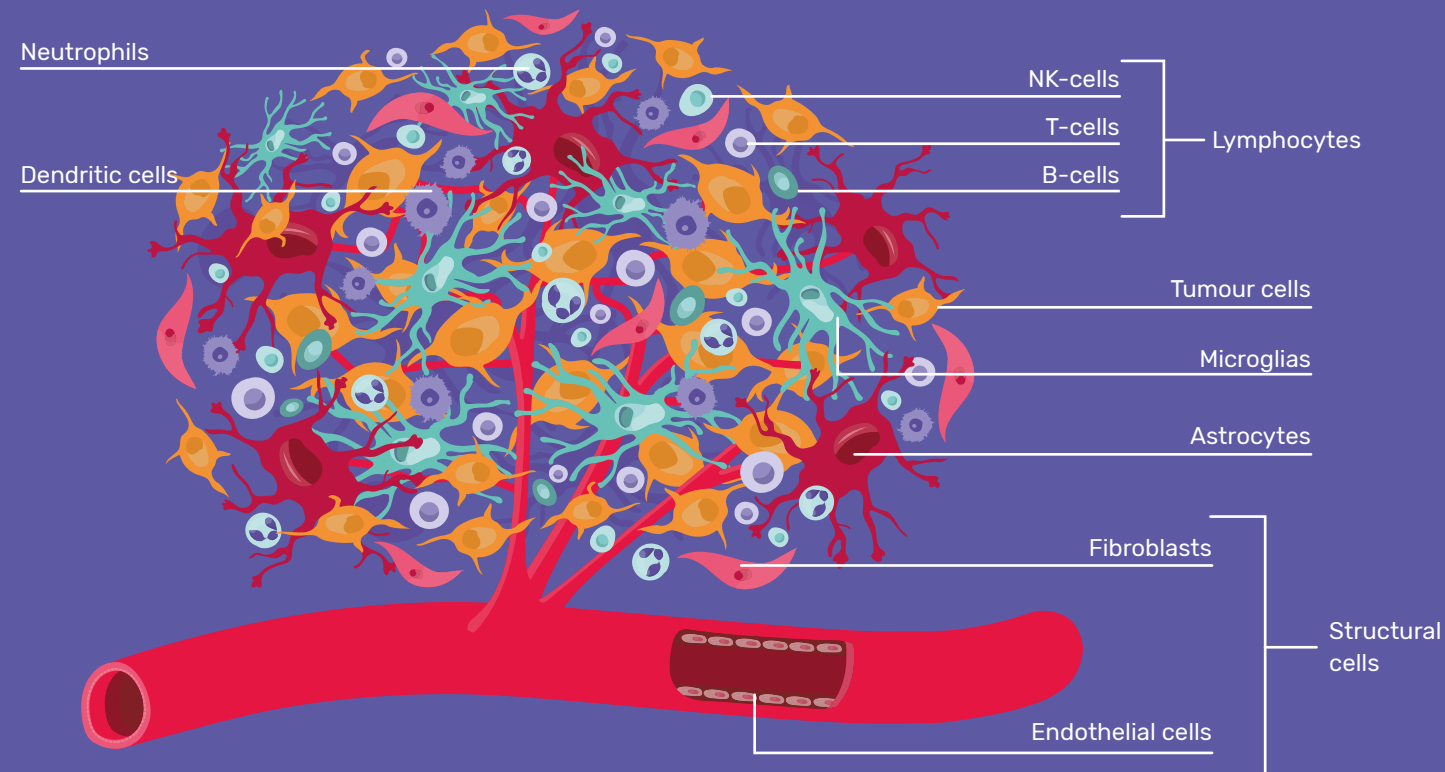
**RESEARCH  
IN FOCUS**

**Researchers are investigating brain tumour microenvironments, which could hold the key to understanding why brain tumours grow, progress and recur.**

# BRAIN TUMOUR MICROENVIRONMENTS



# WHAT IS A BRAIN TUMOUR MICROENVIRONMENT?



**Think about how the make-up of the soil affects the growth of a seed. Or how a child's birthplace decides the language they speak and the food they eat. Scientists have started to realise that the normal cells, molecules and blood vessels that surround brain tumours have a similar impact on the way these tumours develop.**

This so-called tumour microenvironment (TME for short) is being explored by researchers hoping to improve treatments for brain tumours.

The cells, tissues and signalling molecules surrounding brain tumours all have a role to play in where, when and how these tumours grow.

We're still learning about the TME, but we already know that there's a number of ways it interacts with tumours. It can:

- harbour blood vessels that 'feed' the tumour with the nutrients and oxygen it needs to grow
- create the conditions for tumour cells to 'break free' and travel to other organs (metastasise)
- offer a comfortable place for secondary tumours (or metastases) to settle in
- contain cells and substances that affect the body's defences against the tumour
- affect how well drug therapies work.

# TYPES OF CELLS FOUND IN THE TUMOUR MICROENVIRONMENT

**Researchers are now studying TMEs in intricate detail, to see if they hold the secrets to explain how brain tumours grow and spread. We now know that TMEs are home to a wide range of cells and structures.**

The major components of the TME include blood vessels, lymphatic vessels, fibroblasts (which are the basic building blocks of many structures in the body), immune cells and structural scaffolding like the extracellular matrix (ECM), which provides structural and biochemical support to surrounding cells.

The types of cells found in the TME are also found throughout the body. But it seems they can behave quite differently in the brain – even more so when a tumour is present. Here are some of the cells that have been identified in the TME:

## IMMUNE CELLS

### Microglia

These specialised types of macrophages (large white blood cells that are an important part of our immune system) are the front line of defence in the brain. Their main role in the healthy brain is to look for and destroy any infectious agents and to remove any dead or damaged neurons. In the TME, they can be tricked into sending out anti-inflammatory signals, dampening the immune system's ability to identify and destroy tumour cells.

### Dendritic cells

Like night watchmen, these cells constantly scan the landscape, looking for targets for the body's defence systems to destroy. When they find foreign cells, such as those in brain tumours, they help other immune cells recognise them so that a faster immune response can be launched in future. The challenge is helping them recognise tumour cells.

### Neutrophils

These are first-responders that are part of the body's inflammatory response. Inflammation is one of the body's defences against foreign cells and infectious agents but, in some cases, uncontrolled inflammation is damaging. In the brain, neutrophils can either help or hinder tumour progression.

### Lymphocytes

There are three main types of lymphocytes known as T-cells, B-cells, and natural killer (NK) cells. T- and B-cells can cross the blood-brain barrier and enter the brain, where they negotiate both the short-term and long-term immune response to foreign cells.

## STRUCTURAL CELLS

The TME is also home to other cells that aren't part of the immune system. Structural cells form the physical surroundings in and around a brain tumour. Examples of structural cells include fibroblasts, and endothelial cells, which line the walls of blood vessels located in the TME and can form blood vessels that certain types of tumour need to grow.

