

Logbook

ISSUE 11
SEPTEMBER 2020

THE MAGAZINE FROM
brainstrust – the brain cancer people



- **Choose Grey. Change Lives. Wear Grey with us on 1st October.**
- **How coaching can transform your experience of living with a brain tumour.**

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brainstrust
the brain cancer people

Welcome to this special edition of *brainstrust's* Logbook. As someone who has supported *brainstrust* recently or has been in touch for help, you'll be eager to hear what we've been up to, particularly with the global Covid-19 pandemic and how this has impacted our community, our team and our work.

LET'S START WITH THE PEOPLE THAT NEED US. The pandemic has caused heightened anxiety and uncertainty for people with a brain tumour.

It has increased loneliness and made brain tumour treatment even more complicated as hospitals change the way they work. Some people are seeing delays to treatment and investigations (so more anxious waiting) where the risk of contracting Covid-19 outweighs the risk of disease progression, but on the whole most people are getting the treatment they need, with some regional variation where things are better or worse. Where people have felt there has been injustice and disproportionate impact of clinical decisions during Covid-19 we have and continue to work closely with them to get things to where they need them to be.

Everybody with a brain tumour is more alone than before due to shielding, or the broader restrictions applied to society. However, the big

take out for us is that we are learning that our community is resilient. It is desperately sad to write this, but people with a brain tumour are used to being isolated. They are familiar with living under the shadow of a dangerous disease, sometimes with little to no effective treatment, and all are already well versed in managing uncertainty and anxiety as a result.

Here at *brainstrust* the pandemic and restrictions that followed immediately destabilised our ways of working, and public fundraising stopped. But we saw immediately the robustness and resilience of our team and the commitment we all bear to our mission. On the 13th March, we set out to be invaluable – to our community, to each other and to our friends and families. We pivoted at lightning pace, to work from home and take all services online. And today we are seeing sustained reach and impact. People tell us that our help is more useful now than ever before. Our funders, supporters and collaborators tell us that they are confident in our ability to deliver, and they are providing additional support

and flexibility, for which we are truly grateful. You have been incredible – our emergency appeal has to date raised over £100,000 and early calculations suggest that an initial estimate of a 40% drop in revenue has been reduced to 20% thanks to quick and decisive action and this support.

There remains a great deal of uncertainty about the lasting impact of Coronavirus on the economy, the charity sector, and public fundraising in the future. We are, however, an agile organisation and can appropriately adjust our scale to meet this challenge and collaborate where possible to remain efficient and effective for our community.

What is certain is that in the face of these ongoing and existential challenges, brain tumours will not stop. We will continue to see increased demand and need for *brainstrust's* impact, and our help is more relevant and vital than ever. To deliver this work and to achieve our mission, we will need your unwavering support more than ever before.



Thank you

WE ARE continually overwhelmed and grateful for the level of support that we continue to receive.

From the Run, Row, Riders to the elephant knitters; the 2.6 Challengers to the virtual marathon runners; the grafters and crafters; the birthday donors and the social media campaigners. Thank you, all of you. We deeply appreciate your support during such unusual and difficult times.

Thank you to our corporate donors that have rallied to support us during this crisis:

- Royale Life
- Millgate homes
- CSC

Thank you to our grant awarders, both new and existing, for your emergency responses to our funding needs:

- National Lottery Community Fund
- Rank Foundation Resilience Fund
- Children with Cancer UK
- Edward Gostling Covid Response Fund
- Awards for All Scotland
- Sir Jules Thorne Charitable Trust

There is so much that people can learn from the brain tumour community

“The whole country is now facing a scary ‘new normal’ which has weirdly made me feel stronger as my own condition has paled into insignificance, and we are all getting through this surreal time together.”

Patient

BEING DIAGNOSED with a brain tumour, living with a brain tumour, is not a place anyone would choose to be, and to then have life transformed by a global pandemic feels like a double blow. However, with this comes a unique perspective that can be used to help others navigate their way through uncertainty and shape their perspectives.

Living with uncertainty is when we live with the anxiety that something bad may happen. You find yourself living in a space where you can't be sure of anything. It's a scary place to be and can leave you feeling out of control, helpless and overwhelmed. When you, or someone you love, have been diagnosed with a brain tumour, life feels less secure, more fragile than it once was. You know what it is like to live with uncertainty – you could say you're ahead of the game. Of

course, over the last few months it can feel that uncertainty is being piled on top of uncertainty, but we have been astounded by the resilience of our community to cope with this pandemic.

It is sad but true that in life, catastrophes are common – both on a global and personal level. We should steel ourselves to expect them. And we learn from them – they put our past and future problems in perspective and show us the things in life that really matter. This is why we're able to sustain an awful lot of hits and somehow keep going.

“I've learned that some poems don't rhyme, and some stories don't have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next. Delicious ambiguity.”

Gilda Radner

Focus on this truth. You've done this before. **If you are living with a brain tumour, the fact that you are reading this is testament to your fortitude.** You've endured a brain tumour diagnosis and all that entails. Being immunocompromised, needing to do your own research to find trusted sources of information, facing financial worries and accessibility barriers – you have already faced so many hardships because of your brain tumour diagnosis. You've passed every test of life that has been thrown at you. **Take courage from your own example. You've got this.**

Covid-19 has changed our lives. Those living with a serious illness, often relegated to the margins, have a skill set that may help to calm those who are naïve to illness and distress and for whom living with Covid-19 is a new onslaught.

Sometimes you just need to speak to people that understand.

Whether you've got a question you need an honest answer to, a worry you want to share or you're feeling inspired, our private online Facebook community is a safe, welcoming place for anyone with a brain tumour to be heard. Search 'brain tumour support *brainstrust*' on Facebook to request to join.

“I joined the Facebook group and it's community makes me feel not so alone anymore. Just knowing that there is a place where I can go to for advice and support if and when I need it is so comforting.”



Thrive, with *brainstrust* online workshops

Thrive webinars and workshops are meticulously curated by *brainstrust* and hosted by leading experts to help you tackle the challenges that make life with a brain tumour so hard.

SO THAT YOU CAN BE more informed, more engaged, and cope better, you can now access *brainstrust* workshops online. Thrive events are more focused than a Meetup – if you are feeling lost or confused, need practical information and would like a deeper dive into specific aspects of life with a brain tumour, then Thrive events are for you.

