

The Brain Tumour Charity shining a light on

The GREY MATTERS

The **BRAIN
TUMOUR
CHARITY**

Research | Awareness | Support

Issue 10 Autumn 2015

Losing Myself: The Reality
of Life with a Brain Tumour

Start the Christmas season with us

Join our Research Involvement Network

SAVE THE DATE

**BANDANAS
FOR BRAIN
TUMOURS**

4 MARCH 2016

thebraintumourcharity.org



Congratulations to our founders

Neil and Angela Dickson, founders of The Brain Tumour Charity, were awarded MBEs for their services to the brain tumour community on 17 July 2015.

Neil and Angela founded the Samantha Dickson Research Trust 18 years ago following the death of their 16 year-old daughter from a brain tumour. The charity became the Samantha Dickson Brain Tumour Trust, which later merged with Brain Tumour UK and The Joseph Foote Trust to create The Brain Tumour Charity.

We are delighted that what they have done for the brain tumour community has been recognised in this way.

“When my wife Angela and I started the charity from our front room we did not dare to imagine that it would go on to achieve so much. We will continue in our fight to make brain tumours a thing of the past.”
Neil Dickson MBE

Over 9,300 people are diagnosed with a primary brain tumour every year. We remember all those who have lost their life to a brain tumour and those who have lost family and friends.

Last chance to sign up to The Twilight Walk

If everyone taking part in The Twilight Walk raised £100 we could fund a pioneering research project for three years. We need you to #Walkwithus.

Registration is £15 for adults and £10 for children, under fives are free.

Don't miss your chance to #Walkwithus in Windsor, Chester, Warwick or York during September and October.

Sign up at thebraintumourcharity.org/thetwilightwalk



Hello

Welcome to The Grey Matters, a chance to catch up on everything that The Brain Tumour Charity has been doing lately.

After Lewis retired as England Rugby captain, we set up The Lewis Moody Foundation to give children facing serious illnesses enjoyable days out. We also wanted to fund research into brain tumours because they are the biggest cancer killer of children and adults under 40. Working with The Brain Tumour Charity has given us so much more than that; we really feel part of an enthusiastic team who are making a difference to the lives of people living with a brain tumour.

We've loved joining the Family Days in Wiltshire and Gloucestershire which inspired us to create more special days for families. And, because we're in it for the long haul, our foundation is raising funds for The Charity's biobanking project,



meaning that we'll be building something researchers can use well into the future.

As in any good team, we are really happy that The Brain Tumour Charity is supporting our Pass the Ball campaign for Childhood Cancer Awareness Month this September. If you haven't already passed it on, get involved on page 25.

Every step makes a difference, see you on the way!

Lewis and Annie Moody

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Losing Myself: The Reality of Life with a Brain Tumour



You may find the content of this article upsetting, especially if you or a loved one is currently living with a brain tumour, and may not wish to read it. You can contact our Support & Info Line on support@thebraintumourcharity.org or 0808 800 0004 (free from landlines and mobiles).

Image: Rebecca Reed, one of our Young Ambassadors who was diagnosed with a brain tumour after a fall, appears on the cover of the report. Rebecca graduated as a doctor of medicine this summer.



2 in 3 people suffer from fatigue



72% have had physical intimacy affected



2 in 3 have seen a negative impact on relationships with their partner

"Before surgery, when I had my brain tumour, my confidence was at rock bottom. I was very isolated and insular; I didn't even have eye contact with my children. I used to hallucinate dinosaurs flying over the streets of Liverpool and genuinely believed they were real. I knew I couldn't tell anyone in case I got locked up. What I didn't realise is that the hallucinations were temporal lobe seizures; my brain tumour was swelling." Emma, 36, Liverpool

For years before her brain tumour was diagnosed, doctors told Emma that she had a mental illness. Stories like hers inspired our goals of doubling survival and halving the harm that brain tumours have on quality of life. But goals alone are not enough; we also need to bring them to life. That's why, working with our partner Alterline, we've published the *Losing Myself* report.

Losing Myself brings together the stories of how much harder life is when someone's living with a brain tumour. It is not an easy topic to talk about and we are enormously grateful to everyone who so openly shared their experiences. Over 900 people completed our survey, 15 were interviewed and 25 kept diaries, resulting in the most in-depth and significant study into the quality of life for someone diagnosed with a brain tumour that has been done.

The report shows that many people found that living with a brain tumour meant 'losing yourself' as their personality, memories, thoughts and relationships were damaged. Not being able to work, socialise or help around the house ran alongside the daily fear of dying and anxiety for those who would be left behind.

Together we are already supporting thousands of people through our Support & Info Line, face-to-face conversations, online help and Information Days. But we are going to do much better than that.

Our *Defeating Brain Tumours* strategy explains how we are going to make sure that diagnosis is faster and more people have better access to NHS support services wherever they are.



2 in 5 have difficulty with personal care



37% have balance problems



2 in 3 lose their driving licence or can't drive

What's in the report?



Karl lives in Barnsley with his wife and two young children. He describes what daily life has been like since he was diagnosed with an astrocytoma in 2009. With seizures and chronic fatigue, Karl isn't able to work and has left his job as a regional manager for a British Gas training company. He raises funds and helps those living with a brain tumour in whatever ways he can. He said "My three year-old son sat next to me while I had a seizure. He stroked my head and told me that everything would be OK".

"It's strange to think that my cat will outlive Dad."

Phillip, overhearing his son

"I couldn't afford to stay off work, and so I decided to go back just three months after surgery."

Tasmin

"I keep thinking maybe it's all been a bad dream; maybe we will wake up. It took us so many years to find each other."

