

THE GREY MATTERS

ISSUE 24 WINTER 2020

THE
BRAIN
TUMOUR
CHARITY

Artificial intelligence
and brain tumours

Baron Armah-
Kwantreng on
recovery

Coping with change
and uncertainty



HELLO

Welcome to issue 24 of *The Grey Matters*.

It's certainly been a challenging year for us all. From lockdown and shielding, to the new normal of masks and social distancing, it feels like we've had to get used to a new world – one that's constantly changing. The last six months have been especially challenging for our community, many of whom will have faced the additional upheavals of delayed or cancelled appointments and treatments. So, in this issue, we've focused on coping with change and uncertainty, making decisions and plans when you don't know what the future holds, and how to move forward positively from difficult times. We've interviewed a number of people affected by a brain tumour and have included a wealth of information and advice. We hope you enjoy reading it.

Many of us have had to get to grips with new technologies to stay in touch with family and friends this year – and technology is also the theme of our research section. We're shining a light on the use of artificial intelligence (AI) to combat brain tumours, which scientists are using to give deeper insights into understanding the disease.

Throughout the coronavirus crisis, we haven't faltered in our commitments to double survival and halve the harm brain tumours have on quality of life. It's thanks to your support through your regular gift, and the support of others like you, that we've been able to announce a new £4.8 million investment in high-quality, world-class research, as well as evolve our one-to-one and peer support services to meet the understandable increase in questions and requests for help at this challenging time. I'd like to extend my warmest thanks to you for helping us do this.

If you're looking for a way to support us over the holiday season, why not choose your cards and gifts from the beautiful selection in our 2020 Christmas Catalogue? We've enclosed a copy, or you can order online at thebraintumourcharity.org/shop. If you're after a special gift for a loved one this year, do consider a Gift of Hope. Your gift could fund vital support or pioneering research and make a truly life-changing present. See page seven of the catalogue for details.

All that remains is for me to assure you that, in an environment of ongoing change, our focus on brain tumours will be unwavering. With you standing with us, we know we can be the generation to defeat this disease.

Thank you,

Sarah Lindsell
CEO



For every pound we spend, at least 80p will go towards 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:

Online: thebraintumourcharity.org/donate

Phone: 01252 237792

Post: The Brain Tumour Charity,
Fleet 27, Rye Close,
Fleet, Hampshire GU51 2UH.

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JOINING FORCES TO DO MORE

In the summer, we were honoured to announce our merger with Meningioma UK, founded in 1998 by Ella Pybus and Dr Caroline Rutgers, both of whom had been diagnosed with a meningioma,

Meningioma UK offered support and information to people affected by this prevalent type of brain tumour. Of the merger, Ella Pybus said: “Our community was always at the heart of this decision. Together, with unified resource and vision, we will be able

to support more of, and do more for, the thousands of families whose lives are shattered by a meningioma diagnosis. This merger will build on the successes of the two charities and create a stronger, more powerful voice for change in the future.”

The Brain Tumour Charity – created in 2013 – was itself born out of a merger between three organisations. Sarah Lindsell, our Chief Executive, said: “Joining forces will enable us to work more effectively for everyone affected by a meningioma and to accelerate progress towards the cure that is needed so urgently.”

Our high-profile supporter, TV and radio presenter Nicki Chapman (pictured), who was diagnosed with a meningioma in 2019, said: “These two charities have done tremendous work over the years, coming together will enable them to help and support people like you, me and our dearest friends and family which we all know makes such a difference.”

Find out more about the merger by visiting: thebraintumourcharity.org/merger

SURVEYS LAUNCHED TO IMPROVE BRAIN TUMOUR CARE

We’re passionate about ensuring that everyone affected by a brain tumour diagnosis has access to the best treatment and care. To achieve this, we need to firstly understand the differences in experiences across the UK, so that we can help raise standards and support those affected by a brain tumour to make informed decisions about treatment and care.

To do this, we’ve created Improving Brain Tumour Care Surveys, which focus on different elements of brain tumour treatment and care across the UK. There are seven surveys in total asking about respondents’ experiences, including pre-diagnosis, diagnosis, surgery, radiotherapy and chemotherapy, living with a brain tumour, palliative and end of life care, and caring for a loved one.

This will help give us a clearer picture of what’s happening across the UK: what’s working well and what can be improved. We’ll then work with healthcare centres to raise standards and improve outcomes for those affected by a brain tumour.

By sharing your experiences, you’ll be helping to create change. Fill in the surveys at: thebraintumourcharity.org/care-surveys



T-SHIRT RANGE SUPPORTS OUR COMMUNITY’S GREAT MINDS

The Brain Tumour Charity has launched its first range of t-shirts, in partnership with ethical and sustainable clothing brand Teemill.

The Great Minds theme was chosen by our Young Ambassadors, who are living with a brain tumour themselves or have lost a loved one to the disease. The campaign celebrates all the formidable minds in our community striving for change: those affected by brain tumours, our dedicated supporters, and those working hard to find a cure. And we also hope that by wearing our Great Minds t-shirts, it will help our community start a conversation about brain tumour symptoms and the importance of having these checked out by a doctor if people have any concerns.

There are five eye-catching designs exclusively available on a range of t-shirts for men, women and children, with 50% of the profits of each sale being donated to The Brain Tumour Charity. The money raised from every item sold will help fund our pivotal work to support people affected by a brain tumour, and help us drive forward progress and invest in the great minds doing research worldwide.

Buy your t-shirt at: thebraintumourcharityfashion.co.uk



THE TWILIGHT WALK GOES VIRTUAL

We know how much The Twilight Walk means to our community, in celebrating loved ones, and raising awareness and money to help accelerate a cure.

Although we can’t come together in person this year, we couldn’t let October pass by without uniting as a community for The Twilight Walk in some shape or form. So we’re taking it in a virtual direction.

Join us online and walk somewhere that’s special to you. You can walk anywhere, any time throughout the month to your chosen goal – raising vital funds as you go. You can opt for our traditional 10km, or go further with more challenging distances of 50km or 100km.

Whether you tackle a long hike with others or spread your challenge over a number of walks, you can take part however works best for you. Log your progress to help you and your loved ones stay motivated throughout the month. You’ll also be able to add a new medal to your collection at the end!

Unite with us virtually throughout October and join hundreds of others in our community to do The Twilight Walk your way, all while raising more for a cure.

Sign up at: www.thetwilightwalk.com

BLOOD TEST COULD HELP ACCELERATE BRAIN TUMOUR DIAGNOSIS

A simple blood test, developed by researchers at the University of Edinburgh, the University of Strathclyde and Clinspec Diagnostics, which can detect the presence of a brain tumour, could prove to be a vital tool in accelerating diagnosis.

Cheap, easily accessible and non-invasive, this blood test has a high success rate in detection, and could become the first step to diagnosis. Initially, this would be used with adult patients. People who test positive following the blood test could then be referred for an MRI scan to investigate further.

In partnership with Dr Paul Brennan, Senior Clinical Lecturer and Honorary Consultant Neurosurgeon at the University of Edinburgh, we’re calling on the Scottish Government to roll out this blood test, which could transform the way in which brain tumours are detected for people living in Scotland – and, looking to the future, across the UK as a whole.

Sarah Lindsell, our Chief Executive, said: “Brain tumours are notoriously difficult to diagnose. Fast and effective diagnosis is absolutely essential in order to reduce the devastating impact brain tumours can have.

“That’s why this blood test is absolutely crucial to provide the shake-up to brain tumour diagnosis which is so desperately needed. We will do whatever is possible to encourage the introduction of this blood test at a primary care level in Scotland – and then throughout the rest of the UK in the future too.”