Webinar impact

- Hosting events online has meant that we have been able to reach double the amount of people that we normally meet through events. Since April, we've hosted 55 online events with over 366 attendees
- We have covered topics such as fatigue, the ketogenic diet, hypnotherapy, scanxiety, brain tumour related epilepsy and lots more, with an incredible range of qualified guest presenters including consultant neurologists, nutritionists and lots more.
- We know that accessing services online has been an adjustment for lots of people, so we produced a Know How to help you get to grips with Zoom, the easy and free to download programme we run our online events through.
- Over 60 people have filled out our post webinar survey, and 100% say they would tune into another webinar.



“The webinar was really friendly, welcoming, positive and empowering.”

Patient, living with uncertainty webinar

“I feel more confident about managing symptoms and difficulties which are faced when living with a brain tumour ... the peer support of the groups/webinars has been excellent.”

Patient, hypnotherapy webinar



- Where people have completed progress trackers, we can see that webinars are having the most impact helping people to feel **resourced** and **part of a community**.

“I have often been interested in going to *brainstrust* events but have been unable to previously because of transport so it was really great to be able to attend the webinar and interact with everyone virtually.”

Patient and webinar attendee



All of our upcoming events, online and face-to-face, are listed in a calendar on our website:

www.brainstrust.org.uk/get-involved/events/



The future of *brainstrust* online events

With the knowledge that they are having a similar impact to those held face-to-face, we are excited to continue developing and delivering webinars that can help you with different aspects of living with a brain tumour diagnosis.

In the coming weeks and months, you will see an exciting and varied programme of online events, with an incredible range of external speakers who will be using their expertise to present to you on topics that you have told us are important.



Covid 19 and its impact on cancer services: a golden opportunity or a burning platform?

“**Golden opportunities**” describe the incredible potential that the NHS can realise, after transforming itself to cope with the Covid-19 pandemic, so change for good can be a lasting legacy. “**Burning platform**” refers to the challenges that the pandemic has wrought, and a potential downward spiral that can only be arrested if the NHS transforms to correct them. Both stories are true – they can create very different impressions, but there is always more than one version of the truth. The bottom line is that across all cancer services, 85% of treatments were delivered. Given the pressure on the NHS during this pandemic we think that’s a pretty good outcome.

We have been continually monitoring the impact of Covid-19 on people living with a brain tumour, and keeping our community updated through the Corona Comms hub on our website (www.brainstrust.org.uk/corona-comms/). There was a period of 2-3 weeks at the height of the pandemic when people with a newly diagnosed glioblastoma, the most lethal form of brain tumour, were not presenting at some key hospital clinics. At the same time, other hospitals saw no change.

Golden opportunities include **the unwavering dedication of our brain cancer clinical community**, who have gone above and beyond to be there for our brain tumour community. And everybody with

a brain tumour, for understanding risk versus benefit. You got that sometimes it was better for your chemotherapy or surgery to be delayed, by just a few weeks, as this was safer than the risk of catching Covid-19. This has led to more engaged conversations with your clinical team, about your appetite for risk, your context and what’s important to you.

The agile approach to virtual health and care. This has been long overdue and what was thought would take years to achieve was done overnight. During Covid-19 about 85% of consultations were done by telephone, compared to about 14% previously; this will self-regulate over time and will probably reduce. What we need to focus on next is how can remote consultations be optimised so that you get the most out of your appointments.

The way hospitals reorganised themselves to provide Covid-19 free environments so that treatments could continue. Innovative approaches such as home treatments, using mobile units, having ‘dirty’ scanners where Covid-19 patients are scanned and clean scanners for non Covid-19 patients, have been established.

Collaborations have grown that would never have been on the agenda before. The Programme Director for NHS Cancer, the National Clinical Director for Cancer and the National Cancer Director have updated us

every week and in so doing have truly valued the supportive work which charities such as *brainstrust* deliver.

But of course, there have been burning platforms to. Whilst the screening programmes put on hold doesn’t impact people with a brain tumour, **the halt to clinical research** certainly will. Trials were closed and those due to set up were halted. Whilst things are restarting this burning platform will continue for months, if not years, to come.

And for our community, especially those who have a life limiting diagnosis, **being unable to do the things that matter most to them.** We know how important it is to have your best possible day and that having a good quality of life can extend your prognosis. This is a bitter pill to swallow when you can’t see your grandchildren, or you can’t sit and hold the hand of your loved one as they are in hospital.

We may feel better believing there is one single truth, and thinking everyone who doesn’t see things the way we do simply doesn’t have the truth. That’s not true. Everyone has a lens on the situation that’s distorted by what they want, how they see the world, and their biases. This is never more so when you are living with a brain tumour. The one truth we have learnt from this pandemic is that there are multiple truths and that these come in many forms. Our job has been to share some of these.



Geoff Worsley

“I have a friend who told me she had a brain tumour. All the support she received just made me realise that I needed to help people get more support in whatever way I could.”

GEOFF DOESN'T CONSIDER HIMSELF A RUNNER, he considers himself a friend. When Geoff's friend was diagnosed with a brain tumour, she spoke to him about the support she had received from *brainstrust*. Feeling inspired, Geoff set himself a year-long series of challenges to raise funds in support of everyone who has heard the words, “You have a brain tumour.”

“Over the year the plan was to raise as much as possible.” In February, the day after Storm Dennis hit, Geoff completed his first Half Marathon. *“This was way harder than I thought it would be. Two weeks later, I was in Brighton for another Half Marathon! The atmosphere there was amazing. Shortly after, I completed a 10k at RAF Shawbury where I crossed the finish line through hail and a snowstorm. Next came Shrewsbury 10k, then lockdown was enforced.”*

As April approached, the UK went into lockdown. Geoff, along with thousands of others, soon heard that he would no longer get to experience the thrill of being cheered on as he made his way to the finish line. Instead, the world looked very different. Geoff's friend, and everyone affected by a brain tumour diagnosis, suddenly became even more vulnerable. At a time when all public fundraising stopped, our brain tumour community needed support more than ever. Geoff knew this, so he quickly adapted his challenges to continue his fantastic fundraising efforts.