## ASTROCYTES

These star-shaped cells are only found in the brain. They have many different roles, including transmitting messages, providing structural support and transporting nutrients to neurons.

## TOGETHER WE CAN ACCELERATE A CURE

A monthly gift of £6 could go towards specialist equipment to help a researcher test potential brain tumour treatments in the lab. A cure can't wait. Set up your monthly gift today: [thebraintumourcharity.org/donate](https://thebraintumourcharity.org/donate)

# HOW DOES THE MICROENVIRONMENT AFFECT BRAIN TUMOURS?

**The way the tumour, cells and other contents of the tumour microenvironment (TME) interact with each other is complex. The nature of this chemical interaction affects how the tumour grows and how successful anti-tumour therapies might be. And that's why we need to understand more about it.**

Some of the things going on inside the TME can include hypoxia, transformation and angiogenesis.

## HYPOXIA

In the early stages of tumour growth, its cells grow rapidly and may reach a point where they're starved of blood supply and nutrients. This creates conditions in which oxygen levels are low – this is known as hypoxia. A 'hypoxic' environment can trigger a series of events that will eventually make the TME a more hospitable place for the tumour to thrive. Activation of a protein called hypoxia-inducible factor-1 (HIF-1) is a sign that hypoxia is present and it's common in advanced cancers. Hypoxia is also linked to the growth of aggressive tumour cell clones and high grade tumours.

## TRANSFORMATION

Tumour cells can cleverly trick the normal cell residents of the TME, turning their attention from their normal activities towards tumour-promoting jobs. Macrophages (large white blood cells that are an important part of our immune system), for example, can turn into tumour-associated macrophages. This changes their activity from activating an immune response (pro-inflammatory) towards dampening the immune response (anti-inflammatory). Overall, the effect is that the tumour can 'hide' from the body's natural immune defences and continue to grow.

The extracellular matrix (ECM), which provides structural and biochemical support to surrounding cells, is also changed in the presence of tumour cells. Lack of oxygen and the presence of cancer-associated fibroblasts (CAFs) in the TME can cause the ECM to become stiff and disorganised. Not only does this altered scaffolding support the growing tumour, it also helps cells move in and out of the TME.

## ANGIOGENESIS

Angiogenesis is the process by which blood vessels form. Without angiogenesis, tumours can't grow beyond a certain size. Cancer cells can send out chemical signals that turn on angiogenesis, forming blood vessels completely dedicated to feeding the growing tumour.

### A CURE CAN'T WAIT

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

## Q&A

**We spoke to Denise Sheer, research professor at Queen Mary University London, about her research into the tumour microenvironment of low grade gliomas.**

### Q. Why did you choose brain tumours as your research area?

Early in my career I worked under the most amazing director who really insisted that patients had to be part of the research, and having met so many families affected by this disease I really feel a strong responsibility to them.

A father once told me how his son's tumour was discovered and finally managed with a targeted treatment. But he also shared the difficulties that the targeted treatment brought in itself. This just reinforced to me how much we need to understand about targeted treatment. You think it will be a magic bullet, but even when it works well, it may not continue forever and eradicate the tumour completely. The tumour can become resistant. I want to be doing something valuable in the treatment of those children.

### Q. Tell us a little about your research?

My research aims to better understand low grade (slower growing) gliomas in children. Ultimately, I want to find something that can stop these tumours growing – permanently.

Already, we've discovered that almost all the genetic changes in pilocytic astrocytoma, a type of low grade glioma, affect something called the mitogen-activated protein kinase (MAPK) signalling pathway.



Denise won the Research Engagement Award at our Celebrating You Awards 2018

A signalling pathway is like a network of dominoes – one change in the cell signals to another and another and, in the end, the cell's biology changes. I want to know: how does that work? What changes can make the dominoes turn in a different direction?

A better understanding of these pathways will help identify new areas for drug targets.

### Q. Tell us about the work we're funding you to do?

As part of the Everest Centre grant, I'm looking at the tumour microenvironment (TME) in low grade gliomas.

Their initial slow growth is thought to be controlled by a process called oncogene-induced senescence (OIS), where certain pathways are actively trying to suppress the tumour growth. Links with OIS and the immune system around the tumour have also been discovered, potentially making the TME more conducive to growth. My team and I are working to better understand what's driving the OIS and how it interacts with the microenvironment, so they can be influenced to stop progression or even stop tumour development altogether.

The deregulation of the MAPK pathway is thought to be one of the most

important mechanisms behind the relatively slow growth of low grade gliomas. We've recently revealed new information about which MAPK-influencing genes are expressed differently in them and so may be responsible for slower growth or changes in treatment response.

We've also been investigating ways to further slow the growth of tumour cells using drugs that inhibit the MAPK pathway. The MAPK pathway has a lot of steps, and each is a potential drug target, individually or in combination. We hope information gathered during this work will help shape future clinical trials.

**“A better understanding of these pathways will help identify new areas for drug targets.”**



# MICROENVIRONMENT

## RESEARCH GRANTS



### INVESTIGATING DIFFERENCES IN THE MICROENVIRONMENT IN DIFFERENT PARTS OF TUMOURS

**Lead researcher:**  
Dr Gregor Hutter,  
Department of Biomedicine,  
University of Basel,  
Switzerland

Dr Hutter has completed his first year of work on one of our Expanding Theories grants, which support the development of new ideas and approaches.


His research team has previously shown that particular drugs could reprogramme cells within the tumour microenvironment to have anti-tumour effects. But to date this hasn't been done in sophisticated models.

This project uses specialised lab equipment, called perfusion bioreactors, to mimic the natural environment of a brain tumour, including the presence of immune cells such as microglia and T-cells. The team in Basel are using the

bioreactors to investigate differences in the microenvironment at the centre of a glioblastoma (GBM) compared to at its margins. They're also testing different combinations of drugs to reprogramme microglia to attack GBM cells.

Within the first year, Dr Hutter has shown that in his bioreactor systems, tumours and the associated microenvironmental factors, maintain the traits they had in the human head.

They tested different combinations of drugs and found they made measurable changes to the microglia and T-cells and that these changes varied between tumours, and between different areas of a single tumour. They are now working on understanding what this information means and how it could be useful in a clinical setting.



### THE ROLE OF ASTROCYTES

**Lead researcher:**  
Dr Sebastien Serres,  
University of Nottingham

Dr Serres and his team have recently discovered that astrocytes may play

a key role in how tumour cells interact with the healthy brain.

The fast growth of a GBM means it has no time to grow new blood vessels to supply itself with oxygen, and parts of the tumour become hypoxic (lacking in oxygen). This causes astrocytes to form a scar-like barrier around the tumour, but researchers don't yet know how this happens or how the barrier helps the tumour.

The team has shown that when astrocytes and GBM cells grow together in low oxygen, levels of a transcription factor (these turn specific genes on and off) called STAT3 increase by up to 200%. Researchers think the higher levels of STAT3 turn on genes that make astrocytes change their behaviour and form the scar-like barrier around the tumour.