Dafydd

Funding call for quality of life projects

We are now calling on researchers to submit ideas on reducing the burdens that a brain tumour places on quality of life. Projects could focus on any part of the patient pathway from diagnosis to remission, survivorship or end of life care. Funding is for up to £300,000 for up to three years.



1 in 3 have
visual problems



70% have given up sport
or exercise, or reduced
what they do



1 in 4
experience seizures

Our Plan

One of the goals in our *Defeating Brain Tumours* strategy is halving the harm caused by brain tumours, including improving life today. Our own targets are doubling the number of people we support each year until 2020, ensuring that at least 90% of those using our services tell us that their quality of life has improved and they feel more in control of what is happening. We'll also be working with everyone in the care system to:

- Map the patient pathway for treatment, care, research and all the systems around people living with a brain tumour, meaning that they will be able to navigate the road ahead more easily.
- Use the information from *Losing Myself* to develop and prioritise more information and support for each stage of people's journeys, so that no one has to face an uncertain future without support.

- Keep looking at the impact of brain tumours on people's lives to make sure we are on track and are solving problems as they arise.
- Improve the experience of patients with brain tumours in the NHS by developing a patient pathway for treatment and care, and calling for a quality standard.

We believe that our plan will mean that we see more positive results if we run the same survey in 2020. To do it we need to keep listening to the stories that our community shares with us. Together we can create a world where brain tumours are defeated.

Read the report and share your story at thebraintumourcharity.org/losingmyself

Contribute to our work at thebraintumourcharity.org/donate

Look out for our children and families survey coming soon!



1 in 3 are severely isolated



56% have seen a negative impact on their relationship with children or grandchildren



1 in 2 experience financial difficulty

Clinical trial

Only 3% of brain tumour patients are taking part in a clinical trial, compared to an average of 7% for all cancers. Yet clinical trials are the pathway where scientific ideas transform into treatments. That's why we want every patient to have the opportunity to take part.



0 Before a drug can get to trial researchers need:

- Basic research to learn how the disease works biologically and what drugs can treat it.
- Translational research to turn new ideas into potential drugs.

PRE-TRIAL

PHASE

3 Is it better than what we have?

The recovery and side effects in two groups of patients are compared, one on the standard treatments and one on the new drugs.

PHASE THREE

PHASE

Licensing

If a treatment is safe and effective it will be licensed. The NHS considers the clinical benefits and cost.

4 What are the long term risk and rare side effects? Thousands of people take the drug and combinations of different drugs can be trialled.

PHASE FOUR

New trials we're funding

All of these trials are co-funded by The Brain Tumour Charity and Cancer Research UK.

Phase 1

Professor David Walker's team at the University of Nottingham and Birmingham Clinical Trials Unit are delivering chemotherapy directly into the cerebrospinal fluid around the brain. They're hoping to reach tumours in the membranes around children's brains (leptomeningal disease). OSCAR's Paediatric Brain Tumour Charity is also co-funding this trial.

Phase 1/2

Working on drugs to treat childhood glioma, Dr Susan Picton's team at the University of Leeds and Birmingham Clinical Trials Unit are looking at the safe dosage of two drugs, nilotinib and vinblastine.

Phase 2

Aiming to improve survival and quality of life, Dr Darren Hargrave's team at Great Ormond Street Hospital are trialling three drugs to treat Diffuse Intrinsic Pontine Glioma (DIPG) according to tumour subtype.

Dr Richard Baird's team at the University of Cambridge is testing if radiotherapy helps a tumour targeting drug, afatinib, to cross the blood-brain barrier.

Dr Gillian Whitfield's team at the University of Manchester and the UCL Clinical Trials Unit are testing if targeting radiotherapy at a specific part of the brain reduces the memory and learning difficulties that can occur after whole brain radiotherapy.

Phase 2/3

Following our research by Professor Steve Clifford distinguishing lower risk medulloblastoma tumours, Dr Antony Michalski's team at Great Ormond Street Hospital and Birmingham Trials Unit are testing ways to personalise new radiotherapy and chemotherapy treatments for children.

Find out more at thebraintumourcharity.org/currentresearch

Search our online clinical trials database
thebraintumourcharity.org/clinicaltrialsdatabase

1 Is it safe and what's the dose?
A few patients take the drug, and each new group takes a bit more.

ONE

TWO

2 Does it work?
More patients trial the drugs over a few years to see whether it has any beneficial effects on the tumour.



Q&A with Dr Erica Wilson

University of Leeds

Dr Erica Wilson is a Postdoctoral Research Fellow at the University of Leeds. We are co-funding her team, led by Professor Susan Short, which hopes to harness viruses that can kill high grade glioma cells without harming healthy ones. Dr Wilson's been working on the programme since it began in 2014.



Why did you become a researcher?

I've always enjoyed asking 'why?' so I never really thought about doing anything else. Understanding the intricacies of how cells work and interact is fascinating.

What excites you about your job?

Being a researcher means being curious about the unknown and working to understand it. That's a great reason to come to work.

What is your typical day like?

I spend about 70% of the time in the lab and the rest in meetings and organising experiments. At the moment I'm in the office a lot, which is necessary for publishing our work, but I'd rather be in the lab!

What difference will your work make to patients?

I'm part of the group researching viruses that kill glioblastoma cells. Scientists don't have a good understanding of how the immune system reacts to a virus in the brain, so I'm finding out more about how brain cells respond to viruses and if we can manipulate that response. It might seem

a long way from patients but if we can harness the power of the immune system it will be a huge benefit.

Can you tell us something surprising about the brain?

Many of the molecules that help us respond to viruses and bacteria in our bodies have completely different functions in the brain. On top of that the immune system in the brain is very different the rest of the body. The immune cells in the brain spend most of their energy trying not to do anything!