You can find out more by visiting: thebraintumourcharity.org/blood-test-diagnosis

Researchers are using artificial intelligence to analyse data in more detail than humans can. This will help give deeper insights into understanding brain tumours.

ARTIFICIAL INTELLIGENCE AND BRAIN TUMOURS

WHAT IS ARTIFICIAL INTELLIGENCE (AI)?

AI has been around since the 1950s, when people first started to make computer algorithms that were considered intelligent, i.e. that could play checkers or chess. This was the first time that a computer demonstrated some of the skills we thought only humans had, such as planning, learning and decision-making.

HOW CAN AI HELP TO ADVANCE RESEARCH INTO BRAIN TUMOURS?

One of the key things driving the development of AI for research into brain tumours is the availability of increasingly large and complex data sets. This advance in data can be demonstrated by some of the brain tumour diagnoses that are common among our community. What was previously known only as a 'brain tumour' may now be categorised as a medulloblastoma or a glioblastoma. Further tests may then identify the medulloblastoma as being driven by the SHH gene and the glioblastoma as having an MGMT methylation biomarker.

If you then add in any other biomarker information, drug responses and different treatment options used, you can see how the data available for just one person's tumour can add up.

With over 130 different types of brain tumour, the potential for data collection becomes immense – more than any research group could efficiently analyse. This is where the complex analyses of powerful computing systems come into their own.

Different areas of AI have emerged, with the 1980s debut of machine learning (ML) being a key development. A further subset of this called deep learning (DL), recognised from about 2010, is also proving beneficial.

Our new BRIAN mobile app (launching later this year) will use machine learning to help users understand trends in data that could help them manage their treatment and care.

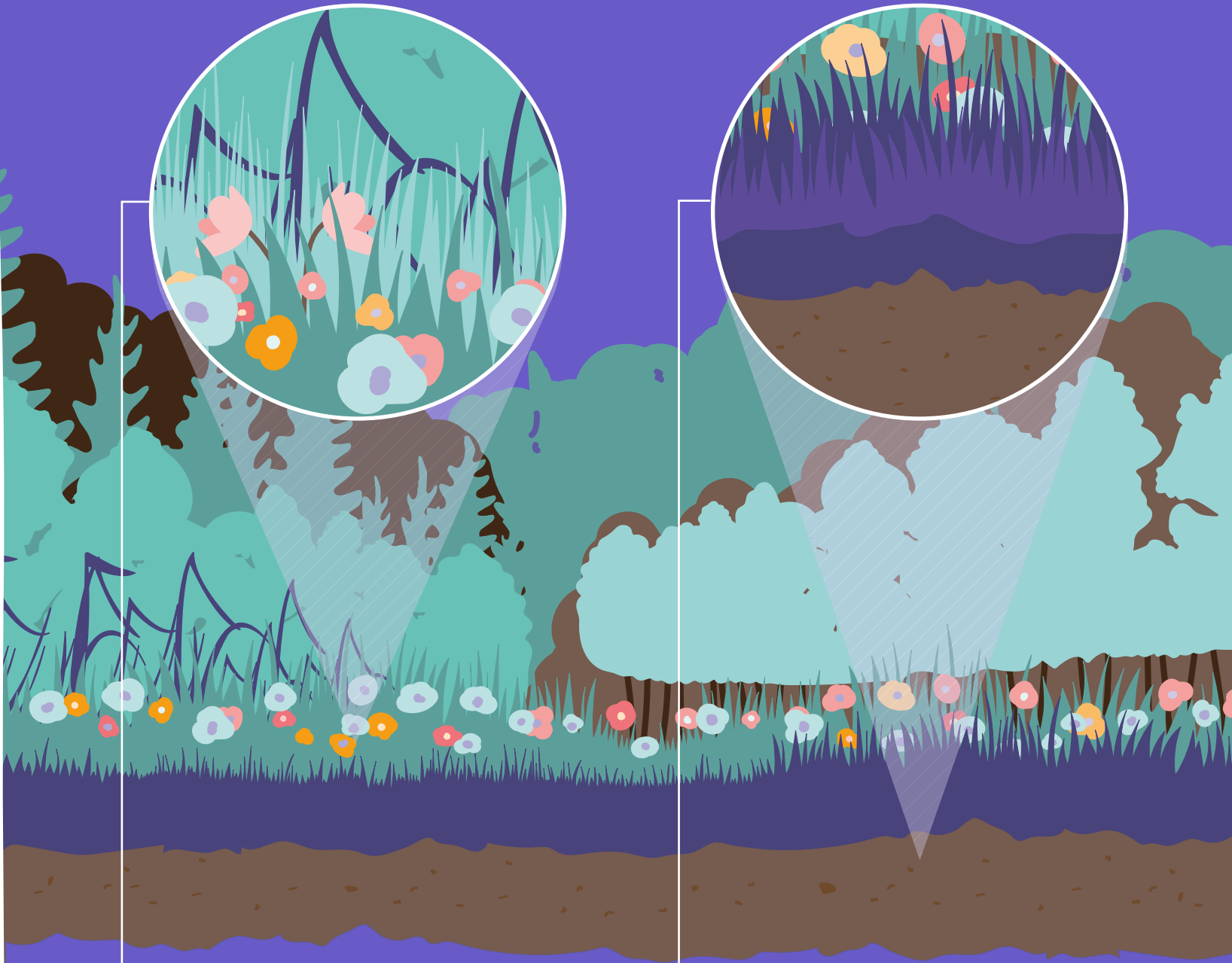
“ The specific type of brain tumour dictates the treatment that someone will receive, so the diagnostic tool that we’re developing, with the use of AI, will ensure that doctors know which treatment is best for an individual and their tumour.

- Dr Phedias Diamandis

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

To use an analogy, in a woodland, AI would be able to describe all the trees, flowers and wildlife, what they need to grow and how they can be used. It could even suggest which flowers would grow best there or how to grow a brand new type of plant.



Machine learning is like focussing in on only the flora in our woodland, with a specific question, and letting the algorithm discover things we don't know yet.

Instead of limiting the algorithm to just looking at the pine tree and the bramble flower, deep learning could add information about soil type, rainfall and density of planting.

MACHINE LEARNING

Machine Learning (ML) focuses on the ability of an algorithm to learn, or in other words to do something that it wasn't specifically told to do. This is like focusing in on only the flora in our woodland, with a specific question, and letting the algorithm discover things we don't know yet.

Simpler, non-AI computer programs can be used to do the same things that a skilled researcher can do, just much faster. ML develops past this – a researcher will teach the algorithm using a small amount of data, i.e. 'this is a pine tree', 'this is a bramble flower', 'this is a rhododendron'. After this initial teaching period, the computer should be able to recognise different types of trees or flowers, as long as they were in the teaching set of data. It might tell us that pine trees and bramble flowers always grow together. But it goes further than this. Once the computer has learned this, we can ask, 'Now, what other patterns can you see?' And the algorithm will highlight patterns that we hadn't recognised – maybe the bramble flowers always grow to the east of the pine trees.

Now put this in the context of brain tumours. The algorithm can be taught: this is a glioblastoma, but this is a medulloblastoma. To date, this type of research is being trialled for things like analysing pictures of microscope slides to make a diagnosis. But in the future, we would learn other things from the algorithm that we couldn't see with our naked eyes, advancing tomorrow's diagnostics for the individual.

When we can add lots more linked information, for example how the pictured tumour responded to treatment, which biomarkers were present in it and how the treatment affected aspects

of quality of life, we get enough data to start using deep learning algorithms.