Also, by using an imaging technique called NRM spectroscopy, Dr Serres showed that cells produce energy in a different way in a low oxygen environment. This might be due to STAT3 levels, but needs further study.

Lastly, the team have been using human tumour samples, obtained through biopsy, to find which part of the tumour has the most STAT3. So far it seems to be mostly in the margins, giving weight to their hypothesis that STAT3 is driving the formation of the barrier around the tumour.

# PICKING UP THE PACE

## A PROGRESS UPDATE



### PREDICTING THE RISK OF MENINGIOMA REGROWTH

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

#### Identifying changes in DNA

In this five-year research programme, Dr Gelareh Zadeh aims to identify key DNA mutations within a cell that start, as well as maintain, the growth of high grade meningiomas.

She and her team are analysing tumour samples from 500 patients around the world to identify common changes in DNA. They're also investigating how changes to the way DNA is folded influences the way the DNA 'code' is used. This analysis will help to identify and target the changes associated with the aggressive nature of high grade meningiomas.

#### Connecting genetic changes to clinical behaviour

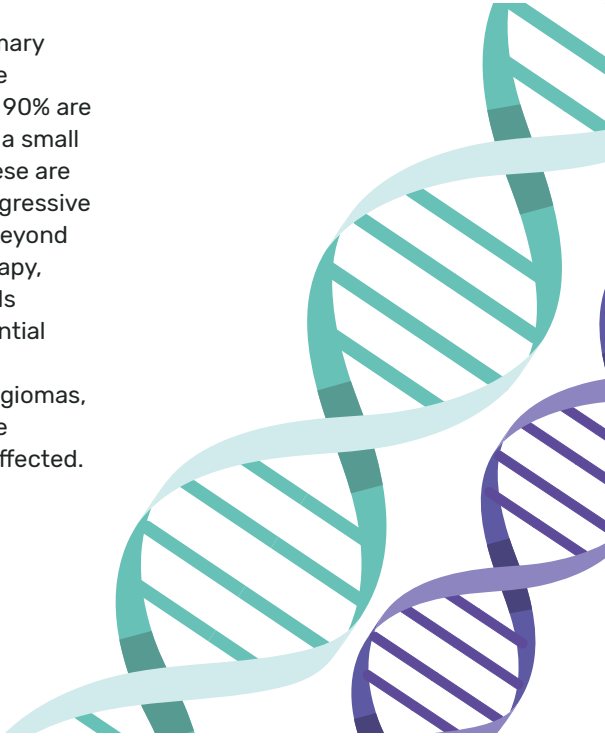
In addition to studying tumour samples, the researchers are also collecting information on the quality of life of people with meningiomas, including persistent symptoms such as fatigue. This information will be used to establish a database of symptoms, which they'll link with clinical information to gain a fuller understanding of how meningiomas impact everyday life.

#### Why is this research important?

Almost a quarter of all primary brain tumours in adults are meningiomas. As many as 90% are considered low grade, but a small subset are high grade. These are referred to as 'clinically aggressive meningiomas', or 'CAMs'. Beyond surgery and radiation therapy, treatment options for CAMs are limited, making it essential to understand the biology of these high grade meningiomas, so we can pick up the pace towards a cure for those affected.

#### Progress so far

Based on preliminary data, the team has built a tool that helps predict the risk of meningioma regrowth after surgery. This means that clinicians know when to give more aggressive treatment, and when the same treatment is likely to do more harm than good. This tool is a great step towards our goal of halving the harm that brain tumours have on quality of life. We're looking forward to seeing what else the team produces in the next three years that can benefit those diagnosed with a meningioma.



**YOUR SIGNATURE IS POWERFUL**

By remembering us in your Will, you'll be putting your name to extraordinary progress. Every gift made, no matter its size, plays a big part in beating brain tumours: [thebraintumourcharity.org/gift-in-will](https://thebraintumourcharity.org/gift-in-will)

# FOUR WAYS BRIAN CAN SUPPORT YOUR MENTAL WELL-BEING

**A brain tumour diagnosis and the treatments that follow not only affect a person's physical health – they can have a dramatic impact on quality of life as a whole, including mental health and psychological well-being.**

As well as accelerating research to find a cure sooner, we're committed to halving the harm brain tumours have on quality of life. That's why we've worked hand-in-hand with people affected by brain tumours to build BRIAN ([askbrian.org.uk](http://askbrian.org.uk)).

BRIAN is our trusted online app that lets you track your experience, compare with others who've been there and get the knowledge you need to make informed decisions. By monitoring your symptoms, medications, moods and more, you can more easily keep on top of things day-to-day, find some clarity in the chaos and feel better prepared.

You can also share your information with anyone you trust, including your medical team, so they can see how you're doing and know how best to support you.

Here, we take a look at the top features in BRIAN that can help you better understand, and take steps to improve, your mental well-being.

## 1. TRACK YOUR QUALITY OF LIFE

BRIAN lets you complete a quality-of-life check-in up to twice a day. This consists of six simple questions, which you can answer in just a few minutes using sliders or by choosing words from a list:

- How do you feel physically?
- How tired do you feel?
- How would you rate your thinking ability?
- How would you rate your memory?
- How are you feeling emotionally?
- Do you have any symptoms?

Over time, these check-ins become a journal of your physical, cognitive (mental) and emotional journey and are plotted on a graph that helps you visualise what you're going through on a daily basis. This lets you see, quickly and easily, how your health and well-being has varied over time.

By tracking your quality of life, you'll be able to see how your treatment could be affecting your physical and mental well-being and where you might be able to make improvements or request support from your medical team.



**“ BRIAN has helped me to keep track of my symptoms and be able to reflect on my fluctuations in health and well-being. Much easier than trying to keep paper notes.**

– Caroline, who's living with a brain tumour



Sabrina, one of our Young Ambassadors, using BRIAN

## 2. LEARN THE POSSIBLE SIDE-EFFECTS OF YOUR MEDICATION

Many medications have side-effects, some of which can affect your mental health. This might be directly – for example, some drugs have been reported to cause feelings of depression in some people. Or it might be indirectly – for example, by causing fatigue, which may in turn cause a low mood.

BRIAN has a tool called 'Medicines search', which allows you to search for the official NHS descriptions of specific medicines and view details of their known side-effects. You could compare these with the side-effects you've recorded as part of your daily quality-of-life tracking and discuss this with your medical team if you think one or more of your medications might be affecting your quality of life.

## 3. COMPLETE QUESTIONNAIRES TO HELP OTHERS

To help us drive progress towards our goal of halving the harm brain tumours have on quality of life, we've included a number of questionnaires for you to fill out in BRIAN.

Your answers will be used to shape our support, improve our services and help other patients. By completing the quality-of-life questionnaires in BRIAN at regular intervals (such as every quarter), you'll be supporting research that aims to better understand and improve the quality of life of people living with a brain tumour.