What does your research add to what we know about brain tumours?

There have been some great strides recently in targeted therapies for cancer, all of which came from basic scientific research. Cancer isn't one thing; it's a million variations of our own cells growing and causing disease. Until we are able to understand that complexity we won't be able to treat it successfully.

Find out more about Dr Wilson's work at thebraintumourcharity.org/harnessingviruses

Funding clinical research training fellowships

With the Medical Research Council (MRC), which is funded by the government's science and research budget, we co-fund doctors to specialise in brain tumour research. We recently awarded funding to Dr William Singleton in Bristol for work on malignant gliomas, the most common primary cancerous brain tumour in adults. Dr Singleton is keen to get findings from his lab research into a clinical treatment as quickly as possible so he's working on developing a new drug and a new way to get it to the tumour.

Our bodies' immune systems usually kill abnormal cells, but gliomas change their environment so that the immune system doesn't do its job. Dr Singleton is going to explore if we can use drugs that have shown immune boosting results in other cancers to provoke the immune system to attack glioma cells, leaving normal brain cells unaffected.

Drugs also need to cross the natural barrier between the brain and the blood-stream (the blood-brain barrier) to reach the tumour so Dr Singleton is testing if surgically implanted micro-catheters could help.

First steps towards reducing adult diagnosis times

We need to understand how long diagnosis currently takes and the difference an earlier diagnosis might make.

With a team in Edinburgh, Bristol and Exeter, Dr Paul Brennan is creating guidelines on referral for GPs. The team will look at what led to the diagnosis of patients with a brain tumour or suspected brain tumour in South East Scotland and what delayed the process.

Dr Fiona Walter and her team in Cambridge are looking at the underlying reasons, opinions and motivations (a qualitative approach) to find out what behaviours can help to make an earlier diagnosis.

British Neuro-Oncology Society annual meeting

In July, many of the researchers that we fund presented their work at the 2015 annual meeting of the British Neuro-Oncology Society (BNOS). There were presentations on the impact of our HeadSmart campaign and an advanced release of the *Losing Myself* report, which was immediately referred to in later presentations and discussions.

We sponsored the Stephen Baker Memorial Lecture presented by Professor Michael Weller, president of the European Association of Neuro-Oncology (EANO) and Chair and Professor of Neurology at the University Hospital Zurich. His work on glioma therapy is producing some interesting results that we hope will develop into new ideas.



Be part of our Research Involvement Network

We believe that people living with a brain tumour and everyone around them are equal parts of finding the solutions that will lead to us defeating brain tumours. By sharing first hand experiences, people who understand what it means to live with a brain tumour can help researchers to shape or evaluate new research. That it is part of what we mean when we talk about being a united community and every patient as a research patient in our strategy. We mean that we have to do whatever we can together to speed up the search for a cure.

That is why we need everyone to join our Research Involvement Network. The network brings together people who have become experts through their experience of brain tumours and professionals to share their ideas and experiences. In turn, research is more relevant and based on more accurate information. The network is online so members can contribute to finding the cures we need as part of their everyday life.

Sign up at thebraintumourcharity.org/researchinvolvementnetwork



Image: Deborah, a member of the network, enjoying a Family Day with her daughter Ella, and son Jacob. Ella was diagnosed with a brain tumour at the age of three.

Dr Kim Bull explains how she used the network to create her latest project:

"We want to look at whether giving information on children's quality of life to clinical staff improves rehabilitation and care. The Charity helped to gather views from young people. At a Paediatric Information Day I explained the project and demonstrated an online system for gathering information about care from parents and their children. We also gave families the opportunity to have a say about the research and to stay involved with it as it progressed.

"The network meant that we have direct contact with families who would otherwise be difficult to reach if they weren't part of such a patient organisation. In this way, The Charity is able to support both researchers and families in our common goal of improving the lives of people affected by a brain tumour."

"Being involved in research is vital in moving forward to help with early diagnosis and treatment of brain tumours. It was great to be involved in this group, for our experiences to be useful and to feel like we were giving something back. It's really important that families, clinicians and researchers pull together to help direct future research and help in the fight against brain tumours."

Deborah



Latest publication

Professor Kennedy and Dr Kim Bull are looking at the behaviour, emotional wellbeing and quality of life of children aged 8-14 years following treatment for medulloblastoma or low grade cerebellar astrocytoma tumours.

In July 2014 their work was published in the scientific journal *Neuro-oncology*. Their findings showed that using questionnaires with children being treated for a brain tumour can reveal reductions in IQ. The next step is to explore whether using the questionnaires would encourage crucial early intervention by clinical psychologists and other healthcare professionals if they were used in hospital or school settings.

Read more about this research:
[thebraintumourcharity.org/
learningdifficultiesquestionnaire](http://thebraintumourcharity.org/learningdifficultiesquestionnaire)

Join our network by completing the online application form or find out more at [thebraintumourcharity.org/
researchinvolvementnetwork](http://thebraintumourcharity.org/researchinvolvementnetwork)



The Supporter Groups

Supporter Groups are a wonderful way to bring friends, family and colleagues together to fundraise in memory of, or inspired by, a loved one. Each group is committed to fundraising on an ongoing basis and is supported by a dedicated team every step of the way.

Alex Thompson lived in Bedlington, Northumberland with his Dad, Brian, his mam, Angela, and sister, Eilish. He was a talented drummer, telling his family that he was living his dream by studying a music degree at the world renowned Tech Music School in London. His long term goal was not to be rich and famous, but to work

as a session musician so that he could play as many styles of the drumming he loved.