DEEP LEARNING

Deep learning (DL) takes the pattern discovery in ML to another level and uses much more data. Instead of limiting the algorithm to just looking at the pine tree and the bramble flower, we could add information about soil type, rainfall and density of planting.

Let's bring it back to brain tumours again. By entering all the microscope pictures, biomarker data, brain scans and drug responses from lots of different people, researchers can learn more about brain tumours as a whole, i.e. 'Which kinds of tumours have a good response to drug X?' Or, more broadly, 'What patterns can you find?' And it's these types of questions that will drive future research questions.

CONVOLUTIONAL NEURAL NETWORKS

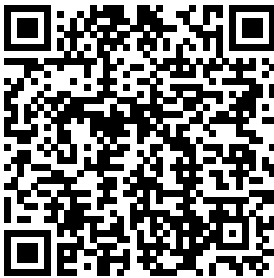
Another term you may see in our research projects is a type of deep learning called convolutional neural networks (CNN). In essence, this is how a computer tries to mimic, or improve upon, how our brains see images.

When we look at an object, say a flower, we can recognise that it's a flower, not a bicycle, based on different attributes like size, colour, the way the petals curve and the way the petals sit next to each other. CNNs take an image, then test all these attributes, and link them, to answer the question: 'Is this likely to be a picture of a flower?' In practice, it's how Google does an image search and Facebook does something similar using facial recognition to suggest who to tag in a photo.

The intelligent aspect will then be able to find other objects that we don't yet recognise as a 'flower' and highlight them.

This would be a great tool for pathologists aiming to diagnose brain tumours more accurately. Just imagine if you could get molecular information about a tumour just by analysing an image of it. This could potentially save weeks of waiting for results, as well as costs to our stretched healthcare system.

So how are we funding researchers to bring this advancing computer power to tackle brain tumours? Read on for some examples.



We're pushing the boundaries of research to help drive change more quickly.

Scan the QR code above (this may work automatically from your phone's camera setting or you may need to download a QR code scanner app) to help us continue to fund groundbreaking new research techniques like those featured on the page opposite.

A cure can't wait.

AI RESEARCH GRANTS



USING MACHINE LEARNING TO SPEED UP DRUG DISCOVERY

Professors Steve Pollard, Margaret Frame and Neil Carragher from the University of Edinburgh are teaming up to use machine learning against glioblastomas, by finding the best candidate chemicals to develop into treatments.

In a previous study, Professor Carragher dyed two different components of glioma stem cells and saw how they changed when a protein implicated in glioma progression (SOX2) was blocked by specific drugs. Glioma stem cells were then treated with 1,280 different drugs or chemicals. Machine learning was used to find ones that looked the same as the cells with inhibited SOX2 and others which made the cells look different again. These may therefore work well with their SOX2 blocker and were prioritised for further research.

As part of our large Brain Tumour Award, with Cancer Research UK, the researchers will use surgical samples from glioblastomas to expand the number of features they identify into thousands. This level of chemical screening and unbiased analysis wouldn't be possible without the advanced computer power of AI.



A COMPUTING VIEW OF BRAIN TUMOUR DIAGNOSIS

Dr Phedias Diamandis from the University Health Network in Toronto, Canada, is putting his experience and computer power to work to get the most accurate diagnoses possible using convolutional neural networks. Our grant of almost £115,000 is backing him to build a computer algorithm that we think will revolutionise image-based diagnosis.

He's taken images that pathologists, like himself, have used to make diagnoses over the last 10 years and entered them into the computer, then written an algorithm identifying which brain tumours were diagnosed from them - these are the teaching images. Now they are working on the validation step, where a new brain tumour is entered and the computer's diagnosis is compared to a pathologist's to check the computer's accuracy.

This has great potential to make the most accurate diagnoses for people globally, where highly trained pathologists aren't available, and to diagnose very rare tumours that most clinicians only see once a decade.

Watch a short video on this research here: thebraintumourcharity.org/diamandis



LEARNING FROM LOW GRADE CHILDREN'S TUMOURS

This work from Dr Todd Hankinson, from the University of Colorado, USA, is a prime example of deep learning revealing useful findings. His £1.5 million grant focuses on understanding and treating a low grade paediatric brain tumour called adamantinomatous craniopharyngioma (ACP). ACP most commonly occurs in children and in adults over 70. Tumour samples from both groups were collected for study.

The researchers wrote a new algorithm, and entered over 40 million data points from each of the nine adults' tumours as the reference. They then asked if the data from the 27 children's tumours could be predicted, if the computer could tell these groups of tumours apart and predict if they would react similarly to a certain drug. The computer found the tumours in both groups were extremely similar and that any treatment found for one group would likely work for the other.

This exciting discovery opens the door for future research, expanding these findings to different tumour types.

Watch a short video on this research here: thebraintumourcharity.org/hankinson

MEET OUR RESEARCHERS

We recently caught up with two of our funded researchers. We asked them about their research careers, their projects, and how their labs have been affected by coronavirus (COVID-19).



DR LUCY STEAD

Lucy is a Research Fellow at the University of Leeds, where she leads her own team. We've been funding her project to study glioblastoma cells using a technique called 'nanobiopsy' since December 2018.

Q. How did you get into brain tumour research?

I left university in 2003 and worked in marketing for a while, but came back in 2006 and have been working in research ever since. My PhD was in biomedical sciences, specifically in sudden cardiac death, and my first postdoctoral role was in cancer research, focusing on head, neck and lung cancers.

This gave me experience of cancer research, and when I had the opportunity after my postdoc to develop my own group, I channelled all my energy into brain cancer research.

Q. Why this field?

It's the biggest challenge. It's a cancer in the most complex organ in the human body and it's the cancer that needs the most progress, so I wanted to be part of the group of scientists who throw their weight behind it.

Q. What is your project?

There's growing evidence that brain tumour cells respond to treatment by adapting. We're looking at how they adapt, so we can identify patterns, stop them adapting and kill them. At the moment, the only way to characterise a single cell is to kill it. This stops us being able to watch it adapt. So we're using a technique called 'nanobiopsy' – tiny needles that can go into a cell and take out material – to characterise a cell without killing it.

For the first time, we'll be able to watch how individual cells respond to treatment without killing them. This can give us the knowledge we need to stop them adapting, so that treatments will work on them.

Q. How has your work been affected by coronavirus?

We had to shut our labs and there's been no lab experimentation since – all that is delayed. But we're lucky as a group, as we're multi-disciplinary. Only 50% of our work is lab-based and the rest is computational.

We can still produce data sets and our team can analyse these data sets, so we can continue a large aspect of our research. The rest will continue to be delayed until we can get back into the labs. Our project is likely to be delayed by about nine months.

Q. Finally, what are the highs and lows of being a researcher?

It's very varied – no two days are the same. And you're always learning, putting that new knowledge into practice and applying it to what you're doing. It can be incredibly fulfilling, but I'd describe it as a roller-coaster! The downs can be very down, but on a day when something happens that makes you think you're getting somewhere, there's nothing like it.



MR OLA ROMINIYI

Ola is a Neurosurgical Trainee and Clinical Research Fellow at Sheffield Teaching Hospitals NHS Foundation Trust. We've been funding his project to develop a new model of glioblastoma since September 2019.

Q. How did you get into brain tumour research?

As a medical student, I had one experience where I was able to help the surgeon during a neurosurgical operation. To see the surgeon find the tumour and take it out, and to see the patient again on the ward doing well – I found that really inspiring. I think that was the moment I decided that was what I wanted to do.