We periodically add new questionnaires to BRIAN to capture the impact on our community of changes in the healthcare landscape. For example, in March, we added a coronavirus questionnaire to find out how COVID-19 was affecting people with a brain tumour and to help improve our support services.

## 4. SHARE WITH THOSE YOU TRUST

The information you put into BRIAN is personal to you. But you may find it helpful to share what you've been going through with others you trust, to help them understand your experience and know how best to support you. This could be your family, your carer (if you have one) or a member of your medical team, such as your clinical nurse specialist (CNS).

Your medical team may regularly ask you how you've been feeling. This can sometimes be difficult to explain or sum up. But BRIAN allows you to quickly and easily look back at your quality-of-life check-ins and know you haven't missed mentioning anything that's important to you.

You can also invite another user to view your information in BRIAN, meaning your medical team can see your data before you speak to them. You can choose which information you want to share and how long you'd like to share it for.

All of this can help you, your loved ones and your medical team better prepare for discussions about how you've been feeling and see how your brain tumour or its treatments might be affecting your well-being.

BRIAN can benefit you whether you're living with a brain tumour or are supporting someone who is. We're adding new features to BRIAN regularly and your feedback will help us improve it even more. To sign up and get started, simply visit [askbrian.org.uk](http://askbrian.org.uk)



# THE IMPORTANCE OF LIVING IN THE MOMENT



Adam with his family

**Everyone has their own way of looking after their mental health following a brain tumour diagnosis. Here, we find out how Adam Blain became an author to help process the negative feelings surrounding his.**

Six years ago, Adam Blain, a corporate lawyer, began having debilitating headaches and waves of nausea. It soon became clear these were being caused by more than the stress of his job. His wife Lucinda, an oncologist, drove him to A&E at the hospital where she worked, for an urgent scan. She later looked up his results to discover a large tumour inside her husband's brain.

She had to break the devastating news that he had cancer and needed life-saving surgery. Adam had a glioblastoma and was given a prognosis of just 12-18 months. However, nearly six years on, he's defying the odds, and recently celebrated his 50th birthday – a milestone he never thought that he would reach.

"It was just after my diagnosis that my brother celebrated his 50th birthday – I thought to myself that I'd never reach that date, but I did. We had a party at home with all the amazing people who've helped and supported me over the last few years," Adam says.

## HUMOUR AND WRITING

Adam has maintained a consistent outlook on life since that original diagnosis – don't plan or project too far ahead as you never know how long you've got left. His 'seize the day' attitude spurred him on to write his books, *Pear Shaped* and *Grin and Pear it*, which are both available from Amazon.

Adam is well-known for his dark and somewhat perverse sense of humour, which he would showcase in both his professional and personal life through after-dinner speeches. He would make notes for these speeches whenever funny, memorable or relatable moments happened in his daily life.

It was a natural progression, therefore, that Adam also charted his experiences after his diagnosis in a journal. This soon became his debut novel and subsequent follow-up, which were named after his tumour that was the size of a pear.

"I never set out to write a book – it's not something I'd ever given any thought to before my diagnosis. It was simply a result of circumstance. My journal was where I mind-dumped and, with the help of those around me, it was slowly pushed into shape.

"I wanted to make sure that my family would be okay when I died, so writing the book was quite a financially-driven decision at the time. But, since then, it's given me a real lift to share the reality of my experience and also get such positive feedback from others who also have a brain tumour."



Adam and Lucinda

Adam was diagnosed with depression following his diagnosis and prescribed antidepressants. He also saw counsellors and psychologists, but with limited success.

However, he found that journaling his thoughts and reactions to surgery, chemotherapy, radiotherapy and recovery was a cathartic way of looking after his mental health.

"It's a real sadness to receive a terminal diagnosis – no one can deny that. But the traditional methods of managing my mental health didn't work for me. They may for some but, for me, it was just platitude. When you're handed that diagnosis, you don't have any choice but to tackle it head-on. Giving up is not an option, you have to pick yourself up and get on with it. But, I still found comedy in some of the most ridiculous and quirky experiences I never thought I would have.

"I'm quite impressed with how I've dealt with it all. If I'd imagined it before it happened, I wouldn't have expected myself to react the way I did. There's been no self-pity – I've been kicking and fighting it as much as possible."

## A NEW NORMAL

Adam knows he's lucky to be here and see his three children – Thea, 10, Sacha, 15, and Jonah, 18 – grow up, but life has been far from easy. After having to take retirement, Adam was

thrown into a new routine with long days to fill. He found that meditative exercise, walking up to five miles a day, doing the school runs and volunteering at a soup kitchen have kept any feelings of isolation at bay. He also practises martial arts, including Japanese sword fighting and tai chi, which helps with both his balance and memory function.

"One minute, I was at the height of my career and the next being told I only had months to live. I wasn't ready to retire, yet found myself with all this new time on my hands. I soon had anxiety about my future, my family and how to fill my time as I stepped back from my busy career.



The family at Jonah's bar mitzvah

"But, the brain tumour has taught me about the importance of living in the moment. I thought it was game over when I heard that terrible news, but it wasn't. The initial panic of receiving a diagnosis subsides.

"Now, I'm wiser, more in control and accepting of my circumstances. I'd urge others to take their time to adjust as well – it will happen and a new normal will be established."

*Pear Shaped* is available from [www.amazon.co.uk/Pear-Shaped-Funniest-About-Cancer/dp/1511860618](http://www.amazon.co.uk/Pear-Shaped-Funniest-About-Cancer/dp/1511860618).

## ADAM'S TIPS FOR HANDLING A BRAIN TUMOUR DIAGNOSIS:

- 1. Accept help from others.**  
Some people will do all they can to help, from looking after the kids to picking up a pint of milk. Welcome it with open arms.
- 2. Establish a new routine.**  
It can be hard when normality is taken away from you. Find activities within your capabilities, such as volunteering, which take you from receiving help to giving it to others.
- 3. Take your time.**  
A diagnosis can make you feel that precious time is running out. Don't panic – embrace what you do have and make each moment count.

**“When you're handed that diagnosis, you don't have any choice but to tackle it head-on.”**

## WE MUST DO MORE

A monthly gift of £15 could cover the cost of giving seven people and their families immediate support and information after the devastation of a diagnosis. Set up your monthly gift today: [thebraintumourcharity.org/donate](http://thebraintumourcharity.org/donate)



**LIVING WELL  
IN FOCUS**

**Looking after mental health  
and emotional well-being is an  
important part of coping with  
a brain tumour diagnosis.**

# MENTAL HEALTH AND WELL-BEING



# COPING WITH ANXIETY

Whether it's waiting for scan results, changes to treatment due to the coronavirus pandemic, or generally not knowing what the future will hold, living with a brain tumour can be an exceptionally worrying time. We asked an expert for advice on how to cope.