“Since lockdown, of course all major events have been cancelled, but so many converted their event into a virtual one. I ran a virtual 100km event, several half marathons and half a dozen 10k races.” Alongside support from friends and family, Geoff has also been sponsored by three generous companies: TBSC, Gemini-Six and SAM Charter, helping to bring his fundraising total to over £1,000! Geoff now feels much closer to *brainstrust* and continues to be passionate about

the community he is supporting. Geoff shared, *"It has meant so much to me to be able see the support from brainstrust that my friend and others have received. I always feel there is more to raise and I have decided to continue to raise money for brainstrust in 2021."*

Here at *brainstrust*, we are always overwhelmed by the kindness and generosity we receive from people like Geoff – people we couldn't be without. It's because of this that

we were able to quickly adapt our services to ensure our vital support continued throughout the pandemic, and beyond. Looking ahead, Geoff shares his plans for the future as he sets his sights on achieving new personal goals, routed by his determination to be strong, resilient and supportive of causes close to his heart.

"In October, I'm hoping to run in the Great South Run. Then I have a 25-hour ultramarathon endurance track

race, just as the clocks turn back! In December, I have the Milton Keynes Half Marathon. It won't be long before I start to train properly for Brighton Marathon in April 2021. I can't wait to finish my first marathon, then I'll re-start swimming lessons so I can take part in my first triathlon." As we cheer Geoff on into the New Year, we would like to thank him for everything he has done and continues to do in support of *brainstrust* and the brain tumour community.

Geoff Worsley Q&A – August 2020

What inspired you to support *brainstrust* and the brain tumour community?

I have a friend who told me she had a brain tumour and all the support she received just made me realise that I needed to help get people more support in whatever way I could. It has meant so much to me to be able see the support from *brainstrust* that my friend and others have received.

What is your background in running?

I don't have a great running background, I've played a lot of sport and cycling was really my main sport up until 2018, when I started to introduce a bit of running to balance out the cycling stresses on my body. In 2019, I cycled my first 100 mile event at Prudential Ride 100, I ran my first official Half Marathon, completed a 24 hour Team Relay Race at Endure24 and a 100km race over two days at Race to the Stones. I ended up with four Half Marathons, a couple of 10k, a 24hour Team Race, 100 mile bike ride and an Ultramarathon over two days.

I didn't really start running seriously until the end of 2018 and I don't consider myself a serious runner, I have some goals and I like to challenge myself.

What challenges did you complete before lockdown was enforced?

At the end of 2019, I decided to support *brainstrust*, but I have

experienced the pressure of raising sponsorship for a particular event so I hadn't planned one event, rather, over the year the plan was to raise as much as possible. In February, I completed my first trail-run Half Marathon which was way harder than I thought it would and it is was the day after the big storm. (See photo of one of the cross points). Two weeks later I was in Brighton for another Half Marathon, the atmosphere was amazing and it's a great course. Then I had a 10k at RAF Shawbury which finished in a hail and snow storm and finally Shrewsbury 10k before lockdown was enforced.

How did it feel to hear that many of your planned events had been cancelled or postponed?

Since locked down of course all major events have been cancelled, but so many converted the event to a virtual event, you run locally, socially distanced and submit your details from Strava and they ship the medal and T-shirt to you. Obviously, the main part of the event is the social side, supporting each other, chatting to people during and after the event. I had planned a non-stop attempt for Race to the King this year and that was a major disappointment to have that cancelled.

I have run a virtual 100km event, several half marathons and half a dozen 10k races.

How have you supported *brainstrust* during lockdown?

I haven't been able to support as much as I would have liked, but the sponsorship I received from three companies (SAMcharter, The Business Software Centre and Gemini-Six) meant that I didn't have to complete one or two events, it was for the year. I want to volunteer at a few events if possible.

How do you feel having raised over £1,100?

Delighted, I always feel there is more to raise and I have decided to continue to raise money for *brainstrust* in 2021 and have had one company pledge to sponsor me into next year.

What exciting events are on the horizon for you?

In October, I am hoping to run in the Great South Run, then I have a 25 hour (It's the weekend that the clocks go back) endurance track race and in December I have the Milton Keynes Half Marathon. After the ultramarathon 25 hour event, I start to train properly for Brighton Marathon in April 2021

What keeps you motivated for the future?

Everything is different, no one really knows what is around the corner, no one knew what 2020 was going to be like for everyone. For me, 2020 was a chance to focus on good training, good eating to make me a stronger individual, more resilient. I want to finish my first marathon, then restart swimming lessons so I can take part in my first triathlon.



Choose Grey. Change Lives.

There are over 60,000 people in the UK living with a brain tumour. 30 more get diagnosed every day. From the most lethal brain tumour, a glioblastoma, to the long-term complications that come with a meningioma, every diagnosis changes someone's life, and the lives of their loved ones.

SO EVERY YEAR ON 1st October, we wear grey – the internationally recognised colour for brain tumours – TO GIVE VISIBILITY TO THIS INVISIBLE ILLNESS. People from across the UK come together to wear grey and show their support for people with a brain tumour.

“Each day I put on my brave face. I bury my fears, try to continue as ‘normal’. I am a wife, a mother, a daughter, a sister, an employee. I am surrounded by many, yet I feel so alone. I’m lost.”

This year has been unlike any other, but brain tumours didn't stop for Coronavirus, so we've been working round-the-clock to keep our support going. We're there for people when things are scariest, and we'll be here every step of the way on their journey, making sure they can have their best possible day, whatever that looks like for them. Through our coaching, workshops and resources, we are tackling isolation and building communities for people with a brain tumour. People we support report a 27% improvement in feeling part of a community and are 24% less alone after working with *brainstrust*. **So when you choose grey, and donate to *brainstrust*, you really are changing lives.**

It's never been easier to join us for Wear Grey. No matter who or where you are, you can take part in three simple steps.

Buy Grey

get yourself some Wear Grey merch – we've got t-shirts, beanies, face masks and more to choose from in our online shop.

Wear Grey

on 1st October, wear your grey gear proudly to show your support for the brain tumour community.

Share Grey

share a photo of you in your grey gear with #weargrey and send a donation to help people with a brain tumour.

Find out more at
www.brainstrust.org.uk/wear-grey

When someone you love has a brain tumour

BECOMING a caregiver for someone with a brain tumour can happen abruptly or creep in slowly unnoticed until one day you realise you are caring more for someone else than you are for yourself. **It is not a job you applied for. This new job as a caregiver can become as frightening as the initial diagnosis.**

We have developed a new section on our website specifically for caregivers of those with a brain tumour diagnosis.

By having access to information that is relevant to you, it should help you to:

- Know how to connect with others going through a similar experience to help you feel part of a community and less alone
- Have access to clear and concise information to help you feel better resourced
- Know where to go to and how to access support for you to help you feel more on top of things and more supported
- Find out the information you want to know about specific treatments to help you feel more engaged with your loved one's clinical care

Becoming a caregiver involves having to take on many new roles that you may not feel prepared for. Our information and support can help you to feel more in control and know where to turn to.