I began my neurosurgical training in Sheffield in 2014 and have been there ever since, but I've taken time during my training to do scientific research as well. I started my PhD in 2016 and submitted my thesis a couple of months ago. Our current project, which is funded by The Brain Tumour Charity, really stems from and flows on from that PhD work.

Q. Why this field?

I feel we're on the precipice of being able to improve things significantly for patients.

Sheffield has world-leading expertise in the DNA damage response – how cancer cells respond to damage to their DNA caused by chemotherapy and radiotherapy. Over the next few years, I feel we'll really start to see the potential of drugs that target the DNA damage response, to see if they can improve the lives of people with brain cancer. That would make such a big difference for lots of our patients.

Q. What is your project?

We know that the cells left behind after surgery are responsible for tumour recurrence. Despite that, most of the research models used in the lab are based on the cells that surgeons normally take out during an operation. We feel there must be some differences between the cells taken out and those left behind. What if there's a better way to treat those cells that are left behind after surgery?

We're using very rare resections, called 'partial lobectomies', where there's some brain tissue adjacent to the tumour that's infiltrated by tumour cells. You can use these unique specimens to generate models of disease left behind after surgery. We can then find out how and why those cells left behind are more resistant to treatments. And most importantly, we can try to develop new and better ways to treat those cells.

Q. How has your work been affected by coronavirus?

Our experiments hadn't been up and running for long before lockdown. In some ways, it's fortunate we weren't further along because if we'd started to generate cell lines that weren't complete or ready to be stored, there may have been lots of wastage.

We're expecting to gain approval to go back to the university in October and be able to start getting patients involved in the research. The impact has been significant and has delayed our project by about six months, but because it came so early in the research, it's avoided wastage of resources or funds.

Q. Finally, what are the highs and lows of being a researcher?

I really enjoy the duality of being in the clinic and being in the laboratory – I'm involved with the patient and with the science as well. I find that very rewarding and exciting. But as a clinician, I found working in the laboratory quite difficult at the beginning. In hospital, you expect the things you do to work – they're tried and tested, and proven. In the laboratory, lots of the things you do don't work or you don't get the results you were expecting. But when you make those discoveries and important findings, that makes it even more rewarding.

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, brings new momentum to the cause and can play a big part in beating brain tumours: thebraintumourcharity.org/gift-in-will

BRIAN ONE YEAR ON

One year ago, we launched BRIAN (Brain tumour Information and Analysis Network), our pioneering online app. Now, we're looking back at what BRIAN has achieved so far.

We worked hand-in-hand with people affected by brain tumours to build BRIAN, and it's been designed to help defeat brain tumours on multiple fronts. First, by improving quality of life for people living with this disease and helping them, and their loved ones and carers, to cope. And second, by revolutionising the landscape of research into brain tumours to accelerate progress towards a cure.

Here, we recap the major developments and achievements during this first year and delve into the impact BRIAN's already having.

We also look ahead to the future as BRIAN launches as a mobile app!

“ I’m finding BRIAN very helpful as I can keep track of how I’m feeling and what appointments I’ve got coming up. The graph is really good as it shows your ups and downs.

- Helen, a BRIAN user

BRIAN'S FIRST YEAR

It's been an eventful 12 months for BRIAN – here's a round-up of our progress so far.

October 2019

- BRIAN launched!
- Insights into brain tumour incidence and number of surgeries per hospital added.

November 2019

- BRIAN's Calendar feature went live.
- BRIAN's memory and stability challenges were added.

December 2019

- We enabled BRIAN to pick up treatment and medication information from the NHS.

January 2020

- We reached 500 registrations to BRIAN.
- Research and prototyping of the BRIAN mobile app began.

March 2020

- We reached 1,000 registrations to BRIAN.
- We loaded the latest release of NHS data into BRIAN.
- Soon after lockdown, we added a coronavirus (COVID-19) questionnaire to BRIAN. Most respondents reported at least some effect on emotional well-being and mental health – we're now using the themes and questions that came out of this survey to help us better support our community and give advice on our website.

April 2020

- BRIAN's Community Chat feature launched.
- Fatigue and memory tracking were added to BRIAN.

May 2020

- We began to hold Benefits Q&A sessions with our experienced benefits advisor, Denise, in BRIAN.
- We began testing the BRIAN mobile app.

June 2020

- We reached 1,500 registrations to BRIAN.

July 2020

- We held a live Q&A session on chemotherapy in BRIAN, with experts from Imperial College. Dr Matt Williams and Lead Clinical Nurse Specialist (CNS) Shivani Soni answered 41 of your questions!

August 2020

- Planning got underway for a series of further Q&A sessions in BRIAN to cover a range of topics, including radiotherapy and rehabilitation.
- We obtained sign-off on the first stage of the three-part review process to allow us access to Welsh data from the SAIL Databank (a bank of anonymised data about the population of Wales). We hope to receive this data in the next three months.

BRIAN'S IMPACT SO FAR

We're incredibly proud of how far we've come since launch. We know BRIAN is already benefiting people's quality of life, with users telling us it's 'therapeutic', 'helpful' and 'supportive'. And it's well on its way to becoming an invaluable resource for information and knowledge sharing among patients, clinicians and researchers across the world.

In April, we set up chat rooms hosted and run by NHS trusts, with Imperial College Healthcare and King's College Hospital taking part in the trials. Both trusts were keen, in the midst of the coronavirus crisis, to use the BRIAN check-ins and chat room functionality to stay in touch with their patients and carers while they were unable to run clinics. Going forward, the functionality will allow NHS trusts to get a better idea of how their patients are doing and give them more tailored advice.

BRIAN'S GOING MOBILE!

We're currently in the final stages of releasing BRIAN as a mobile app, so that users can access it anytime, anywhere, in the way that's best for them. The app will be free and available on Android and Apple, so look out for it in your app store.

THE FUTURE OF BRIAN

As well as giving patients and their carers the knowledge they need to make informed decisions and better manage the everyday aspects of their treatment and care, BRIAN was designed to accelerate research. We're working towards giving researchers access to BRIAN's data, which will transform the landscape of research into brain tumours.



Ultimately, with better access to data, research projects will cost less and take less time, increasing the number of projects that get off the ground. Brain tumour treatments will have fewer side-effects and offer better outcomes, and care will become more consistent.

“ BRIAN will be a very useful tool and we are already starting to use it at King's College Hospital in a variety of ways. By looking at the data, we can assess which interventions are benefiting our patients, which make them feel better and improve their quality of life, and which ones don't.

- Professor Keyoumars Ashkan, Consultant Neurosurgeon at King's College Hospital

BRIAN IN NUMBERS

OVER
1,900
people signed up

OVER
5,700
quality-of-life
check-ins added

OVER
670
instances of
treatment logged

OVER
1,000
appointments recorded

OVER
2,000
tumour logs added

OVER
1,600
questionnaires filled in

OVER
1,900
memory and stability
challenges taken

BE PART OF BRIAN

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

A MARATHON NOT A SPRINT



Baron Armah-Kwantreng shares how he's taken control of his brain tumour diagnosis and managed the ups and downs of his recovery from surgery.

“The problem with ‘living in the moment’ is what if your current moment is really awful? So I decided the moment I’d like to live in was sitting out in the garden with my family in the sunshine.

After noticing a deterioration in his eyesight, an eye test in March 2018 led Baron to be diagnosed with a tumour of the pituitary gland called a pituitary adenoma. The pituitary gland controls hormones and so can have a big impact on well-being, and sits where the eye nerves cross, explaining the effect on his eyesight.