Dr Clare Jacobson

"Everyone will react a bit differently to news of a brain tumour, but there's no right or wrong way – it's about finding a helpful way," says Dr Clare Jacobson, Specialist Clinical Psychologist at Guy's Hospital. "Often, after diagnosis, people go into action mode and focus on what they can do, like starting treatment. But after that, there's an adjustment to living with the effects of the tumour and/or its treatment. That is often when the psychological challenges begin."

## WHAT IS ANXIETY?

Clare describes anxiety as both a useful emotion and a physical experience. "We need to change society's view that anxiety is something awful to get rid of. Without anxiety we wouldn't have survived as cavemen. If our ancestors were confronted with a tiger, their fear response released adrenaline to give a burst of energy to fight or escape (the 'fight or flight' response), enabling survival."

When this response is triggered, blood moves away from our digestive organs and head, causing symptoms such as 'butterflies', nausea or dizziness, and our hearts pump oxygen more

quickly so we're ready to attack or run. But this is less helpful when we can't solve the problem by fighting or fleeing – we can't fight medication or run from the scanner. Without a burst of energy the adrenaline stays in our system, causing the unpleasant sensations we associate with anxiety, such as rapid breathing, pounding heart, shaking, sweating and a general sense of 'impending doom.'

Clare also points out that the location of a brain tumour could itself cause anxiety, if it's in a part of the brain that regulates emotions and arousal. "In this case it's important to understand that anxiety can just be meaningless physical sensations," she says.

"You experience similar sensations if you drink too much coffee or you're out of breath from exercising, but you interpret them within those frameworks, so they don't activate 'worry thoughts' as a result."

## WHEN SHOULD YOU SEEK HELP?

The *Diagnostic and Statistical Manual of Mental Disorders* (fifth edition) classifies anxiety as a set of symptoms experienced for at least two weeks, impairing your functioning in some way – for example, your ability to work, study or manage your house. Clare says most people know when to seek help. "You're the expert on how much distress you're in. You'll know when it's impacting enough on your quality of life to be a significant problem," she says.

"Anxiety can impact your mood, sleep, appetite, relationships, libido – almost every aspect of life.

On top of that, people often judge themselves negatively for experiencing anxiety, and that can activate low mood. These are signs to notice if you think someone may be experiencing anxiety."

To get help, Clare suggests contacting your GP or searching online for Talking Therapies services in your area.

## CAN YOU LEARN TO LIVE WITH ANXIETY?

You may have to accept that there will be times you'll feel anxious, such as waiting for scan results (known as 'scanxiety'). Clare advises, "Don't let the presence of anxiety itself make you believe there must be something wrong. Try to accept anxiety as part of life. Allow it into the room and accept that it'll take up space. Sometimes it'll feel huge and overwhelming and that's okay – it can't stay that big forever. At other times it'll shrink down to the size of a peanut. You're in a relationship with anxiety, it's not a part of you. Think of it as the uninvited party guest who you have to tolerate and try out different ways of relating to.

**“Don't let the presence of anxiety itself make you believe there must be something wrong.”**

We have more information on anxiety at: [thebraintumourcharity.org/feeling-anxious](https://thebraintumourcharity.org/feeling-anxious)

Don't forget you can call our Support and Information Line on **0808 800 0004**, Monday to Friday, or email [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)

## CLARE'S TOP TIPS FOR COPING WITH ANXIETY

If you're feeling overwhelmed, imagine you're a ship in the sea that's caught in an emotion storm. The waves are high and you feel you could drown. You can't stop the storm, but you can focus on keeping steady until it passes. Here are some ways to anchor the ship:

01

### Control your breathing

For five breaths, exhale for two seconds longer than you inhale (time this accurately). This changes carbon dioxide levels in the blood, helps process the adrenaline and has a calming effect. Focusing on your breathing also gives your mind a break from 'worry thoughts'.

02

### Use the 'four, three, two, one' mindfulness technique

Take a breath and notice four things you can see, three things you can hear, two things you can feel and one thing you can smell or taste. Engaging all five senses brings you back into the present moment.

03

### Do what matters to you

It's usually the things that matter to us that cause anxiety to knock on our door. Try to stay connected to the things you value in life. Accept that anxiety will be present, but it doesn't have to get in the way. Do what you love alongside the anxiety, as if it's one side of a coin and all the joyful elements of what you love are on the other.

04

### Change your relationship to anxiety

Create an image of anxiety, or even craft it from play dough, then start a conversation with it. What would anxiety say to you or want you to do or not do? What would you say back? What would your loved one say to it? Creating a conversation develops your relationship with anxiety and can give you more freedom.

05

### Try worry time

Choose a specific time to worry each day, e.g. 6.00-8.00pm. If a worry thought pops into your head, notice it and label it as just that – a worry thought that you'll concentrate on at 6.00pm. Writing down your worries during the time slot can make them feel smaller, reducing their power.



# LOOKING AFTER YOUR WELL-BEING AT HOME

**The impact of a brain tumour diagnosis on mental health and emotional well-being can be significant, but this can be intensified if you need to stay at home, due to the coronavirus pandemic or your treatment.**



## Gardening is a wonderful therapy for both grief and anxiety.

Finding the right coping mechanisms for conditions like anxiety or depression can be key. Seeing friends or family and doing regular outdoor activities or exercise are just some of the things you may have found beneficial in maintaining good mental health. But the coronavirus (COVID-19) pandemic means these activities may not currently be possible.

With many of our community self-isolating or following shielding measures, we asked them what they're currently finding helps them to cope. Here are their top tips...

### 1. Keeping in touch with family and friends

**"The best thing for my mental health was seeing friends and family for lunch or a drink."**  
- Sarah

Even under 'normal' circumstances, people living with a brain tumour can find themselves feeling lonely or isolated. Being able to meet loved ones for face-to-face support – and a hug – can really help. But if you're self-isolating or shielding during the coronavirus pandemic, or due to treatment such as radiotherapy, this isn't an option.

Keeping in touch with family and friends virtually – by phone, social media or video calls – helps many cope. Organising a weekly virtual quiz can be a fun way to regularly connect.

And you may find chatting safely online can also be a real comfort.

Visit our website to find out how you can connect with others who understand, in our safe and welcoming spaces: [thebraintumourcharity.org/facebook-support-groups](https://thebraintumourcharity.org/facebook-support-groups)

### 2. Being active

**"My daily walk in nature, while listening to some great tunes, has helped me to get through lockdown and remain positive, even though my life is in complete turmoil."**  
- Kerry

Gentle, frequent exercise is known to help relieve stress and improve mood. So, if you're able to leave your home to exercise, the benefit of a walk outdoors can't be underestimated.

**"I started yoga last year – the teacher is lovely and managing to do this online at the moment. I find it so relaxing. It definitely helps me totally turn off for an hour."**  
- Micky

Online fitness classes are proving a real hit at the moment. For those who are unable to exercise outside, it's a good way to feel connected if you'd normally go to a class. Remember, though, if you're not used to exercising it's important to start slowly and to speak to your consultant or GP.