Alex's drumming meant that he was very fit so it was unusual when, in April 2011, he started suffering from severe headaches and sickness. He was repeatedly diagnosed with stress until an urgent MRI scan at Charing Cross Hospital showed a massive tumour on the right frontal lobe of his brain requiring immediate surgery at the Royal Victoria Infirmary in Newcastle.

In March 2012 another MRI showed that the tumour had returned and, sadly, further surgery was out of the question.

Despite recognising the excellence of his hospital care, as his health deteriorated his family made the decision to keep him at home for the remainder of his days. Alex passed away peacefully on 23 July 2012 surrounded by his family. On 29 November 2012 he graduated posthumously with his peers at Wembley Stadium. Eilish collected the award on his behalf.

When Alex was first diagnosed he told Angela that, if he died, he did not want any floral tributes. Instead he wanted any money to be donated to The Brain Tumour Charity. He felt that the only way to stop other people and their families going through what he and his family had was to research and develop new treatments and eventually find a cure for this devastating disease.

After his death, his family promised to fulfil his wish. They formed The Alex Thompson Fund, raising money for The Brain Tumour Charity. Since that point the family and friends have raised thousands for research into brain tumours.

In July 2015, Brian sent an email to our Supporter Group team saying: "We held an event at the weekend, a family fun day, which did suffer a little from the poor weather but still made around £1,000 and everyone had a good laugh. The Thompson family contribution was a cake stall; Angela and Eilish are both very good cooks and spent days baking in preparation."

Through their group the Thompson family have a way to honour the words of Alex, "We must all fight on and never give up hope that a cure is just around the corner".



To find out how to set up your own group contact us by email or telephone:

supportergroups@thebraintumourcharity.org

thebraintumourcharity.org/supportergroups

01252 749043

Welcome to our new groups

The Selina Keshav Fund

The Sandy Woolett Fund

The Bobby's Fund

The Small but Mighty Fund

The Jean Wright Fund

Images (above): Cakes from The Alex Thompson Fund cake sale.

Influencing people with the power to make a change

As the brain tumour community comes together, our voice gets louder. We are building the scientific and personal knowledge of treating and living with a brain tumour, using our knowledge to influence decision makers by spreading awareness and understanding of the disease so that, when they make decisions, our community benefits.



Find out more from
policy@thebraintumourcharity.org

Find your MP on
theyworkforyou.com/mps

All Party Parliamentary Group on Brain Tumours

Our APPG is a cross-party group of MPs that meets to get a deeper understanding of the issues around brain tumours. Managed by us with other brain tumour charities, the APPG meetings are open to all those affected by a brain tumour as well as MPs and clinicians so that the discussion is filled with the expertise of those with real experience of the disease.

In July, our open day gave MPs a chance to show support for our work. Rebecca Harris MP was re-elected as chair and we welcomed new members, including the newly elected Caroline Ansell, MP for Eastbourne and Willingdon, whose son was treated for a brain tumour.

You can increase the influence of the APPG by asking your MP to attend the meetings, speaking to them about your experiences at local events or coming along to the APPG yourself.

Images (left):

Caroline Ansell MP joins our APPG.



Accelerated Access Review English Cancer Strategy

Earlier this year the Westminster Government began the Accelerated Access Review to find out how to speed up access to promising new drugs for patients across the UK. The review is guided by an advisory group of researchers, charity representatives and people from industry and is due to report in December. It will look at using drugs that have been approved for one disease to treat other conditions. Our research strategy, *A Cure Can't Wait*, explains how this could reveal new ideas for treating brain tumours. Drugs such as hydroxychloroquine, previously used to treat malaria, have shown potential for treating gliomas.

Our team will be contributing to the review making sure it considers the dramatic impact this could have on drugs to treat brain tumours. We will highlight the Early Access to Medicines Scheme which allows some patients to access new medicines before they have gone through full regulatory processes. The scheme has been used for DCVax, a brain tumour vaccine for glioblastomas.

In the Independent Cancer Taskforce's report *Achieving world class cancer outcomes: a strategy for England*, charities took the opportunity to set out how cancer services should be delivered by the NHS in England for the next five years. Together we now need to make sure that NHS England and Public Health England take action. We must also ensure that patients in Scotland, Wales and Northern Ireland also have access to the best standards of treatment and care.

The taskforce suggested that Public Health England and NHS England should look closely at the findings of the HeadSmart research to understand what leads to late diagnosis in children. They recommended a new target for 95% of patients to be diagnosed within four weeks of being referred for testing by a GP.

The taskforce also set out the need to improve support for people living with a cancer diagnosis, also shown in our *Losing Myself* report (page 4). Finally, they said that commissioners should meet the extra treatment costs of non-commercial research in the NHS, which could help increase participation in clinical trials, another issue addressed in our strategy.

start the season with us

Why not make The Brain Tumour Charity a part of your festive celebrations and reflections with our fundraising gifts and events?



Cards and presents

Our Christmas catalogue 2015 is full of cards and gifts for you to choose from. Order all you need in one go from thebraintumourcharity.org/shop



Last year our seasonal sales raised over £55,000. That's enough to pay for a research project such as Dr Jennie Jeyapalan's work at Queen Mary University of London for the whole year.

Dr Jeyapalan is looking at low grade astrocytoma brain tumours in children. She's finding out which genes are active in tumour cells compared to normal

brain cells and looking at the small molecules (microRNAs) which regulate the genes to see if she can make a difference to what happens in the tumour.

Dr Jeyapalan said, "The Brain Tumour Charity has an excellent peer-review system for choosing research projects, which means that only the best work is chosen."



Carols at Christmas

Come and sing along to popular carols.