Visit www.brainstrust.org.uk/caring to see how we can be there for you when someone you know has a brain tumour.



Follow the Seagulls

50 miles makes an incredible difference. We know.

FOLLOW THE SEAGULLS is our iconic long-distance charity trek to help people beat brain cancer. It's your chance to do something truly incredible that matches your passion to help the 60,000 people in the UK who are afraid and alone because of their brain tumour diagnosis. It will take all you've got, but it will mean the world to thousands of people, and you'll make treasured memories to last a lifetime.

If you'd like to be a Seagulls Superhero, join us next April as we put on our walking boots to trek 50 miles over two days. It's a challenge

like no other, and there's no better time to take on your next great adventure in either Scotland, North Yorkshire, Devon or the Isle of Wight.

“Not only was it an epic physical and mental challenge, it was also one of the most humbling and rewarding adventures I've been on. It was an incredible achievement and opportunity to truly see the best in people; sharing stories, support and collective goals. As the aches begin to fade, my gratitude for this amazing charity, and the people it has connected me with, just grows stronger and stronger.”

Sammy (Seagulls walker 2019)

Follow the Seagulls and the superheroes that take part have now raised over £150,000 to help people with a brain tumour to be less afraid, less alone and more in control.

Registration is just £20 per person (£10 Early Bird available until 1st December 2020) all we ask is that you raise at least £500 in sponsorship to help *brainstrust* change the world for the brain tumour community. Every step you take truly will make an incredible difference.

Get in touch for more information – sophie@brainstrust.org.uk

Fundraising appeal

THE ARRIVAL of the Coronavirus pandemic and the lockdown that followed it, threw our fundraising strategy into turmoil. As events and challenges were cancelled across the country, we found ourselves in a worrying situation where our fantastic fundraisers were not going to be able to take on the challenges that they had committed to.

In response we created an appeal to help us to fundraise through other methods and were truly humbled by our supporters at all levels for their dedication and continued support.

We have seen individuals take on the Run, Row, Ride: LOCKDOWN EDITION challenge from home, raising over £4,000, with a further £4,000 coming from Facebook birthday donations. Corporate

supporters like Royale Life, CSC and Millgate Homes have gone out of their way to donate in the region of £16,000. We have also been lucky enough to secure over £130,000 in grants from emergency funding schemes.

We are incredibly grateful for all the donations that we have received from our supporters at every level, but we are not out of the woods yet. As the landscape continues to change

around us, and we start to return to some degree of normality, we are still very much in need of your support. The service we provide to the brain tumour community is unparalleled, and we have no intention of going anywhere, but many of our fundraising mechanisms remain untenable for now. Large fundraising events like races, gala dinners and festivals are still impossible to stage and we continue to look for new and innovative ways to raise money. In the meantime, our appeal remains active.

If you would like to support our work and make a donation, however large or small, please visit our website and click on the pink “Donate to keep our support going” button at the top of the page. Thank you so much for everything that you continue to do for us.

RUN, ROW, RIDE:

LOCKDOWN EDITION

All over the country in June, team *brainstrust* superstars took on Run, Row, Ride: LOCKDOWN EDITION to raise vital funds for people with a brain tumour during the Coronavirus pandemic, at a time when all other fundraising was halted.

EVERYBODY TOOK PART for different reasons. For some, it was in memory of a loved one lost to a brain tumour. Others wanted to give back to *brainstrust* after the support they received. People we had never met before raised vital funds because they know the importance of support for people when they receive a brain tumour diagnosis. Together, they ran over 500 miles and raised over £4,000!

Here we'll showcase some of the incredible, inspirational people that took part in the lockdown challenge.

Margaret

Margaret finished stereotactic radiotherapy in April, and she walked the challenge to rebuild her confidence and prove her strength. By the end, she had walked, cycled and ran throughout the 30 days and was on cloud nine. *"Somewhere buried deep and hindered by my weight gain is the ability to "run"! The fear of triggering a seizure has conquered. I just loved it. I felt like singing for you all!"*



Ellen and Amanda

Ellen and Amanda, long time supporters of *brainstrust*, ran their 30 miles and joined our Strava running club to stay motivated. Ellen said: *"We took on the challenge as we are now living together and*



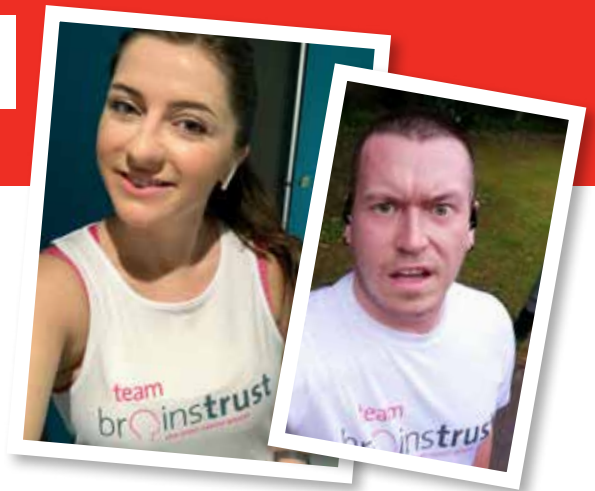
have always supported brainstrust as a team with previous fundraising events. The reason we support brainstrust is for the incredible support and resources they gave my mum and our family when she was diagnosed with a brain tumour."

Adam

Adam decided to really crank up the challenge and took on 30 miles of running, rowing AND cycling – all in 24 hours! He's been on a journey to take on as many epic challenges as he can, all in memory of his wife Jenna, and he's taken to YouTube (check out his channel Up4thechallenge) to share his experiences of them. If you've got a challenge that you think will test him, let us know, as Adam is always on the lookout for the next crazy thing.



We're so grateful to everyone that took part in the challenge and helped us raise vital funds to keep our support going through a period when



all physical events were cancelled or postponed. The funds raised by everyone were indispensable and meant that we could continue to be here for the people that needed us during the summer months.

RUN, ROW, RIDE RETURNS AGAIN IN NOVEMBER

Whether you want to build up your confidence like Margaret, or you're more like Adam, a seasoned athlete looking for the next big push, Run, Row, Ride is the challenge for you.