Baron was also told that his tumour was benign. “My response was, ‘Oh, thank God for that!’” he remembers. “But, in retrospect, that was bad information and it made what happened in the next few months very difficult to deal with. It wasn’t benign, it just wasn’t cancerous. That’s a very different statement.”

Due to being under the care of a different hospital for a heart

condition, Baron then faced a long and uncertain delay while the two medical teams communicated to confirm he could undergo surgery.

He had been running a digital start-up company, but with poor eyesight and the overwhelming fatigue he now realised was part of his condition, he was finding it increasingly difficult to work. So when he was offered some counselling, he took it. “I thought I was coping okay but the counsellor helped me realise that I wasn’t,” Baron says. “I could be completely honest with her and come to a better self-understanding.” He also found talking through what the surgery would entail, going for walks with his family and leaning on his faith helped him move into a better mental space.

The counsellor helped him to prioritise different areas of his life and make positive decisions, including getting a less demanding job. “The goal I identified was to get to the best place to get the best outcome from surgery,” says Baron.

By the time of his surgery, six months after his diagnosis, Baron felt ready. It was a success and his eyesight was almost instantly restored. However, an MRI revealed a chunk of the tumour had been left and a second surgery would be needed.

Recovery

“Recovering from surgery felt like emerging from a chrysalis,” says Baron. “I felt a real sense of rebirth. I was moved to a hospital room on my own where I could really reflect on my life and my new priorities. That was a very positive personal journey.”



Baron in ICU (May 2019)

Knowing he needed to contribute to the family to take some pressure off partner Caroline, Baron took a role in the Policy team at The Brain Tumour Charity on a transitional basis, starting in January 2019. “It was tough at first because I was still recovering, but they were very understanding,” remembers Baron. “But I enjoyed it and by April was ready to work full-time, but then I was told I needed to have the second surgery.”

Baron found the second surgery, in May last year, much harder. A dark moment in ICU made him focus on the future. “The problem with ‘living in the moment’ is, what if your current moment is really awful? So I decided the moment I’d like to live in was sitting out in the garden with my family in the sunshine,” he says. “So I lived in that future. And then one day it was just that moment and I said to them, ‘This is what got me through, being here with you.’”

Recovery from the second surgery has taken much longer. On days when Baron struggled to even concentrate on reading, he found listening to repetitive music, his ‘recovery soundtrack’, a comforting aid.

“I was keen to return to work after only a few weeks, but it wasn’t practical. I eventually went back in September 2019, made the mistake of driving, got massive brain fatigue then had a car crash on the way home! Luckily it wasn’t serious. I can’t imagine what

I was thinking, but I thought I was okay to drive,” Baron remembers. “Then in October I had a medical assessment and realised I wasn’t going back to work until at least the new year. I wanted to do something positive, so I took up hospital broadcasting and it gave me a whole new lease of life.”



Baron at work

Baron’s diagnosis has put huge pressure on Caroline, who has become the main earner to support them and their two teenage children. “She’s had to shoulder my surgeries and recovery as well as looking after the family and working. At one point she had to take some time off due to stress,” Baron says. “I think that shows just how much pressure it puts on other members of the family.”

After-effects

In addition to MRI scans, Baron now has regular eye tests and hormone level checks. The effects of the tumour and surgery have left him with a permanent deficiency in cortisol, adrenal insufficiency and low levels of testosterone and growth hormone.

In the spring, the coronavirus (COVID-19) pandemic hit, and many of Baron’s appointments were postponed to next year or made virtual. Then, over the summer, he began to struggle with fatigue again.

“I felt like I was wading through treacle,” he says. “I called my endocrine team and they slotted me in for an emergency blood test in August to review my thyroid function. But if circumstances had allowed them to be more interventionist they may have got to me sooner.

“Recovery isn’t a linear thing, it’s a process. It comes in waves. You can’t assess yourself when you have brain fatigue; you can’t think properly. So it would help to have someone else assess your capacity when you’re struggling. I’m a positive person though – my brain tumour diagnosis has changed my life forever – but I’m truly grateful for my treatment and positive relationships, and there’s still lots of good life to be led.”

Baron’s tips for navigating diagnosis and recovery

- 1. Don’t Google on your own.**
It’s a really lonely, scary place. However strong a person you are, you need somebody else to help you through it.
- 2. Ask for help.**
Getting the right help, both emotional and physical, at the right time could be a key part of your recovery.
- 3. Don’t give up on work; do what you can, when you can.**
My neurosurgeon said this to me. You can get back to work and doing things but there will be days, maybe weeks or months, where you’re not going to feel that capable. That’s okay. Pace yourself and don’t try to push it.

WE MUST DO MORE

A monthly gift of £12 could cover the cost of giving five people and their families immediate support and information after the devastation of a diagnosis. Set up your monthly gift today: thebraintumourcharity.org/donate

LIVING WELL
IN FOCUS

Change can feel uncomfortable and overwhelming, but understanding our reactions can help us to adjust.

COPING WITH CHANGE AND UNCERTAINTY

COPING WITH CHANGE AND UNCERTAINTY

Not knowing what the future may hold, or losing some control of day-to-day life, can make us feel insecure, leading to anxiety and worry. Here we share tips on ways to cope with change and uncertainty.



The coronavirus (COVID-19) pandemic has brought huge change and uncertainty to all of us – in ways that were unimaginable a year ago.

Where once we may have valued being able to make decisions and plans for the future that helped us to feel we had some control over aspects of our lives, the resulting uncertainty around the current and fast-changing situation has proved a challenging time for our community.

Finding ourselves in any situation we can't control can be difficult to cope with – taking away our feeling of security and making us anxious about what might happen.

This is especially true for our community, who have had to cope with the impact of their own or a loved one's brain tumour diagnosis

and treatment – bringing sudden and, at times, unexpected changes to their everyday lives. And along with the diagnosis, waiting for scan results, changes to treatment due to the coronavirus pandemic and not knowing what the future will bring, may mean that the feelings of uncertainty they experience lead to a range of emotions in response, including anxiety, fear and anger.

UNDERSTANDING OUR REACTION TO CHANGE AND UNCERTAINTY

Our brains dislike change and uncertainty and can see them as a threat that switches on our fight or flight responses. This is because early humans needed to be able

to react quickly to the threat of predatory animals, meaning that any perceived change to their surroundings could be a warning sign of imminent danger. Today, no matter how evolved we think we are, our brains still operate in this primeval way when faced with a sudden change and a future that we're unsure about.

Because the human brain dislikes uncertainty so much, it tries to create certainty where it doesn't exist by attempting to make sense of what might happen. Our brain's preference for certainty over ambiguity means that it creates a series of worst-case scenarios around what could happen to us, but this does little to reassure us and can leave us anxious and worried.

WHY DO SOME OF US STRUGGLE, WHILE OTHERS DON'T?

Looking at the difference between change and transition can help us to understand how we react in situations that bring uncertainty into our lives.

We can choose to make changes – like moving house, starting a new job or getting married, for example. These are changes we've planned and made decisions about, meaning that we feel we have some control. But when change happens quickly and unexpectedly, we can find ourselves in a period of transition where we're still holding on to the past because our brains take longer to adjust to the sudden change we're experiencing.

The pace of transition varies hugely from one person to another. Some people adjust quickly, while others find it takes them a lot longer and is harder to deal with.

As our brains try to play catch-up, the emotional impact can include a range of feelings as we try to cope. Based on the work of the psychiatrist Elisabeth Kübler-Ross, which looked at people's transition through grief, the change curve has also been used to help us understand our emotional reactions to change and uncertainty.