When: 8 December 2015

Where: St Giles-in-the-Fields, London

How much: £10 (free for children under five)

Book now for your family and friends at thebraintumourcharity.org/carols

“Because we’re integrated into The Charity, we can showcase the research which is finding cures for brain tumours by hosting visits to the lab for fundraisers and people who’ve been affected by this devastating disease. These interactions cement our resolve to understand brain tumours and to make a difference!”

The Christmas Angels

If you want to give a little extra, why not volunteer as a Christmas Angel, selling our cards to friends and family? Sign up for a sales pack at volunteering@thebraintumourcharity.org



Santa Run

Sign up to dress up at the 5k Santa Runs across the country on Sunday 6 December. Book your place today: thebraintumourcharity.org/events



Improving life today

Improving life today is a crucial part of halving the harm caused by brain tumours. We know how important quality of life is, especially now that we have the *Losing Myself* report. Providing services to everyone affected by a brain tumour is what we do, as is working with others to make sure that everyone affected is able to access the services and information they need.

A Clinical Nurse Specialist for Shrewsbury

Having a local Clinical Nurse Specialist improves equal access to treatment because a key worker is available to answer clinical questions, meaning that people being treated for a brain tumour can raise concerns, bring scans forward and get links

to more information when problems arise day-to-day.

That's why we called on the government to give every brain tumour patient access to a clinical nurse specialist by 2020 and supported the Shropshire Cancer Forum to make the case for a CNS in Shrewsbury to the local hospital trust. Di Evanson was appointed in April 2015 and since then she has set up brain tumour support groups that are used by people from both England and Wales.

Let us know if you don't have access to a brain tumour clinical nurse specialist. Our operations managers will help to put a case for improving local services. Find your local operations manager at thebraintumourcharity.org/supportteam



Photo credit: Shropshire Star

Scottish Adult Neuro-Oncology Network

By sitting on the Scottish Adult Neuro-Oncology Network (SANON) we are part of a group that links together health professionals, patients and people from the voluntary sector. This gives us a stronger voice to influence service delivery, through reviewing clinical management and guidance documents for example.

The Powys Neuro-Café

Last year, The Brain Tumour Charity, Headway and Epilepsy Action saw the need for a support group in the Powys area of Wales but we knew that there were not enough people with each condition to start free-standing groups. Working together, we created the Neuro-Café in Ystradgynlais, Powys, which is open twice a month to anyone who is affected by a neurological condition, including families and friends. By collaborating with other charities, people affected by brain tumours are also part of the wider neurological community and have support near to them.

Dates for your diary

30 September - 21 October
Coping Better Together
Information Afternoons, Liverpool
Four sessions to learn how to cope with living with a brain tumour.

1 October
Information Day, Glasgow
A chance to meet experts, patients and carers.

10 October
Way Ahead Day, Derby
A chance to ask questions and get the most recent local information.

14 November
Family Day, Manchester
A fun day out for children with brain tumours, their siblings and parents.

24 November
Information Day, Brighton

For the latest news on support dates near you and to sign up email support@thebraintumourcharity.org



Support for Northern Ireland

Ricky Devlin is our new Operations Manager in Northern Ireland. He's dedicated to ensuring that all people in Northern Ireland have access to the support that they need when faced with a brain tumour diagnosis. Ricky will be working closely with patients and healthcare professionals to ensure that everyone has equal access to treatment and care. Get in touch at richard.devlin@thebraintumourcharity.org

Alice and Emma

"I hope you can look at Alice and see that things can turn out fine in the end."

In July 2015 Alice was discharged after nine years of treatment and monitoring for a brain tumour. Her mum Emma talks about what it means to get to the end of treatment.

My youngest daughter, Alice, was diagnosed with a pilocytic astrocytoma in July 2006, shortly after her third birthday. The news hit our family like a train, and even now the memories of those early days can catch me off guard and overwhelm me. But, over time, the small piece of tumour that was too close to her brain stem for the neurosurgeon to remove has been closely monitored and amazingly it has shrivelled away to nothing.

So here we are, nine years on, and at her most recent scan her consultant told us that our journey with the paediatric oncology team has come to an end. We are discharged. It's a little strange, learning to live without the background presence of the oncology team providing a quiet reassurance that all is well. Alice, of course, is delighted; no more cannulas and no more scans and I am taking my lead from her, not least because of all the other families we have met along the way who long for the day they are in our position.

If anyone was to ask me what going through this experience has taught me, it is to never take anything for granted.

Working as an emergency nurse and then as a paramedic for over 20 years, you'd think I would have known that already. But until that day in July 2006 I'd only ever dealt with other people's life threatening situations. Then Alice's illness crashed, uninvited, into our lives and taught me that it really can happen to anyone.

Now I am thankful every day that Alice is not only well, but a happy, kind, sensitive and very loving little girl. She is doing well at school, enjoys seeing her friends, having sleepovers, and is developing a love for the theatre. Anyone who meets her for the first time these days is none the wiser to the fact that she was ever ill.

To anyone in the early stages of this journey, my heart goes out to you. I hope you can look at Alice and see that things can turn out fine in the end. I'll never forget the early days when everything was uncertain, but I don't always think that's a bad thing. Remembering the worst of times has given me a sense of perspective on life that few people ever achieve.

The Story of Hope



Happy Birthday Jake

This autumn we are celebrating one year with Jake. In the past year our animated eight year old boy has been viewed over 6,000 times and all the children we've asked told us they feel less scared of going in to hospital and are happier talking to others about their brain tumour. Siblings, parents and adults who have a brain tumour also told us how much he has helped them.

View the animations and let us know what you and those around you think about Jake at thebraintumourcharity.org/jake

"Before I watched Jake I was really scared of needles. Jake had a needle and made it less scary. I still don't like them but I try to be a lot braver because Jake is."