Even now, months on from the start of lockdown, the future of fundraising is still incredibly uncertain. This means that virtual events like Run, Row, Ride are more important than ever. Help us keep our support going into 2021 and join us for this challenge. **Visit www.brainstrust.org.uk/run-row-ride for more information.**



How coaching can transform your experience of living with a brain tumour

PATIENTS WITH CHRONIC CONDITIONS like brain cancer live with their condition 24/7, and only spend a fraction of their time visiting clinical experts: the rest of the time, they have to manage their condition themselves.¹ Put simply, most of the time you are a person, not a patient. And there are countless decisions related to your condition that you alone must make.

When we are no longer able to change a situation, we are challenged to change ourselves. You are the person who is ultimately going to have the greatest impact on your life.

Through coaching, you can learn how to face challenges, develop resilience and utilise resources to help you live better with a brain tumour.



How does coaching work at brainstrust?

Coaching is in our DNA; it informs the way that we run our Thrive events, it leads the conversations we have on our phone line and by email,

and is at the heart of our support at *brainstrust*. Coaching can help you realise what means the most to you and guide you as you produce a plan to reach your specific goals. This means that you can make your own informed decisions about living with a brain tumour. You are the one in control.

Our coaching relationships are built on collaboration, between you – the brain tumour patient or caregiver – and one of our trained support specialists. The role of our coaches is to listen intently, and ask key questions that will help you to understand and prioritise what matters most to you. We focus on achieving immediate goals which relate to specific areas. For example, weighing up the pros and cons of having a particular treatment, or overcoming a problem with caring. Coaching will help you to make courageous decisions about your life, focusing on the future to achieving a better quality of life.

“Thank you so, so much for your help and advice the other day, I think the best thing is I feel more in control now as I have a plan of action as such, whilst before I was floundering, and I don’t have any support network to help me with things ... thank you for that.”

Patient

“Today I am taking your very good advice – I have written down my priorities and I am going to sort them out one by one. That might sound very black and white but my goodness it’s a good feeling that it just might get me somewhere. What you have said to me is brilliant! I know what I am doing.”

Carer

Get in touch

Some people find regular coaching conversations to be the most valuable, whereas others prefer them on an ad hoc basis – perhaps before a scan, or when a new issue arises that needs careful consideration. If you’d like to see how coaching can help you to live better with a brain tumour, email us at hello@brainstrust.org.uk

¹ National Voices (2014) Supporting self-management: Summarising evidence from systematic reviews

Visit shop.brainstrust.org.uk

Christmas Cards – £10.00 for 3 packs
Grey Beanie – £8.99
Light Grey Tee – £10.00
Dark Grey Tee – £10.00



Visit shop.brainstrust.org.uk to shop to your heart’s content knowing that every penny you spend directly supports the brain tumour community. Whether it’s a gift for you, or a present for a loved one; by purchasing items from our shop, you’re ensuring that no-one feels alone, isolated or afraid after they hear the words “you have a brain tumour.”



Doodles for distraction

Looking for a way to unwind? We know that living with a brain tumour can make switching off and relaxing feel almost impossible.

So we spoke to Mr Woody Woods, Art Director, Illustrator and self-proclaimed “obsessive doodler”, to work on some doodle tutorials perfect for helping our community chill out. Together during lockdown we drew monsters, wrestlers and animals, and the 30 min tutorials are all still available over on our YouTube channel. Simply search for ‘brainstrust’ on YouTube.



No previous doodling experience required, as Mr Woody Woods takes you through every step.

Resources to help you cope: COVID-19 Brain Tumour Know Hows



During the pandemic, alongside our webinars and virtual events, we’ve produced several new Know Hows to support our community from home.

Money worries

When you are diagnosed with a brain tumour, you may find yourself worrying about finances. You may be worried about losing your job, about being on reduced pay, about running your own business and being unable to work. Or perhaps you are a caregiver, and you are not sure how you will manage being a caregiver whilst working. You can suddenly find yourself in financial difficulties for any number of reasons. This Know How provides you with a framework so that you can deal with money worries.

Mindfulness

The practice of mindfulness is about taking the time to focus on one particular task or activity, feeling relaxed yet awake and aware, and being completely present in the moment. When practised regularly, mindfulness can help to reduce stress and anxiety, which can help your emotional well-being and aid sleep. This Know How explores ways that you can practice mindfulness when living with a brain tumour.

Living with uncertainty

The Coronavirus pandemic has created uncertainty nationwide, but for people with a brain tumour this has had a deeper impact. As well as this collective shared uncertainty, they have faced further complexities around continuation of treatment, being required to “shield” and isolate from loved ones indefinitely and the upheaval of trying to adjust to a significantly “new” personal normal following diagnosis.

These problems are not something that can be easily solved, and so the aim of the Living with uncertainty Know How is not to provide solutions, but to help people get comfortable with living with uncertainty.



You can find all our online resources at www.bit.ly/brainstrustresources

Adam Parsons

Last year, Adam set himself a series of fundraising challenges shortly after his wife, Jenna died from a brain tumour at just 33 years old. The couple had been married for three-and-a-half years when she lost her battle against the disease in November 2019. Ever since, Adam has been supporting *brainstrust*.

A DAM SAYS: 'My wife was a nurse and when she was very ill, I asked what I could do as I felt so useless and she told me to help 'brainstrust'. Raising money for the charity means I can help people who are in the same position as we were and it gives me something to think about and focus on.'

Adam began his fundraising efforts by organising the Runaway challenge, where groups raise money for charity by getting as far away from Canterbury as possible in 36 hours – with no money, not for travel, accommodation or even food. Adam made it to Tel Aviv and the teams involved raised close to £1,700!

Soon after, Adam completed two half marathons in two weeks: Vitality Big Half and Cambridge Half Marathon. Due to Covid 19, all major events were cancelled, but this didn't stop Adam. During lockdown, the 35-year-old completed the London Marathon 2.6 challenge – which saw him rowing a total of 26 hours and 26 minutes over five days. Redefining the definition of a challenge, he then completed 30 miles of rowing, 30 miles of running and 30 miles of cycling all in less than 24 hours!

Adam has a place in next year's rescheduled Edinburgh Marathon. As a further tribute to his wife, who had always wanted to run a marathon, he will be taking part and carrying a second race number which has been registered in her name.

When the couple married after only eight months together, Jenna was in remission following treatment for a brain tumour.

Adam says: 'She was in remission when we met, she had undergone

treatments, including radiotherapy, but they found it had returned when she went to have one of her regular scans. They initially said they had found something, but weren't worried as it could just have been scarring, but a few months later we found it was back, then after months of chemo and treatment we found out it was inoperable.'