As with grief, what the change curve shows is that we move through a number of different stages:

ANXIETY: Can I cope with this sudden change?

DENIAL: If I ignore it, this change and uncertainty will go away.

EMOTION: I recognise that things are different, but I don't know what's going to happen in the future and I'm sometimes feeling angry and/or frustrated about this change to how things were before.

FEAR: I'm worried about how this is going to affect me and my loved ones. I feel low and lacking in energy.

ACCEPTANCE: I have come to terms with the new situation.

REALISATION: I can see what I need to do.

ENERGY: I'm motivated and doing what I need to do.

GROWTH: This is working and I need to continue with this approach.

The way we react may not follow each of these stages in order. For example, some people may not feel anxious or fearful and just accept the new situation they find themselves in.

On the other hand, some people might get stuck in one of the stages. It's quite common for people to find themselves stuck in denial at the start of a change and carry on regardless, pretending it isn't happening.

ROLLER-COASTER OF EMOTIONS

Often there's a roller-coaster effect as people move through the stages of change. For example, someone's reaction might see them start off in denial, before feelings of fear begin to creep in. But just as they start to feel better and start moving towards acceptance, something happens and they feel fearful again.

This roller-coaster of emotions can happen within the same day and you may sometimes feel that you've taken a step backwards in your efforts to try to cope with the worry and anxiety you may be feeling. Try not to feel too discouraged that you're not making the progress you'd like. We all move at a different pace through transition. Experiencing a setback is common and there are things you can do to help you cope (see page 22).

How our community has coped with change and uncertainty

"I try to focus on what I can control and to let go of the things I can't. It's a little bit of 'fake it until you make it' behaviour, but I honestly don't stress about a lot of unnecessary things anymore."

"Try to remind yourself that the scary, anxious thoughts you're having aren't facts. It's just your brain going to the worst-case scenario. Try to focus on what you know for certain."

"I try very hard to acknowledge what's going on around me and recognise how I'm feeling and put a name to it. I then let myself feel that emotion, but try not to invest energy into it. Instead, I put my energy into things that I can influence."

Dr Selina Makin, Clinical Neuropsychologist at Salford Royal Hospital, has put together some top tips to help you cope with change and uncertainty.

“Uncertainty and change can feel very uncomfortable as they can both lead to anxiety, causing lots of physical sensations and thoughts that aren’t very pleasant. Here are some ideas on how to adjust things when uncertainty and change are more present in your life.



1. RECOGNISE UNCERTAINTY

Notice if you find yourself thinking, ‘What if...’ or ‘What might happen if...’ These are the types of thoughts we have about a possible future event, or when we can’t answer a problem as it has no current solution. Recognising that these thoughts are popping up is the first step in putting things in place to feel less anxious, or to feel like we can make space for these feelings as we can see them for what they are.

2. CONTROL WHAT YOU CAN

When so many things feel uncertain or we’re in a process of change, think about which aspects of your life you can control. These can then feel like your anchor. Think about who you can call on the phone, what you’re eating, and make time to do less – which leads to tip three...

3. MAKE TIME FOR DOWNTIME

We can overdo the sense of needing to be on the go and being busy when things are uncertain or changing, as it can seem like a good way to solve something that’s unsolvable at the present time. It’s also exhausting. So make the time to try mindful breathing, pop outside and observe what your senses notice, pick up a book or settle into a bath. This can give you some space when life feels full.

4. DELEGATE

Uncertainty, worry and anxiety can feel like an overflowing saucepan on the hob and sometimes we need to turn down the heat or empty out some of the contents. Is there anything you can ask someone else to do, or is there something you can do a bit less of to help create some breathing space in your daily life?

NEUROSCIENCE OF CHANGE

Scientists have looked at the way our brains react when the threat response is triggered and how this affects not only how we respond, but also how it makes us feel about ourselves. They identified that the loss or reduction in any of the six factors below triggered the threat response and feelings associated with anxiety.

All of us need all six, but some of us need some more than others. For instance, a lack of certainty triggers the threat response in a lot of people, but for others losing their sense of purpose has more impact.

Self-esteem

Sometimes referred to as ‘status’, self-esteem is the feeling that we matter in the world and we have some importance. This gives us a positive sense of our identity and that we’re learning and growing.

Purpose

This stems from being connected to something outside ourselves, such as our work, our role as a parent or training for a sport or charity run. Feeling that we’re making a difference to other people gives us a sense of purpose.

Autonomy

Feeling that you have autonomy comes from having the perception of being in control, feeling that you have choices about what’s happening to you and being able to set your own direction.

Certainty

Knowing what’s going to happen next is the certainty our brains crave. Having a routine, as well as access to the information we need to make decisions in our lives, is also important.

Equity

When we’re experiencing change, we start to think about how we’ll get access to what we need to help us through. But if we feel that others are being treated differently and we aren’t being treated fairly, this triggers a fight or flight response.

Social connections

Being connected to others who understand the world as we see it, having people who care about us and whom we trust, and feeling included are all important. It’s been found that our brains experience social exclusion or isolation in the same way as physical pain.

Other sources of support

How the coronavirus pandemic is affecting treatment and some advice on how to cope: thebraintumourcharity.org/COVID-19-and-treatment

Information on shielding and how it can impact on our community: thebraintumourcharity.org/shielding

Tips on coping with change after diagnosis and treatment: thebraintumourcharity.org/coping-with-change

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

Don’t forget you can call our free Support and Information Line on **0808 800 0004** or email support@thebraintumourcharity.org

Taking charge of treatment during lockdown

“At the beginning of lockdown my oncologist was keen to delay treatment. I talked to my oncology nurse as I wasn’t happy about his decision. She helped me by reinforcing my request to stay on treatment and the oncologist let me go ahead with the treatment plan.”

– Wendy

“During lockdown we’ve had an interruption with the physiotherapy my husband was having, but a physiotherapist was able to visit him the other day to check how he was doing. Thankfully, he’s been going through YouTube checking videos and found an excellent one he finds easy to follow and that’s basically the same as the sheet the physiotherapist gave him.”

– Karen

TAKING CONTROL OF HEALTHCARE

A brain tumour diagnosis and the subsequent treatment and care can feel very much out of your control, but there are always some choices you can make. Here, three inspiring people explain how they've taken control.



“We decided that her treatment wouldn't define her.

TAKE AN ACTIVE ROLE

Claire Evans

When our four-year-old daughter Ella was diagnosed with a grade 4 medulloblastoma, my husband Rob and I decided we wanted to take an active part in her treatment. We made sure we understood the care she received and how we could help maintain it. We did some research and made sure we always felt we were being offered the best solutions to her care.

Ella had some complications after her surgery which slowed down her recovery. She also had to learn to walk again. I took the decision to step away from the business I run with Rob and dedicate my time to her recovery. We made adaptations to our home for her and we also relied on a network of family, friends and nursery to maintain

consistency for our two-year-old son. To give her the best chance of a recovery, we put Ella forward for a clinical trial of proton beam therapy, although it meant travelling to Germany for six weeks. We decided that I would go with her and Rob would remain with our son. We also chose to pursue a private physio so Ella could make progress more quickly.

On our return, Ella had chemotherapy and, together with the consultants, we made the decision to swap her last treatment for a different drug because it was affecting her hearing. This meant her having haemoglobin and platelet transfusions, but it was the right decision in the long term.

Her healthcare teams always listened to Ella and made sure she was comfortable. Feeling informed and able to choose certain elements of her treatment was a major factor in her journey. We also decided that her treatment wouldn't define her and spent as much time doing fun things and making memories, so she'd feel the joy that any four-year-old should.