A child living with a brain tumour

"Now all our family and friends, from age 93 to a tender two-and-half year old, can talk, ask questions and draw pictures of their feelings. The brain tumour has hurt and affected us all but Jake has united us."

An adult living with a brain tumour

"The change in my son's reaction to hospital visits is nothing short of miraculous. The nurses said he was probably the worst patient they had had. After watching the cartoons, he is so confident and happy in appointments and scans."

Parent of child living with a brain tumour

Find our latest animation, **Mummy Has a Brain Tumour**, at thebraintumourcharity.org/mummyhasabraintumour



Get involved in Childhood Cancer Awareness Month



Along with some of our loyal celebrity supporters, we're delighted to be backing Childhood Cancer Awareness Month this September.

Childhood Cancer Awareness Month puts the spotlight on raising funds and awareness for childhood cancer. As brain tumours are the biggest cancer killer of children in the UK, we've been spreading the word about our HeadSmart campaign throughout the month. We need to ensure as many people as possible are aware of the common signs and symptoms of childhood brain tumours to reach our goal of reducing diagnosis times to under five weeks.

Former England rugby captain and supporter of The Brain Tumour Charity, Lewis Moody MBE is also getting behind Childhood Cancer Awareness Month.

In 2014, Lewis set up The Lewis Moody Foundation to help children and families affected by serious illness after meeting Joss Rowley Stark, a promising young rugby player who sadly lost his fight with cancer at the age of just 16. As well as offering Family Days, the foundation funds cutting-edge research projects through The Brain Tumour Charity.

Throughout September, Lewis and other celebrity friends will be participating in the Pass the Ball campaign. The campaign asks people to nominate their Facebook friends and Twitter followers to #passforLMF during Childhood Cancer Awareness Month. Everyone who passes the ball will be asked to donate £5 to The Lewis Moody Foundation.

As around 500 children and young people in the UK are diagnosed with a brain tumour each year, Childhood Cancer Awareness Month is a cause that's especially close to our hearts. Please help us spread the word about our HeadSmart campaign this September and join us in getting behind the Pass the Ball campaign.

Find out more about our work with children and families:



**facebook.com/
thelewismoodyfoundation**



**@LewisMoodyFdn
#passforLMF**

The Perfect Partnerships

Last year our corporate partnerships raised £532,031. No matter the size of your organisation there is a way we can work together.

Venn Group

We are Charity of the Year for Venn Group, a national recruitment agency. They've exceeded their £14,000 fundraising target and are advising us on how we can develop our LinkedIn strategy.

Betterware

Betterware, who reach over two million people each month, are raising awareness of brain tumours by advertising our work in their catalogues and donating a percentage of their profits.

Bluecube

Bluecube Technology Solutions provide our office IT and support as a gift in kind.

Aykroyd & Son's

Aykroyd & Son's donate hundreds of pyjamas for The Brainy Bags each year.

CTN

CTN Communications, an independent communications agency and film maker, arranged media training for our team to help us raise awareness.



Zurich

Zurich Insurance's Farnborough office is sending volunteers to line the route for The Twilight Walk in Windsor.

New partnership: ICAP

The global financial company ICAP has chosen us as one of the charities to benefit from their annual Charity Day on 9 December 2015. Some of our celebrity supporters will take to the trading floor and ICAP will donate all their revenue from the day to their chosen charities. The funds they donate to us will support our work on earlier diagnosis of adult brain tumours.



Chiltern Railways

After being chosen by their staff as Charity of the Year, Chiltern Railways have been fundraising and raising awareness of the HeadSmart campaign amongst their staff and passengers in their stations.

dunnhumby

As well as giving pro-bono support, dunnhumby's staff ran marathons, skydived, rode bikes, held a charity sale and Christmas auction to raise over £89,000 in our two year partnership.

Hays Recruitment UK

As part of our partnership Hays Recruitment UK sponsored The Twilight Walk last year by donating over 1,000 bottles of water.

Get your organisation on board:
corporate@thebraintumourcharity.org

"For too long there has been a wilderness and an attitude of 'Oh well'. Now we have an organisation which is not just listening to us but is hearing what we have to say and making a difference."

Shona, Tasha's mum

Image: The Young Ambassadors with our patron, Tom Daley at the launch of our strategy in the House of Lords.



Our Defeating Brain Tumours Strategy

Our Defeating Brain Tumours strategy was launched this summer. Our community is unashamedly ambitious about the world we want to see, one where we have doubled survival and halved the harm. We want both because each day would mean so much more if the lost quality of life didn't also mean being unable to hold your child's hand, to give your wife a cup of tea or to play outside with your dad.

This is a big ambition, to build the path to 2020 that takes us all forward. We need to know exactly what we're dealing with, which is why our work on halving the harm began with collating experiences of people living with a brain tumour in the *Losing Myself* report (see page 4). Now we have that evidence we can explain to those who hold

the power why they need to listen to us. We've also made the first funding awards under our *A Cure Can't Wait* research strategy, created after we brought the most brilliant minds in brain tumour research together last year.

But part of our plan is that the whole community works together. That is why, on 2 July, over a hundred people gathered to share our ambitious goals. Our Young Ambassadors met as many people as they could to share the message about what we want to achieve. One of them, Tasha Floyd, spoke to the room about being diagnosed after seeing her optician. A delay in diagnosis by her GP contributed to the fact that Tasha is now blind.



We brought people living with brain tumours, carers, policy makers and business people together, including Rob Ritchie, whose son is living with a brain tumour. Rob recently led the Everest in the Alps skiing expedition raising over £3million for The Brain Tumour Charity and awareness of how this disease affects children.