Adam says Jenna tried a variety of treatments to halt the progression of the tumour. He says: 'She had chemo, she went on a trial and she even tried CBD oil, she refused to give up and we carried on planning things like holidays, including a trip to Edinburgh and a holiday in Tenerife.'

Jenna carried on working, as a nurse advisor on the 111 NHS phone line, but her health declined rapidly as the brain tumour spread. Adam says: 'She was incredibly strong and wanted to carry on working. On the Saturday she was working on 111, but by the Monday she couldn't talk because the tumour had spread.'

Although Adam and Jenna didn't have children, they had a dog who Adam now treasures. He says: 'It was part of the deal of getting married, he was around before me – he had to like me if we were going to be together.'

'Jenna was pretty much everything that I'm not, everything I lack she made up for. She was the most



generous and kind person I have ever known, and she loved kids and not having children was one of the biggest regrets, she always said she wanted to be a mother, and she had so much love to give.

'Taking part in these challenges, running marathons, cycling, rowing, whatever it is, if it's a challenge then I want to do it and push myself. I remember my amazing wife and the challenges that she took on and fought.'

In celebration of our charity's anniversary, Adam has set himself an extraordinary challenge which will see him complete 15 marathons over 15 consecutive days in April 2021. Following this, he'll be completing an overseas trek and another series of iconic events, including the London Marathon.

As if all this isn't enough, Adam would like you to set him an ultimate challenge that surpasses everything he's taken on so far. **If you would like to help Adam in remembering his wife, Jenna, please visit his Just Giving page: www.justgiving.com/fundraising/adam-charles6** To submit a challenge request for Adam, please email sophie@brainstrust.org.uk

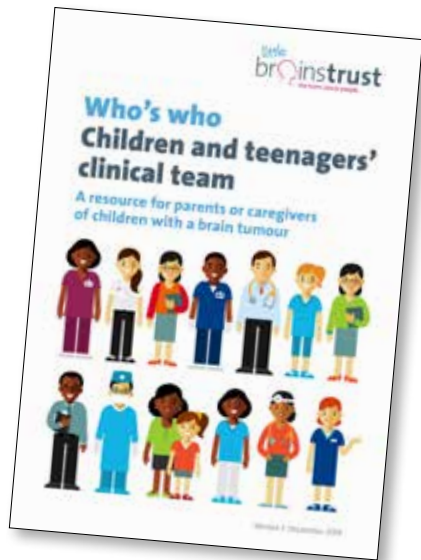


Runaway Challenge participants.

Support for children with a brain tumour

We know that once diagnosed with a brain tumour, children feel scared, and their carers isolated. You don't have to go through this alone.

WE HAVE WORKED with esteemed healthcare professionals, as well as parents of children with a brain tumour, to produce a brand new resource: the Who's who: Children and teenagers' clinical team guide.



The Who's Who has been designed for parents, children and teenagers to gain an insight into the role of the many professionals that they will encounter in and out of hospital.

We also have a series of little *brainstrust* Know Hows, on topics including Cannabinoids, How to get a second opinion, how to handle conflict and how to deal with overwhelm.

Little *brainstrust* cubs!

Build-A-Bear kindly donated an incredible sleuth of little cubs for us to send out to our incredible little *brainstrust* community. The bears are an excellent addition to our little brain boxes – the free of charge, essential toolkit specifically designed to support children and their carers following a brain tumour diagnosis. As a personalised service, each box is filled with child-friendly resources covering topics such as radiotherapy, proton beam therapy, fatigue and how to have a difficult conversation.

We appreciate how difficult things can be once a little person you love is diagnosed with a brain tumour; the '4am moments', the travelling to and from appointments, the stream of questions that pop into your head, trying to remember the jobs of all the people that you'll meet on your journey, and knowing who to turn



to and when. We know that this is a juggling act you simply don't need when you just want to focus your energy on making them feel better. This is why we created the brain box to help you keep on top of things.

Because we're passionate about well-being, we love to include special treats in every brain box. The kindness and generosity we receive from businesses like Build-A-Bear allows us to do this. In and amongst the devastation that a brain tumour diagnosis brings, these little touches create smiles, and prompt the need to focus on well-being.

To get your hands on any of our little *brainstrust* resources or to chat about how we can support you and your family following a child's brain tumour diagnosis, email Khadijha, our support specialist for children and families: khadijha@brainstrust.org.uk

little
brainstrust
the brain cancer people



Emma's brain tumour journey

“Life may never be the same after the operation, but the key word is LIFE and I am grateful to be here for both myself and for my family and friends. If it's an altered life going forward, then so be it.”

EMMA WAS DIAGNOSED with a brain tumour at the end of 2019 and has been sharing her updates on her blog detailing how she has approached life after diagnosis. This is Emma's story so far.

2019 was already a tough year for Emma and her family, including the loss of a close family member, so it was a shock to receive her brain tumour diagnosis towards the end of the year. Emma had been finding it difficult to focus and concentrate and went to see her GP with a number of other symptoms, including a prominent eye, tinnitus and severe headaches. She was quickly referred to an eye specialist and for a CT scan. They discovered that Emma had an intraosseous meningioma which is pushing her eye out and putting pressure on her brain.

At the end of 2019, the ophthalmologist and the neurosurgeon were talking about the complex surgery that Emma would need to have to remove her tumour. However, it is in a difficult location



which meant that the risks of surgery far outweighed the benefits, so the decision was taken to scan again in six months and review the options.

What the future holds

Emma was understandably curious to understand everything that is going on, and what may or may not lie ahead, which is when she found *brainstrust*. Having firstly received a brain box, which Emma treats as her Bible, she has also been receiving regular personal support from Jodie, the *brainstrust* Support Specialist for the Midlands. Spurred on by the support she had received from *brainstrust*, Emma decided that she wanted to give something back and got stuck into fundraising so that others can benefit in the same way.

Prior to lockdown, Emma hosted two events as part of Brain Tumour Awareness Month, firstly running a refreshment stall and a raffle at a rehearsal by the Warwick Rock Choir, generating over £200. For her second event Emma delivered a Charity Family Afternoon at her local community centre, with refreshments and a raffle running alongside a giant playdate, this time raising over £250! Alongside this, Emma has also been championing a JustGiving page for donations.

“It's the least I can do to say a big thank you. brainstrust's vision is that everyone with a brain tumour should feel less afraid, less alone and more in control. They provide invaluable support to patients and their families and are a definite worthy cause. If you can help, please do so where you can.”