Visit the NHS website for ideas on exercises you can do at home: [nhs.uk/live-well/exercise/free-fitness-ideas](https://nhs.uk/live-well/exercise/free-fitness-ideas)

Find out more about the benefit of doing regular exercise at: [thebraintumourcharity.org/benefits-of-exercise](https://thebraintumourcharity.org/benefits-of-exercise)

### 3. Gardening in your green space

**"I spent a lot of time in the garden when my husband died of a GBM4 last year and found it very soothing. Gardening is a wonderful therapy for both grief and anxiety."**  
- Wendy

Whether your outdoor space is a balcony or you have your own garden, growing fruit and veg or tending flowers and shrubs can be calming, therapeutic and a chance to enjoy nature through the seasons. Creating your own garden show of vibrant, colourful blooms or cooking up your home-grown veg can give a real sense of achievement and satisfaction.

There are lots of online resources for inspiration, as well as how-to guides. Visit the Royal Horticultural Society website for ideas – even if you're a beginner: [rhs.org.uk](https://rhs.org.uk)

### 4. Spending time in the kitchen

**"Cooking has helped me a lot."**  
- Mary

Cooking and baking can also bring a real sense of achievement, and a chance to be creative as you try out recipes. Spending time online or looking at cookery books to plan your next culinary adventure can help focus your attention away from the anxiety, low mood or stress you may be feeling.

If you enjoy cooking, now is a good opportunity to try something new – like baking, or making jam or chutney. Cookery programmes can also be a great source of inspiration.

### 5. Hobbies can help

**"Playing my guitar, and music in general, helps me every single day. Listening to music takes me to another place where all my problems are put aside."**  
- Shane

Learning a new skill, taking up new hobbies or spending more time on old ones can be a really good way of taking your mind off your worries and lifting mood. Getting absorbed in drawing or painting, playing or listening to music, learning a new language, sewing

or reading can help shift your focus. There's plenty of ideas online – including courses and video guides.

For some, a trip to an art gallery, the theatre or seeing a film is something to look forward to. Since lockdown, virtual tours of art galleries, free-to-watch plays and musicals, and even virtual walks around gardens, such as the Royal Botanic Gardens, Kew, have sprung up online.

Podcasts, too, have really taken off in the last few years and with so many available, there's bound to be something that interests you.

If you're new to podcasts, BBC Sounds is a good place to start: [bbc.co.uk/sounds](https://bbc.co.uk/sounds)

### Other sources of support

BRIAN, our trusted online app, can help you track your well-being. See pages 14-15 to find out more and sign up at [askbrian.org.uk](https://askbrian.org.uk)

We have information about mental health and brain tumours on our website at: [thebraintumourcharity.org/mental-health](https://thebraintumourcharity.org/mental-health)

You can find up-to-date advice for coping with self-isolation on our coronavirus hub: [thebraintumourcharity.org/covid-19](https://thebraintumourcharity.org/covid-19)

Don't forget you can call our free Support and Information Line on **0808 800 0004** or email [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)

You can find apps to help with mental health on the NHS App Library: [nhs.uk/apps-library](https://nhs.uk/apps-library)

Using apps doesn't help everyone, but may be worth a try. However, we don't endorse or recommend any specific mental health apps.



# COPING WITH FEELINGS OF ISOLATION AFTER DIAGNOSIS

Being diagnosed with a brain tumour can be a lonely experience. Three of our supporters described the isolation they felt and the ways that helped them overcome it.



“Reconnecting with my friends... showed me the value in having a few people to turn to.

SAY YES TO MOST THINGS

Scott Butterfield

“Following my diagnosis with a brain tumour in September 2016, I became very frightened. My son was only 10 months old and there were issues with my relationship with my wife. The diagnosis took me to a fearful and dark place - I became isolated and alone. I wanted reassurance and support. I wanted my wife to understand what I was going through, but I felt she wasn’t able to do that - for her own reasons.

Eventually, we separated and she took our son and moved to her parents’ house. After a while, we started marriage counselling, but this was put on pause while I was in hospital having my tumour debulked and then rehabilitating.

We later completed the counselling and reconciled, going on to have our second child - a daughter, but things didn’t work out and we divorced last year. I’m now single and live alone, with the children staying with me a couple of times a week.

What helped me to feel less isolated was reconnecting with my friends following the separation and divorce. It showed me the value in having a few people to turn to. Genuine friends are concerned and just want to help. So reaching out to friends and loved ones is what I’d recommend to someone going through a similar experience. Also try to say yes to most things, even if you might not feel up to doing something. Saying yes to a meal or trip out, if circumstances allow, or even just a phone call, will more often than not lift the spirits.

It’s also worth considering that not everyone knows the right things to say to you. So being honest with them about how you feel will help people communicate with you better. Even if it’s things that you wouldn’t normally say, like if you’re feeling scared, worried or sad.”



“We’ve all been there, so it’s reassuring to know you’re not alone.

JOIN AN ONLINE SUPPORT GROUP

Amy Sellers

“After I was diagnosed with a grade 2 oligodendroglioma, I had a lot of dark and lonely thoughts about whether I was going to die. In fact, it was one of the first questions I asked my doctor. I hadn’t had any symptoms at all, so I was totally unprepared for what was happening to me.

I’m typically a glass-half-full type of person so I wanted to find out more information to help maintain a positive outlook. I searched online and found The Brain Tumour Charity, particularly their closed Facebook groups. They’re great for linking up people of a similar age who are also affected in some way by a brain tumour. It’s also an ideal way to be in touch with others when, like me, you’re unable to drive after having surgery and isolation could hit you.

I’ll read other people’s stories, their pleas for advice or rants about having a bad day. We’ve all been there, so it’s reassuring to know you’re not alone. There are also people there to help answer your queries if you’re feeling or noticing something on a particular day. There’s never a stupid question and there’s a whole online community

there for you no matter how random or small your concern may seem. For example, I had a phobia about choking so taking my medication was scary. Someone in the Facebook group recommended a mindfulness app which helped me to overcome it through some distraction techniques. It changed a lot.

After surgery, my body felt battered and bruised. I needed rest. Although it’s important to listen to your body, I got dressed and went outside if I had the energy. Even just a walk around the block helps. Actively doing something meant I slept better, had more appetite and kept in a good routine.”



“Recognise when you need support or someone to talk to.

TALKING REALLY HELPS

Chandos Green

“Being a young person and finding your place in the world today is hard enough, never mind when you’re a teenager with a brain tumour. I felt so lonely and isolated because there was no one else like me. People told me that I was different because of my diagnosis and I believed them.

I felt that I couldn’t be like anyone else or do anything everyone else was doing. I didn’t want to prove people right by failing so I’d stop myself from

doing things, whether that was seeing my friends or studying for my degree. That’s no way to live. So, I surrounded myself with close friends and family who challenged me to step outside of my comfort zone and get back out there and also to do things more spontaneously. I pushed myself to open up and reach out to others when I was feeling scared or isolated, which I found incredibly hard to do. But, talking really does help.