Introduced by our chair of trustees Sir Martin Narey, the guests heard from Lord Watson who talked about why he's supporting The Brain Tumour Charity and why we are the Charity of the Year for CTN, an organisation he chairs (see page 26).

Our patron Tom Daley spoke passionately about the cruel personal cost of losing his 40-year-old dad to a brain tumour in 2011.

He told the guests how he and his dad had worked hard towards an Olympic medal, and his happiness on the day he achieved their goal was joined by an incredible sadness that his dad couldn't share in his joy.

Our chief executive Sarah Lindsell emphasised the importance of achieving our goals so that we can see a world where brain tumours are defeated. Many of the guests energetically asked how they could help, creating a real sense that together this is possible.

Be part of it:
thebraintumourcharity.org/defeatingbraintumours

Meet Julie, Collection Tin Co-ordinator

Julie has been volunteering with us since October 2013. As a Collection Tin Co-ordinator she travels around her local area encouraging different companies and organisations to host one of our collection tins and monitoring the income.

Why did you choose to volunteer?

This charity is close to my heart because 15 years ago I lost my mom to a brain tumour. At that time there was no information or support available. I vowed then that, when I had the opportunity, I would do something towards ensuring that other families who found themselves in the same position as us did not have to suffer in silence and could get the information they needed to help them cope.

What do you enjoy the most about being a volunteer?

It provides you with a 'feel good' feeling and I get to do a variety of different tasks in my role. The charity is so appreciative of all that you do, no matter how great or how small, and as a volunteer there is no pressure.

Which memories from your time with us stand out for you?

Each time I meet someone who is either in need of our support or is just happy to help raise funds for such a worthwhile cause.

How do you keep in touch?

I keep in touch regularly with The Charity by either phone or email to provide updates or, if I need to ask a question, Jen, my staff contact, is always quick to respond.

In addition, a few of us volunteers meet every couple of months by hosting either a brunch, lunch or tea and cake. We get on so well that we will text or email each other regularly.



Volunteer with us:
[thebraintumourcharity.org/
volunteer](http://thebraintumourcharity.org/volunteer)

Leaving a legacy

Writing a Will is a great opportunity to leave a gift to a cause close to your heart. The Brain Tumour Charity receives fewer legacy donations than many other charities but the amazing Vicky Galbraith is one of the people changing that trend.

Inspiring international rugby player Vicky Galbraith was capped over 30 times for Scotland, won the Women's European Championships and the English Women's Club Championships in 2001. In November 2010, while pursuing a successful career in anti-cancer drug development at Roche, Vicky was diagnosed with a glioblastoma. She died on 19 May 2013, aged just 40.

Throughout her treatment Vicky raised an incredible amount of money for charities. She completed the first of many triathlons and organised a 215 mile Big Walk to Clinic from the Isle of Skye to Glasgow. With wit and personal strength she called her friends to "live, love and laugh", and she was keen to make sure that the futures of those around her were brighter even after her death. Instead of funeral flowers Vicky asked friends to plant trees or bulbs, enjoyable for years, or for donations to The Brain Tumour Charity to fight the disease which took her life.

Vicky left us a gift in her Will and many of our supporters have told us that they would like to do the same. If you would like to add a lasting gift to us in your Will, you can easily do so using a codicil, a document that is used to change a Will that has already been made.



"I am disappointed in my tumour: it seems to have not taken notice of the 'You are not welcome here' message it was sent in 2010-2011."

Vicky

If you are writing your Will for the first time or updating your Will, you can take our suggested wording on our website to your professional Will writer or solicitor.

Every gift, no matter the size, will be used to defeat the harm done by brain tumours. By leaving just 1% of what is left over from your estate after friends and family have been cared for you can make a difference.

Read Vicky's funny and insightful blog: vixbigstuff.wordpress.com

Find out more at thebraintumourcharity.org/legacy

Ocean Valour's record breaking row

On 3 May 2015 Tom Rainey and Lawrence Walters left New York in a tiny two man rowing boat. At 4.53pm on 4 August 2015 they touched land again for the first time, arriving in Salcombe Harbour to become the youngest duo to row across the Atlantic unaided. They did it all to raise money for The Brain Tumour Charity.

In 2012, just before Christmas, Tom lost his dad, Luke, to a brain tumour. As a passionate sailor Luke taught Tom so much about the ocean. His death rocked Tom and his family to the core. But, through The Brain Tumour Charity, they had help and advice which Tom described as “an invaluable port in an otherwise un-weatherable storm”.

In tribute to his dad Tom founded team Ocean Valour to raise money for research into brain tumours by rowing across the Atlantic. He spent months preparing with teammate Sam, fitting bench presses and squats into every spare moment. A boat was built and named Yves after his dad's own boat.

Crests and troughs marked their progress. Team mate Sam injured himself weeks before departure date so Tom's childhood friend, Lawrence Walters, took up the vacant seat. The day they reached the

Gulf Stream that would push them across the ocean, the pair celebrated Luke's birthday. But they were soon trapped in circles around an underwater mountain. Shortly after setting a new world record of rowing 112.5 nautical miles (208km) in 24 hours, they were hit by a 48-hour hurricane.

By the time they reached Salcombe harbour they'd broken four world records and raised over £56,000 online. Their rowing blades were quickly auctioned raising £6,500 and collection buckets were circling the crowd late into the night. They've now raised over £90,000.

Tom spoke to the crowd with a message that will resonate across the brain tumour research community, “If you have any sort of dream, I guarantee, if you keep on trying, again and again, I promise you, you will smash it”.