We're so lucky that Ella's treatment has been successful and she was able to 'ring the bell' to signal the end of it in January.

GET SUPPORT

When you need support, you can call our Support and Information Line on **0808 800 0004**, Monday to Friday, or email **support@thebraintumourcharity.org**

BRIAN, our online app, can help you take control of your healthcare. Visit: **thebraintumourcharity.org/brian** to find out more.



“I made the decision to visit the same clinic.

EXPLORE ALL OPTIONS

Catherine Reeve

My symptoms were originally misdiagnosed as depression in 2016. I was given anti-depressants, but they didn't help. When one day I couldn't get out of bed, my husband called my mum in Chelmsford and told her that he didn't want me looking after our three-year-old daughter by myself. My mum took me straight to a hospital in Chelmsford for a second opinion. The next thing I knew I was in an ambulance being transferred to a different hospital.

I was diagnosed with a grade 4 glioblastoma and had surgery to de-bulk it. The surgeon then explained he'd need to operate again but that it might affect movements on my right-hand side. This worried me as I play the piano. He suggested an awake craniotomy and I chose this as it gave me the best chance of still playing the piano and looking after our daughter.

Soon after my diagnosis, a friend sent through an article about someone who had survived with cancer for longer

than expected. I made the decision to visit the same clinic where I met with a doctor and was given some medication that was being repurposed for cancer. I'm still taking this now.

I asked about clinical trials and my doctor identified one. I went to visit the doctor in charge only to be told that I couldn't be included due to an anomaly in my tumour. Some would say this was a wasted trip, but I needed to hear this in person.

I made a phased return to my role as a deputy head teacher in February 2017, but it was a stressful job and I know stress isn't good for a person with cancer. So I've recently moved to another school, as a speech and language teacher, which suits me better.



“It ended with me insisting on a second opinion.

YOU ARE IN CHARGE OF WHAT HAPPENS TO YOU

Sarah Kallend

I lived with a number of symptoms for 20 years before being diagnosed with an epidermoid brain tumour. As soon as I received the diagnosis

I researched in great detail everything I could about these super rare tumours. When I met with the consultant, I found his opinions very imbalanced. He started by saying my tumour was very rare, dangerous and inoperable, and then suggested it was harmless, not causing my symptoms and 'probably really common'. He refused to believe that successful surgery was taking place on these type of tumours elsewhere. It ended with me insisting on a second opinion.

A nurse, who'd seen how confrontational the meeting had been, offered me an appointment with the senior skull base surgeon the next day. That couldn't have been more different. He talked through his experience with this type of tumour and gave a really rational overview of my options.

I was offered medication to deal with some of the symptoms before surgery, but my research had shown this would only help for a short period and I'd most likely end up on medication for life and still not escape surgery. Also the tumour can cause permanent nerve damage, so I wanted the pressure on my cranial nerves and brain stem to be relieved sooner rather than later. My health was worsening by the week, so we decided on surgery, which took place six weeks later. My acute symptoms like pain and seizures went immediately, but I've been left with other effects including memory deficits. I now work part-time hours as I don't have the stamina to sustain the full-time corporate career that I used to easily maintain.

It's important to find out everything you can, write down questions and always ask what the alternatives are. Be gracious, but be clear that YOU are in charge of what happens to you when decisions need to be made.

TO MYSELF BEFORE THE DIAGNOSIS



Dear Matt,

Who would have thought that the shocking and scary diagnosis of a brain tumour could turn the lives of you and Hayley upside down in so many unexpected ways – and that some of those ways could even be for the better.

The headaches and problems with your vision you’ve been having will not go away. Doctors’ suspicions of possible meningitis will be replaced by the terrifying news that you have a grade 4 glioblastoma brain tumour. You’ll be given just 18 months to live.

At 27 years old, this will be understandably devastating. Nothing prepares anyone for news like that. Upset and confused won’t even cover it. What does it even mean to have a brain tumour? You’ll know little about the disease which is threatening to take away your hopes of a future with Hayley.

A quick Google search will bring you to The Brain Tumour Charity. The information on their website will be a huge source of help and comfort in those early days. You’ll be shocked to find out that brain tumours are the number one cancer killer of people under 40 years old. The research they

fund will also be your and Hayley’s motivation to support The Charity in the near future too.

With fear echoing around your mind, you’ll have surgery to remove the tumour. You’ll be told about the risks of paralysis and even death from this surgery that’s supposed to be saving your life. That won’t happen. In fact, you’ll wake up from surgery to devour cups of tea and second helpings of pudding in your hospital bed with Hayley by your side.

Chemotherapy and radiotherapy will follow and life will become almost unrecognisable. During radiotherapy,



you’ll wear a mask so tight that you’ll feel suffocated, even though you know it’s there to protect you. But, you have your life – and a good few years of it ahead too.

You’ll have to stop working and driving – two of the things you really love. Instead, Link the sausage dog, the pet you and Hayley always wanted, will get you out of the house when you want to do anything but. He’ll curl up in your lap and provide companionship when you need it the most.

Dog walks will be your introduction to a new and healthier way of life. Together, you and Hayley will follow Joe Wicks diets and exercise plans and thrive off the endorphins they provide. You’ll be surprised at what your bodies can do both physically and mentally at such a tough time.

The Brain Tumour Charity will also grant you membership to a club that no one wants to be part of. Through online support groups, events and meet ups, you’ll meet new people and make new friends, founded on shared experience and common ground. You’ll find out that you’re far from alone.

Hayley will truly embrace this new energetic lifestyle – so much so that she’ll soon head off to trek the Sahara Desert for The Brain Tumour Charity to help fund research. Her dedication will contribute to raising over £32,000 for The Matthew Smith Fund through

gala balls, bake sales and challenge events. Your friends and family will astound you with an outpouring of love. They’ll stand by your side and support you every step of the way. Laughter will be the best medicine. You’ll belly laugh when, after surgery, a friend says you look like you belong in *Game of Thrones*.

Four years later, 2020 will see everyone’s lifestyle stripped away from them without a moment’s notice because of the coronavirus (COVID-19) pandemic. You’ll know the feeling, having experienced it when you were first diagnosed. You’ll have done this before so you can do it again. Sudden change is manageable and you’ll have the coping mechanisms in place to prove it.



Then, after a routine scan, you and Hayley both know something’s wrong when you’re asked to attend a hospital appointment for the results, even though lockdown is underway. You’ll be told that the tumour has regrown. On confirmation of these worst fears, your fragile world comes crashing down again.

Treatment won’t be an option because of the pandemic and so you’ll be told to watch and wait. You have no choice but to try and stay positive. Yet, a more detailed scan three fearful months later will say it hasn’t grown back after all. Confusion will creep back in.

But you’ll get through it. You’ll walk out of the front door nearly every day. Time at home during lockdown will be filled with Mexican nights, afternoon tea parties and spa days organised by Hayley. They’ll take your mind off what could be happening in your head. It will also help Hayley to discover her passion for helping others and she’ll change careers to become a community fundraiser. This will give her the professional satisfaction that she didn’t even know she was missing.

Right now, ahead of the next scan, there’s no way of knowing what the future will hold. But don’t let that get you down. Keep planning for what may be around the corner. That could be more surgery. That could be more treatment. That could mean the right opportunity to start the family you and Hayley so dearly want.

Amazing things are happening to stop brain tumours from tearing people’s lives apart. So, never lose your sense of hope that this isn’t the end of your world. Not every day is good but there is good in every day. So, take one day at a time, stay positive, keep strong and keep your chin up.

Your mate, Matt.