Staying positive and supporting others

Emma's six-month scan recently went ahead in June, during lockdown. The scan revealed her tumour to be largely stable. Active monitoring will continue and, if/when surgery takes place, radiotherapy may also be offered to slow down any re-growth. Emma knows her symptoms won't magically disappear, but continues to remain as positive as possible. She's been a regular at the online “Brew with *brainstrust*” events with *brainstrust* staff and other brain tumour patients and caregivers via Zoom. It's a fantastic relaxed forum to talk with others about your brain tumour journey.

During lockdown Emma took her fundraising one step further and completed the Run, Row, Ride: LOCKDOWN EDITION, travelling 30 miles in 30 days. Alongside her young daughter Charlotte, Emma smashed her target and travelled 42 miles in total through a combination of walking, scooting and cycling locally, raising a further £200+ taking her total raised for *brainstrust* to £925!

If you're inspired by Emma's story and want to fundraise for *brainstrust*, visit our website or get in touch.

You can read Emma's blog by visiting happyfamilyhub.co.uk



Emma at her fundraising events.

Living with a brain tumour in a post-Covid world: face masks and anxiety

Unless we are medically exempt, it is now our obligation to wear a face covering in certain public places, such as on public transport and in shops.



Does making a mask make you feel anxious?

We know that the idea of wearing face coverings can be scary and uncomfortable, too. We know that there are some consequences of brain tumour treatment that can make wearing a mask more unpleasant – such as having a permanently dry mouth, caused by radiotherapy. If you're a glasses wearer, masks can be difficult because they cause your specs to fog up!

Do you wear glasses?

Specsavers have shared some helpful tips to help avoid your glasses fogging up:

1. **Make sure your mask fits snugly.** You can tighten the ear loops by twisting them into an X shape
2. **Secure the mask around your nose.** You can rest your glasses on top of the mask to help seal it, or use a little piece of surgical tape to secure the mask to the bridge of your nose.
3. **Breathe downwards into the mask.**
4. **Clean your lenses!** Glasses that could do with a clean tend to fog up more easily.

We also understand that for all sorts of reasons, wearing a face mask can make you feel anxious, so we've put together some practical tips to help you manage this new challenge.

Wear the mask more often

You may find that wearing a mask for short periods of time in a safe space, such as at home, or in the company of a trusted companion, might help. By safely and gradually exposing yourself to the concept of wearing a mask, you may overcome your fear.

Know that mask wearing is safe

Long before COVID-19, healthcare professionals and others have routinely been wearing masks as they go about their daily routines.

Reassure yourself that wearing masks is considered to be safe.

Re-focusing

Try listening to a podcast, or your favourite music, whilst wearing the mask to help you focus on something other than the mask. Focusing on your breath and observing your surroundings can also help.

Grounding techniques

When you're feeling panicked, try to notice 5 distinct things that you can see, smell and feel. Take your time to really focus on each thing. This will help ground you in reality and combat anxiety and panic.

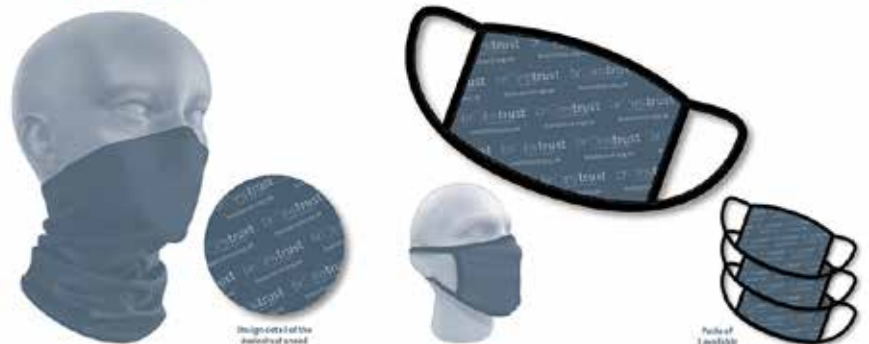
Understand the root of this anxiety

By identifying the trigger, you can begin to understand your response. Perhaps masks remind you of time spent in hospital. Positively remind yourself you are no longer in that place – you are safe.

Make it more 'you'

'Owning' your mask can help you to feel more positive and in control. So go for something fun, perhaps with a pattern that you like, rather than a medical style mask.

brainstrust face coverings



We launched our *brainstrust* branded face coverings for the brain tumour community, and we have a limited stock remaining. Comfortable, affordable and reusable, they meet the government's requirements and will help you feel safe and protected when out and about.

Give As You Earn

Feel good every payday with Payroll Giving. Donating this way is quick, simple and actually costs you less.

Your donation

Per month



Cost to you

Standard rate
tax payer



Higher rate
tax payer



Through Payroll Giving, any donation is tax free. That means when you give we get an extra 25% towards directly supporting people with a brain tumour.

Payroll Giving benefits

Payroll Giving provides us with regular, reliable donations that allow us to plan ahead, budget for the future, and reach more people affected by a brain tumour.

If payroll giving is something you'd be interested in, speak to your employer. If it isn't already set up, it's easy for them to do so. Visit the CAF website for more information.

Our impact 2019/20

Headlines:

- Our work continues to drive positive, holistic change in people's well-being across six indicators, which closely reflect the challenges our community faces.
- On average, people progress just over one point, or 23% (1.16/5), across the six indicators having received support from *brainstrust*, showing sustained impact since last year.
- We are having the most impact in tackling isolation and building communities for people with a brain tumour. Beneficiaries are reporting a 27% improvement (1.35/5) in feeling part of a community, and are 24% less alone (1.22/5).

How we made an impact:

- We supported 911 new people with events and/or coaching services.

- Our team handled 4,948 patient contacts, including 2,807 caregivers and 2,164 people who have a brain tumour.
- We posted 633 brain boxes, 57 of which were to children.
- During the year, 478 people attended 41 *brainstrust* supportive events, including 26 Meetups, 13 workshops and two full-day events.
- A total of 111,605 people came to our website for help, and they looked at 220,668 pages. Of the respondents, 92% said that the information on our website helped them to feel more resourced, more confident or more in control.

For more information on the difference we are making for people with a brain tumour, look out for our 2019/20 impact report.

Annual Report and Accounts

Every year we have to prepare a report, accessible to all, that explains our Charity's purpose; our vision and strategy; what we have achieved during the previous year and what we have done to achieve our goals. The report is accompanied by our annual accounts.