Everyone works differently so, if you find yourself feeling isolated, come up with a system that works for you to recognise when you need a little support or someone to talk to. This could be as simple as just going for a short walk or writing down the signs of when you’re struggling and sharing it with someone who can then look out for you.

I also found one or two people who I knew I could always turn to. I got in touch with The Brain Tumour Charity’s young adults team. I also became a Young Ambassador for The Charity and a mentor. Here, I found a community of people who know what it’s like to feel alone, as well as how to overcome it and it’s really made the world of difference.”

CONNECT WITH OTHERS

Visit [thebraintumourcharity.org/get-support](https://thebraintumourcharity.org/get-support) to learn how we can help connect you to others affected by a brain tumour:

- chat to others and share experiences on our online support communities
- connect with others aged 16-30 through our Young Adults Service
- visit our relationships hub if your relationship has been affected by a diagnosis.

You can also call our Support and Information Line on **0808 800 0004**, Monday to Friday, or email [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)



# 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.**



## HOW CAN WE SUPPORT THE MENTAL HEALTH, LATER IN LIFE, OF THOSE WHO'VE HAD A BRAIN TUMOUR?

Dr Selina M Makin, Clinical Neuropsychologist, Salford Royal NHS Foundation Trust

Mental health is an important part of well-being and quality of life. When you first receive a diagnosis, there's a focus on treatment and it may not be until later down the line that you think about mental health and the impact of the diagnosis, treatment and secondary effects of the tumour. Then it might feel like others are less aware of your tumour and its impact on you.

The first step is recognising that you're having a difficult time and feeling ready to make a change. There is support available and it's important for you to access this if you need it, regardless of how long it's been since your diagnosis.

To start with, you may consider taking time away from your thoughts if they feel overwhelming – with mindfulness.

Although fatigue and motivation can be difficult to manage; if you can, try something different – like a new activity at home or with a group.

Reach out to talk to, or be, with others. It can help to talk to someone close to

you about how you're feeling. The specialist nurse at the NHS Trust where you received treatment, your consultant or your GP could direct you to services or refer you to a clinical neuropsychologist or therapy service.

Many find the support they need via charity websites, such as The Brain Tumour Charity, where you can find information about online support communities or local support groups.

If you feel life isn't worth living, and it feels urgent, call 999 or contact your GP for immediate help. Your GP can direct you to a Crisis Team and give ongoing support. Or call the Samaritans free on 116 123 any time, any day.

## WHAT EMPLOYMENT SUPPORT IS THERE FOR UNEMPLOYED PEOPLE WITH A BRAIN TUMOUR?

Denise Fairbrother, Financial Inclusion Project Worker, Citizens Advice, Rushmoor

If you have a brain tumour (low or high grade), help for disabled people will often apply to you, even though you may not see yourself that way. For workers or jobseekers, there are a number of schemes specifically aimed at helping people with disabilities or health conditions find or return to work.

These include the Access to Work Scheme, available across the UK, and voluntary, government-supported schemes, available in the individual nations. For example, the Work and Health Programme (England and Wales), Work First Scotland and Work Able Scotland, and Workable (NI).

Access to Work provides financial help with some of the additional costs of adaptations and equipment or travel for people unable to use public transport. The voluntary programmes support you into work and help you stay in work. They help with identifying your skills and suitable jobs, interview practice, support and awareness training for employers, training needs and workplace adjustments.

Every Jobcentre Plus office (or Jobs and Benefits Office in NI) has a specialist adviser for people with disabilities and for employers, who can advise on the various schemes and how to access them. Find out more on Gov.uk or nidirect.

If you're having money worries or would like advice, why not book an appointment with our Benefits and Money Clinic? Find out more at [thebraintumourcharity.org/benefits-clinic](https://thebraintumourcharity.org/benefits-clinic)

## WHAT EVIDENCE SUPPORTS THE KETOGENIC DIET AND INTERMITTENT FASTING FOR THOSE WITH BRAIN TUMOURS?

Louise Henry, Senior Specialist Dietitian, Royal Marsden Hospital

Ketogenic diets (KD) are very low carbohydrate (low sugar/starch) diets, usually with restricted protein, but very high levels of fat. It was developed following observations that starved epilepsy patients, particularly children, had fewer seizures. When people starve/fast, blood sugar levels drop, depriving cells of their energy source. So the body produces ketone bodies (small chemicals derived from fat) that most cells can use for energy instead. The KD mimics this starvation, but without fasting.

Some scientists have promoted the theoretical benefit of KD/intermittent fasting in managing brain tumours because some tumour cells struggle with ketone bodies, preferring glucose for energy. So a low-carb KD could theoretically starve the tumour cells, while normal cells survive.

However, some tumour cells can process ketone bodies, so aren't starved, and many non-tumour cells could struggle to process ketone bodies, so are starved.

Also, there's little supportive clinical evidence. Most research is laboratory-based and uses cells or mice. Any human studies are poor quality and often don't look at the effect on tumour growth.

We don't know if there's harm in following a KD. It could promote brain tumour cells that can process ketone bodies, as well as tumour cell activity elsewhere in the body. Or it may promote health problems linked to a high-fat diet.

Following a KD is difficult and will often need support from family and friends. It can be expensive, nutritionally unbalanced, and cause side-effects, from constipation to potential liver or kidney problems.

So NICE (National Institute for Health and Care Excellence) and most cancer specialists advise that evidence doesn't support using KD for treatment of brain tumours. If you still wish to follow a KD, only do so under the supervision of your doctor and a trained dietitian, to make sure your diet is safe, pleasant to eat and provides all required nutrients.

## SEND IN YOUR QUESTIONS

Do you have a question? Send it to us via email: [comms@thebraintumourcharity.org](mailto: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.



# TO MYSELF BEFORE THE DIAGNOSIS



Dear Julie,

Life is good. You have no idea what's going on inside Billie-Rae's head – why would you? She had no symptoms. It will only be when she bumps her head at her flat that a scan will reveal the brain tumour, which will become known as Fifi, on a dark day in October 2014 when Billie-Rae is 22 years old.

You won't know how to handle the news. Who really knows how to sit with their child and hear that there's something menacing in their brain? Feelings of despair and panic will set in that may never fully leave.

You'll know that you have to do something rather than nothing. As a mother, you'll want to protect Billie-Rae and try to fix it all for her. Brain tumours are cruel, but that won't

mean you can't do anything at all to help. As you process your own gut-wrenching pain, you'll become a mother on a mission.

You'll make sure that Billie-Rae has everything she needs – toiletries, comfortable clothes, new bedding, new anything which could help her through the surgery and recovery which was to come. You'll know that you have to keep your mind busy to cope with worry and stress when neither of you can think straight.