SHARE YOUR STORY

If you’d like to share your story with us, we’d love to hear from you. Visit our website and tell us more: thebraintumourcharity.org/share

ASK THE EXPERTS

Got a 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.



IS IT POSSIBLE TO RETURN TO A 'NORMAL' RELATIONSHIP AFTER ONE PARTNER HAS BECOME THE OTHER'S CARER?

Dee Holmes, Senior Practice Consultant SE, Relate

Receiving a diagnosis of a brain tumour will be a trauma for both partners and can create shockwaves through your relationship. It can send you on different paths – one on a journey of treatment and recovery and the other a journey of support for your partner and family around you. This can create distance between you and make it harder to ride the normal ups and downs of a relationship, not knowing how much leeway to give your partner for being ill or for looking after you.

The first thing is to be kind to yourselves. It's a difficult time and if you naturally fall into the roles of carer and being cared for, it can be hard to get back to an equitable relationship again. It might not be easy for the person with the diagnosis to assert themselves without seeming aggressive or angry, or for their partner not to feel their support is being rejected. There may also be practical things to overcome in regaining your closeness and intimacy.

The second thing is to communicate. Both partners need to evaluate where they are, what they want to change and be able to express that to the other. If the impact of the illness is irreversible, then you need to accept that your former relationship has ended, mourn it and move on to the new relationship you have together now.

Thirdly, consider if you might find some counselling support useful to facilitate this journey. It can help you to think in a more constructive way and go beyond what you can do as a couple on your own. You don't need to wait until things feel unmanageable. Early intervention could help you get back on track in just one or two sessions, or you may find you need longer-term support.

The Brain Tumour Charity has partnered with Relate to offer a free counselling service. Find out more at thebraintumourcharity.org/relationships

IS THERE ANY RESEARCH INTO BRAIN STEM TUMOURS?

Dr Chris Jones, Professor of Childhood Brain Tumour Biology, Institute of Cancer Research

Tumours that arise in the brain stem are among the biggest challenges in all of cancer research and treatment. They tend to occur in young children,

spread throughout the brain from part of the brain stem called the pons – here they are known as diffuse intrinsic pontine glioma, or DIPG. Because the cancer cells are found mixed with the normal brain, and due to the critical role the brain stem plays in regulating our breathing, heart rate, blood pressure and more, surgery to remove the whole tumour isn't an option for DIPG patients.

Our understanding of these tumours has increased dramatically over the last few years, thanks to the availability of tissue to study, either from biopsy or the generous donation of tissue after the child has passed away from the disease. We now know that DIPG, like other tumours in what we call the 'midline' areas of the brain, have a completely unique biology, and are driven by errors in genes not found in other cancers. They are also comprised of multiple different types, so identifying new treatments is increasingly going to be based on the specific make-up of an individual's tumour.

One area that we're particularly interested in is a gene called ACVR1. This has not previously been linked to cancer, however it's also responsible for a terribly debilitating condition called fibrodysplasia ossificans progressiva, or FOP, where a person's soft tissue (like muscle) turns to bone. It's remarkable that two such awful, but completely different, diseases are linked by this same gene, and we and others are trying to understand exactly how this occurs. More than this, we're working with both academic and commercial partners to evaluate drugs targeting ACVR1 and bring

them to clinical trials for children with this subtype of DIPG. These cancers are very complex, and in particular we're trying to find out which other treatments could be combined with ACVR1 inhibitors to give the best chance of improving survival for children with this devastating disease.

We recently held a live Q&A session on chemotherapy in our online app, BRIAN, with experts Dr Matt Williams and Lead Clinical Nurse Specialist Shivani Soni from Imperial College. Here are some of the questions they answered.

My son is currently receiving a 'maintenance dose' of chemotherapy due to the risk of coronavirus (COVID-19), but no monitoring is taking place. Is this standard practice everywhere or is there somewhere my son could go – possibly abroad – to receive better treatment and monitoring?

COVID-19 has reduced our ability to scan. Most patients who develop progressive disease will have symptoms that tell you if things are getting worse. We have to make these decisions on a per-patient basis, but now that scanners have to be cleaned

between each patient, capacity has gone down. Also, more scanning means more time spent at the hospital which means more risk of COVID-19. So for many patients, we're giving chemotherapy with virtual appointments and posting tablets, and not scanning.

I have a glioblastoma multiforme (GBM) and was wondering if anyone is looking at why some people survive years, yet others only months?

Unfortunately, there's a lot we don't know about brain tumours. However there's a lot of data published which shows that factors such as age, good surgical resection and MGMT methylation status (whether the gene that controls DNA repair in the tumour is turned on or off) all affect outcomes. However, they are only partially good at predicting survival and there are clearly other factors at play – but I don't think we know what these are yet.

www.imperial.ac.uk/people/matthew.williams

www.imperial.nhs.uk/our-services/cancer-services/neuro-oncology

You can join future Q&A sessions by signing up to BRIAN at thebraintumourcharity.org/brian

SEND IN YOUR QUESTIONS

Do you have a question? Send it to us at 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.

YOUR LETTERS



When I was first diagnosed, I felt very alone and didn't know who to turn to for support. I felt the same way when I was told to shield because I didn't know anybody else who was in my situation.

The Brain Tumour Charity's young persons' virtual meet ups were a huge comfort to me in lockdown and, just like when I was first diagnosed, The Charity's team were all there for me.

Grace
Pictured: Grace



I shared your post on World Brain Tumour Day and put a link in my Instagram bio. Just found out today that it prompted a friend to take her little boy to A&E and he was diagnosed with a brain tumour. Just wanted to say thank you for the brilliant work you do as it really does help people.

Nikki
Pictured: Know the signs – visit bit.ly/1Symptoms



I thoroughly enjoyed being a part of The Big Bake in March. Not only did I get the chance to speak to colleagues I wouldn't normally cross paths with, I was also able to help raise awareness for The Charity and its Young Ambassadors – both of whom I find truly inspiring. I'm delighted that we were able to raise some funds for such an excellent cause and hope to bake some more super-sized treats for next year!

Jessica, staff member at TI Media, one of our corporate partners
Pictured: The TI Media Big Bake



Wearing my Brain Tumour Charity face mask is about more than protecting myself and others against COVID-19. It's about reminding people that while we battle against a global pandemic we're still battling against this horrific disease, and a cure really can't wait.

Kate
Pictured: Kate

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 or calling **01252 237867**.

FAMILY DAYS AND YOUNG ADULT MEET UPS

Over the last few months, we've taken the precautionary step of replacing our Family Days with Virtual Family Day Experiences. We know how much you enjoy these events (as do we!) and are regularly reviewing the situation, as well as exploring further alternative options to get together safely. For more information and dates of upcoming events, visit: thebraintumourcharity.org/family-days

We're also continuing to hold weekly online meet ups for young adults affected by a brain tumour – a brilliant way to connect with others and play some fun online games. For details and dates, visit: thebraintumourcharity.org/online-meet-ups

Finally, we 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

OCTOBER 2020

FEBRUARY 2021

MARCH 2021

APRIL 2021

Throughout the month	The Twilight Walk (see page five)
Saturday 27 February to Saturday 6 March	Sahara Trek
Sunday 14 Sunday 28 Sunday 28	Bath Half Marathon Cardiff Half Marathon London Landmarks Half Marathon
Sunday 11 Sunday 11 Sunday 11 Sunday 18	Royal Parks Half Marathon Greater Manchester Marathon Paris Marathon Brighton Marathon

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

BRAIN TUMOURS MOVE FAST. HELP US MOVE FASTER!

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

thebraintumourcharity.org 01252 749990

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