OUR 2019 REPORT is hot off the press and is available to read here www.brainstrust.org.uk/about-brainstrust/annual-report.

The difference we make.

The report and accounts are nearly 60 pages long, but key highlights include the fact that 93% of the people we helped reported a positive outcome. We've gone into

some more detail about our impact above, but encourage you to keep an eye out for the publication of the report to find out in more detail how we are supporting people with a brain tumour in the UK.

We can't do this without raising funds.

In 2019 you helped us raise £606,754. An increase of 2% on last year's income. There are many highlights and wonderful stories

that contribute to these headlines. Read these, and more about our work, how we are governed, our collaborations and our financial performance, in the full report, here:

www.brainstrust.org.uk/about-brainstrust/annual-report

Find the latest impact headlines at:
www.brainstrust.org.uk/about-brainstrust/our-impact/

The latest addition to the *brainstrust* team – meet Josie!

I'VE RECENTLY JOINED *brainstrust* as Support Specialist for Central Southern England covering Berkshire, Oxfordshire, Dorset, Wiltshire, Hampshire, the Isle of Wight and West Sussex.



It's my role to deliver our coaching and information service to help people living with a brain tumour diagnosis access the information and support they need.

I'm really looking forward to meeting more of our community and building on the support we offer in the South Central region.

If you live in one of these regions and would like to get in touch with Josie, send an email to josie@brainstrust.org.uk

Events Calendar

Wear Grey	October 2020
Run, Row, Ride	November 2020
Cambridge Half Marathon	March 2021
Follow the Seagulls	April 2021
Lincoln 10k	June 2021
London Marathon	October 2021
Loch Ness Marathon	October 2021

Find out more at brainstrust.org.uk/events, email sophie@brainstrust.org.uk or call 01983 217 154

Letters from lockdown



Matty is 15, and he's been through more than most go through in a lifetime.

He was diagnosed with a brain tumour in December 2016, following which he had

a major operation to remove as much as they could, as well as chemotherapy and radiotherapy. He was in remission for a while and then he relapsed in December 2018. He had been in remission since the summer but unfortunately earlier this month, his family got the heart-breaking news that Matty now has two further tumours, and chemotherapy has resumed.

Lockdown has understandably been incredibly difficult for Matty. But when he came down one morning to find a letter on the doormat from his lovely Aunty, his mood was transformed. This set her off on a mission to get Matty as many letters as possible. We sent Matty a parcel, a little brain box and a letter from the *brainstrust* team, and then asked our incredible community on social media to send their letters too.

Matty has now received over 800 letters, parcels and video messages, from strangers, famous people and loved ones across the world. One extra special delivery coming from our patron Stephen Venables.



A special delivery

Matty got a parcel and letter today from someone who has shown true courage and bravery. Stephen Venables is a mountaineer, explorer, writer, broadcaster and public speaker

– in 1988, Venables became the first Briton to ascend the summit of Mount Everest without bottled oxygen. Stephen is also one of the patrons of the amazing *brainstrust* charity – something very close to his heart – as he lost his son to a brain tumour aged 12.

He told Matty that he had found out from Will at *brainstrust* that he has been having a tough time with his tumour. However, he had seen the great pictures on our Facebook page of him laughing and looking courageous. He sent his congratulations on coping so well and his best wishes for a good recovery. He hopes that Matty may enjoy his book about Mount Everest which he climbed many years ago.

Thank you so much Stephen, Will and all at *brainstrust*. This was a very special letter and parcel and – Stephen – don't worry – we could read your writing!

Moving forwards on your brain tumour journey:

SARAH'S STORY

In March 2018, Sarah was diagnosed with a meningioma.

SHE REACHED OUT to *brainstrust* after searching for help and answers online, and has since received regular support from Jodie, our support specialist in the midlands, as well as fundraising many thousands of pounds with the support of her husband Paul and their FootGolf league.

brainstrust resources such as the brain box and fatigue book, together with coaching from Jodie, have helped Sarah move from a place where she felt lost and confused, to a place where she feels confident and part of a community.

“Thanks to brainstrust, I now feel like I am part of a community and feel comfortable and confident whenever I have needed to ask for help. I stopped feeling lonely and scared, as I now know there is always someone who will help. When you hear the words ‘you have a brain tumour’ your

life changes in a split second. Having brainstrust there has helped me to deal with it, and I will be forever grateful.”

Thanks to Sarah sharing her experiences, and completing three *brainstrust* Progress Trackers since 2018, we can visualise the difference that our support has made for her.

Sarah's progress

- When Sarah first connected with *brainstrust*, her average score was 2.3, meaning she started in a place where “things are difficult but I'm working on it”

- From July 2018 to April 2020, Sarah reported a 43% improvement (2/5 points) across all areas of well-being
- The greatest improvement has been in how supported, resourced and part of a community Sarah feels. She scored five for these areas, equating to “I'm as good as I can be in the circumstances”

“I have had email and phone support from Jodie – whatever questions I have, or if I am struggling with things, I can contact Jodie, who always helps me. We have regular coaching sessions over the phone, as after my operation I was struggling with my confidence. Jodie has talked to me, listened to my worries and helped me to come up with ideas of how to rebuild my confidence.”

Sarah and Paul have been incredibly committed to their fundraising efforts, and they haven't let the Coronavirus pandemic stop them! During lockdown, the UK National FootGolf Club League has held two online race nights, raising £131 through donations and an auction race. Thanks to Sarah, the Buxton Virtual Garden Trail has supported *brainstrust*, allowing people to enjoy beautiful gardens and stunning shots of nature from the comfort and safety of their home.



Give the gift of...



Community (£10)



Give the gift of...



Support (£20)



Give the gift of...



Knowledge (£40)

Having access to knowledge, support and community can transform the lives of people affected by a brain tumour diagnosis. You have the power to make that happen.

shop.brainstrust.org.uk

Give a gift with meaning...

Registered charitable trust – brainstrust
is a registered charity in England and Wales
(1114634), and Scotland (SC044642).


Change the way you hear from us



Your personal data is very important to us because it allows us to help people living with a brain tumour. Your details will only be used by *brainstrust* in adherence to our privacy policy. We will never give your information to other organisations without first seeking your specific consent. You are free to change your mailing preferences at any time. To change the way you receive news and information from *brainstrust*, please visit www.brainstrust.org.uk/contact, email preferences@brainstrust.org.uk, or call us on **01983 292 405**.