When it comes to brain tumours, no-one will have all of the answers. But any information is better than none – a battle plan isn't possible unless you know what you're dealing with. So, turning to The Brain Tumour Charity for help, support and advice will make perfect sense for you and Billie-Rae.

You'll realise it's vital to look after both physical and mental health following a diagnosis. When navigating this alien world, dark thoughts and real fears will crop up. Yet, trained professionals, counsellors and the amazing support team at The Charity will be a lifeline for you and Billie-Rae. Reaching out for help will be good, healthy and positive.

The Charity's event The Twilight Walk will become a means of looking after your health too. It's one of the only ways in which you know that you can do something to help. You can't stop Fifi or the pain that Billie-Rae is in, which is agonising as a mother. So, you'll walk. Putting one foot in front of the other will be your way of taking control. They will be small but mighty steps on the right path to change, to find a cure for this horrific disease and to help other families like yours.



The first time you take part in The Twilight Walk will be in 2015 and you'll vow to complete it every year until Billie-Rae reaches her 10-year all-clear date. You'll find that there's something so powerful about the simplicity of that walk. It's 10K, so it's not tramping through the wilds and it can even be a gentle stroll if you want it to be. But it's an army all going in one direction for a single cause.

The walkers will all be bonded by shared experiences and stories that nobody else could possibly understand. You'll walk, you'll talk and you'll harness a sense of belonging. You'll all be connected by the brutal reality of brain tumours. You didn't choose to have that connection, but it will be there as soon as you put that red t-shirt on.



You may turn up on your own, but no-one crosses that finishing line solo. New, but lifelong friends, like Bridget, will ensure you'll all get through it together, because not finishing is not an option. People you've met on social media will become your walking buddies and help to get you through. Just dress warmly and comfortably and enjoy being cheered along every step of the way.

You'll cry at the end. You'll find a quiet spot, such as in your car or the hotel room, and sob like a child. The relief that it's done and the release of emotions including pride, fulfilment and empowerment will hit you. But, it's also okay to not be okay, so succumb to negative feelings too and embrace all aspects of the experience.

No mother should have to walk the same walk as you. No mother should have to sit in a day room while the doctors delve into their child's head. Even six years on from that original

diagnosis, things will be difficult and, at times, unbearable. You'll only find peace when Billie-Rae is given that all-clear sign-off and the scans, followed by the terrible waits for results, are over.

Until that day, smile. Accept help from friends, family and The Brain Tumour Charity. Laugh at the crazy times that still happen. Beam at Billie-Rae's beautiful, happy face and the kick-ass attitude she has. One day she'll say, "Brain tumour? Yeah, I had one of those. She was called Fifi and I didn't like her much – and I still don't like the name." Yes, she's a fighter – she's her momma's girl all right.

Love Julie

Register your interest to be one of the first to receive updates on The Twilight Walk by visiting: [thebraintumourcharity.org/thetwilightwalk](http://thebraintumourcharity.org/thetwilightwalk)



## 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](http://thebraintumourcharity.org/share)



# YOUR LETTERS



My brother, James Waring, passed away just over seven years ago from a brain tumour. Over the past six years, my mum has been raising money for your charity.

The main fundraising is through a summer produce sale in her garden in Shaldon, Devon, and she has raised almost £10,000 so far. I've attached a photo of the latest event.

**Tim Waring**  
Pictured: Tim's mum's produce sale



Thank you for the most incredible, informative lab tour. The technology is way beyond anything we did at medical school in my day, so meeting the team was incredible.

I found meeting other supporters and hearing their stories so helpful, and I came home even more determined to help and support others living with this horrendous cancer.

The day was surprisingly therapeutic, which was encouraging and a tiny step forward in my long journey to finding peace.

**Debi**  
Pictured: Supporters on our lab tour in February



We got the devastating news recently that my four-year-old son Carson has an aggressive brain tumour and is now facing a long, aggressive treatment to cure him.

The Brainy Bag we received was so nice and brought a huge smile to my son's face, and the hand-written note really meant a lot.

Thank you very much.  
**Mark**  
Pictured: One of our Brainy Bags



I just wanted to inform you that I took part in The Big Bake and have donated the money that I raised. I was diagnosed with a benign brain tumour at the end of September 2018 and went on to have it partially removed in June 2019. The diagnosis turned my life upside down. I knew nothing about brain tumours and I really welcomed the information provided by your charity.

I feel very fortunate to be in the position that I am in and wanted to say thank you for your support by supporting you and taking part in The Big Bake. I aim to support The Charity as much as I can in the future.

**Sharon**  
Pictured: Sharon

# KEY DATES OUR EVENTS AND MEET UPS

**We know that in these uncertain times, many events are being postponed or cancelled. Below, we've included the new dates of postponed events where these are known.**

However your event has been affected, we're here to support you in your efforts and answer your questions – you can get in touch by emailing [events@thebraintumourcharity.org](mailto:events@thebraintumourcharity.org) or calling **01252 237867**.

## FAMILY DAYS AND YOUNG ADULT MEET UPS

Due to the current situation, we're reviewing our upcoming Family Days and Young Adult Meet Ups. For the latest, please visit: [thebraintumourcharity.org/get-support](https://thebraintumourcharity.org/get-support)

But we still want to give you the chance to get to know new people and share your experiences, so we've introduced online meet ups – a brilliant way to connect with others who understand, wherever you are. For details and dates, visit: [thebraintumourcharity.org/online-meet-ups](https://thebraintumourcharity.org/online-meet-ups)

We also run a number of Facebook Support Groups, where you'll find a welcoming community of people who've been there and understand how you feel. For more information and to request to join, visit: [thebraintumourcharity.org/facebook-support-groups](https://thebraintumourcharity.org/facebook-support-groups)

## SEPTEMBER 2020

<b>Saturday 5</b>	Snowdon by Night
<b>Saturday 5 to Sunday 6</b>	Edinburgh Marathon Festival
<b>Saturday 12 to Sunday 13</b>	Thames Path Challenge
<b>Sunday 13</b>	London to Brighton Cycle
<b>Sunday 13</b>	Great North Run
<b>Saturday 19</b>	Marathon Walk London
<b>Sunday 20</b>	Brighton Marathon

## OCTOBER 2020

<b>Sunday 4</b>	Virgin Money London Marathon
<b>Sunday 4</b>	Cardiff Half Marathon
<b>Sunday 11</b>	Greater Manchester Marathon
<b>Sunday 11</b>	Royal Parks Half Marathon
<b>Sunday 18</b>	Paris Marathon

## FEBRUARY 2021

<b>Saturday 27 February to Saturday 6 March</b>	Sahara Trek
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## TBC

<b>Dates to be confirmed</b>	The Twilight Walk
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To find out more about any of these events, visit our website: [thebraintumourcharity.org](https://thebraintumourcharity.org)



WE MUST  
DO MORE,  
A CURE  
CAN'T WAIT!

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

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

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