Watch the film of their homecoming at thebraintumourcharity.org/oceanvalour

Read more and donate to Ocean Valour at oceanvalour.co.uk



© Ocean Valour



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Thank you to The Brainy Bunch

Every day you inspire us with your dedication, effort and passion to change the odds and make a difference. Here are just a few highlights from your fundraising over the last few months.

Join The Brainy Bunch today: 01252 749043 / fundraising@thebraintumourcharity.org



Paddy, who is living with a brain tumour, and 46 of his friends beat the 12 mile Tough Mudder obstacle course raising £4,794.



Kevin, his son Neil and their lovely dog Pod set out on a six day challenge walking along Hadrian's Wall in aid of cousin Mandy who is living with an inoperable brain tumour. They have raised a fantastic £1,197.



At the Touchwood Shopping Centre in Solihull Ann Atkins, who has a 13 year old daughter living with a brain tumour, ran a Row For It! event. 36 people raised over £12,000 by rowing for either 10km, a half or full marathon. The students of Downing and Churchill colleges at The University of Cambridge also took part in Row For It! raising almost £4,000.



Durham University students Oscar and Justin drove from London to Cape Town in under 50 days in memory of Oscar's dad Alistair. They have raised over £14,500 for The Brain Tumour Charity. On their 8,900 mile journey they've been through France, Austria, Hungary, Romania, Greece, Egypt, Sudan, Ethiopia, Kenya, Tanzania, Zambia, Zimbabwe and South Africa.



The Jessica Green's Fund has recently taken part in the Manchester Colour Run, a Pretty Muddy Race, the Great Manchester Run and much more. Over £20,000 has been raised so far in memory of Jessica.



Haarlem Globetrotter Michael Cole and a group of friends raised more than £10,000 in support of their friend Duncan Weaver who is living with a brain tumour in the West Midlands.



Audrey set up a glamorous Ladies Lunch at Hamilton Racecourse in Lanarkshire in memory of her mum raising over £7,800.



Liz Smith and friends organised a charity concert to celebrate her sister's birthday and mark seven years since her sister's diagnosis with a glioblastoma. The concert, featuring three live bands and compered by comedian Hal Cruttenden, raised £9,000.

Brain tumour patient Carol, friends, family and The Greensand Ridge Rovers undertook a 26 mile 'marathon' walk raising over £3,400, celebrating with a fantastic cake.



After sadly losing their dad, David, to a brain tumour in December 2014, his two young children were joined by 17 other families. Making a team of 90, they raised £17,000 doing the 'Haddock's Hike' climb up Snowdon.



The Think Pink Fund has smashed their fundraising target of £10,000 in just seven months. One of their latest fundraisers was a Mad Hatter's Party in Palma, Majorca, attended by over 500 guests.



Two year old Finley is currently undergoing chemotherapy. With a charity dinner, auction and the Colour Run he and his family have raised an amazing £3,171 for The Brain Tumour Charity. They popped into the office to present us with this giant cheque and sweet, lively Finley was very popular with all of the team!



On 27 June 2015 The Big Match came to Farnborough FC for a day of fundraising and football in the sunshine! The annual event, organised by Neil Humphries in memory of his dad, saw members of the public join with ex-pros and celebrities including Razor Ruddock, Ossie Ardiles and Kerry Dixon on the field. The Big Match has raised £90,000 so far for The Brain Tumour Charity.



Year seven student Georgia Jones, with a little help from some friends, organised a West End Gala at Solihull School which raised £7,700. West End star Ria Jones joined the students on stage.

Thank you for all you do.

Together we can defeat brain tumours.

If you know someone who would like
to support our work why not give them
your copy of this newsletter so that they
can see the difference we make.

Or they can make a donation online:
thebraintumourcharity.org/donate

If you would like more copies please contact us:
enquiries@thebraintumourcharity.org
01252 749990

For queries about making a donation:
donations@thebraintumourcharity.org
01252 749043

Please return your donations to:

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



We rely 100% on voluntary donations

Please complete your details for any donation you'd like to make

Name: _____

Address: _____

Postcode: _____

Email: _____

Phone: _____

Signature: _____ Date: _____

giftaid it Make your donation worth 25% more!

☐ I confirm that I'm a UK tax payer and want to Gift Aid my donation and any other donations I have made in the past four years or make in the future to The Brain Tumour Charity. I'm aware that The Charity will reclaim 25p of tax on every £1 that I give and understand that I must pay more Income tax and/or Capital Gains Tax for that tax year than the amount of Gift Aid claimed on all my donations. I know it's my responsibility to pay any difference. If my circumstances change, I will notify The Brain Tumour Charity.

☐ I am interested in leaving a gift in my Will - please get in touch with me

Yes, I pledge to help change lives by becoming a regular giver

Please pay The Brain Tumour Charity the sum of:

☐ £25 ☐ £10 ☐ £5 ☐ Other £ _____

☐ per month ☐ per quarter ☐ per year

Account name: _____

Account no. _____ Sort Code: _____

Bank name: _____

Bank address: _____

Postcode: _____

Start date for payments: ____/____/____

Signature _____ Date _____

For bank use only to The Brain Tumour Charity, Lloyd's Bank. Account No: 50290568, Sort Code 30-93-74

Complete this form and post it to:

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

Yes, I pledge to help change lives by making a single donation

☐ £250 ☐ £100 ☐ £50 ☐ £25 ☐ Other £ _____

☐ I wish to donate by cheque

(made payable to The Brain Tumour Charity)

☐ I wish to donate by credit/debit card

Card type: ☐ Visa ☐ Mastercard ☐ Maestro

☐ Visa Debit ☐ CAF

Card number: _____

Start date: ____/____ Exp date: ____/____

Issue no: _____

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*see terms and conditions at thebraintumourcharity.org/waystodonate

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