

The Brain Tumour Charity shining a light on

The GREY MATTERS

The **BRAIN TUMOUR CHARITY**

Research | Awareness | Support

Issue 9 Summer 2015

EVEREST

IN THE ALPS

VERBIER

2015

The **BRAIN TUMOUR CHARITY**

*Defeating Brain Tumours:
Our New Strategy 2015 – 2020*

Building connections to better care

Register for The Twilight Walk 2015

thebraintumourcharity.org



Sir Martin Narey becomes Chair of Trustees

We are delighted to announce the appointment of Sir Martin Narey as our new Chair of Trustees.

Sir Martin, formerly Chief Executive of Barnardo's and ex-Director General of the Prison Service in England and Wales, took up his post on 1 April.

Our Chief Executive, Sarah Lindsell, said: "We are tremendously excited to welcome Sir Martin as the new Chair.

"His knowledge and experience of both the charity sector and Whitehall, coupled with his early career in the NHS, make him the ideal candidate to lead our board at this crucial stage.

"We are determined to drive brain tumours up the national agenda, giving a voice to everyone affected by this devastating disease and accelerating the search for more effective treatments."

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

Join us online



Sign up for our monthly e-newsletter and help us save on postage. Read the latest issues and sign up at thebraintumourcharity.org/enews



Website thebraintumourcharity.org



YouTube youtube.com/BrainTumourCharity



Facebook facebook.com/thebraintumourcharity



Twitter [@BrainTumourOrg](https://twitter.com/BrainTumourOrg)



Pinterest [The Brain Tumour Charity](https://pinterest.com/TheBrainTumourCharity)



Instagram [thebraintumourcharity](https://instagram.com/thebraintumourcharity)

Hello

As a supporter of The Brain Tumour Charity and a member of the staff team, I am always moved by reading the latest research breakthroughs and inspirational stories in *The Grey Matters*.

This issue of the newsletter is particularly exciting for me because it is the first since the launch of *Defeating Brain Tumours*, our new strategy for the next five years.

We believe we are at a crucial turning point. Shockingly, outcomes for people affected by brain tumours have hardly changed in decades, but we are now uniquely positioned to take collective responsibility for challenging the status quo and catalysing real improvements.

Our ambitious strategic goals are to double survival and to halve the harm that brain tumours have on quality of life. We will only be able to achieve these by working together, relentlessly and courageously – and so we need your support every step of the way.



I lost my son Alec to an inoperable brain stem tumour at the age of nine, and I raise money in his name through our family's Supporter Group, to fund The Charity's pioneering research. Whatever your reason for being a part of the brain tumour community, please turn to the next page, find out about our strategy and then get involved.

Thank you so much for leading the way with us.

Clare Normand

In this issue

Defeating Brain Tumours: Our New Strategy 2015 - 2020	4
The latest breakthroughs	6
Focus on clinical trials	12
HeadSmart	16
Building connections to better care	18
Story of Hope	20
Supporter Groups	23
Thank you to The Brainy Bunch	28

Don't miss...

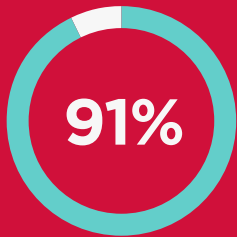
Q&A with Dr Janet Lindsey	7
New funding for pioneering research	10
Surviving Terminal Cancer	14
Where did you wear yours?	22
The Twilight Walk: walk with us	24
Everest in the Alps raises £3million	26
Give hope and life	30

-20

Brain tumours reduce life expectancy by an average of 20 years, the highest of any cancer.¹



Children survive a brain tumour who are left with a life-altering, long term disability.²



Adults reporting that their brain tumour affects their emotional and mental health.³

Defeating Brain Tumours

Our new strategy 2015 – 2020

Over the past four decades, the number of people who survive for five years after a leukaemia diagnosis has more than trebled. The number of people who survive for five years after a brain tumour diagnosis has not even doubled.

Currently, more than 55,000 people are living with a brain tumour in the UK and most of these will be coping with a reduced quality of life – in fact over 62% of children who survive a brain tumour are left with a life-altering, long-term disability.

Now is not the time to be timid if we want to change this shocking position.

After hearing the experiences and expertise of people affected by a brain tumour and key opinion leaders in brain tumour research globally, we have developed a new strategy with two ambitious goals: 1. double survival and 2. halve the impact on quality of life for people affected by a brain tumour.

Achieving these goals would transform the lives of patients and carers, and we are starting work now so we can be successful.

Defeating Brain Tumours defines how we want to unite the global brain tumour community around our vision for the future. It drives the research we fund, how we provide support and how we influence our partners. It sets out how we talk about what we do, and to whom, for the next five years.

Our strategy can be a crucial step forwards, but to deliver our plans we have to double the amount of money we raise annually by 2020. We know that we can meet this target with your ongoing support, and we are so grateful to have you with us. Together we can create a world where brain tumours are defeated.

Read the strategy in full at

thebraintumourcharity.org/defeating-brain-tumours

¹ Burnet NG, Jefferies SJ, Benson RJ, Hunt DP, Treasure FP. Years of life lost (YLL) from cancer is an important measure of population burden – and should be considered when allocating research funds. *Br J Cancer*. 2005 Jan 31;92(2):241–5.

² Macedoni-Luksic M, Jereb B, Todorovski L. Longterm sequelae in children treated for brain tumors: impairments, disability, and handicap. *Pediatr Hematol Oncol*. 2003 Mar;20(2):89–101.

³ The Brain Tumour Charity. *Losing Myself: The Reality of Life with a Brain Tumour*. 2015.

**A WORLD WHERE
BRAIN TUMOURS
ARE DEFEATED**

**GOAL 1
DOUBLE SURVIVAL
WITHIN 10 YEARS**

**GOAL 2
HALVE THE HARM THAT
BRAIN TUMOURS HAVE
ON QUALITY OF LIFE**

**A cure
can't wait**

**Every
patient is
a research
patient**

**Equal
access to
treatment
and care**

**United in
our battle to
defeat brain
tumours**

**Early and
accurate
diagnosis**

**Improving
life today**

PIONEERING

PASSIONATE

COLLABORATIVE

SMART

The latest breakthroughs

Searching for a cure

We fund ground-breaking research to find new treatments, increase understanding and develop better diagnostic techniques. Read more about our latest breakthroughs and how they could help to improve survival and quality of life: thebraintumourcharity.org/researchnews



Discovery on cause of brain tumours

Research at our Samantha Dickson Brain Cancer Unit at UCL has found that energy generators (mitochondria) which malfunction in our brain cells may contribute to the development of a brain tumour.

It has been known for some time that the genetic changes seen in brain tumours can cause the energy generators in their cells to go wrong, contributing to the growth of the tumour. The new research shows that this may also occur the opposite way around – the energy generators can malfunction first in a way that is damaging to cells, triggering the genetic changes that lead to brain cancer.

Professor Salomoni, who led the research, said: “These findings give us important insight into how aggressive, high grade glioma brain tumours may form. If we can target the faulty mitochondria with new treatments this could help stop tumour growth.”

Treating medulloblastomas differently

Professor Steve Clifford and his team at Newcastle University have linked a gene called VAV1 to a type of medulloblastoma, the most common malignant brain tumour in children.

When they blocked VAV1 in laboratory tests, the researchers found that medulloblastomas grew much less. This shows that doctors could test patients for VAV1 to give a more accurate prognosis, and that drugs could be developed against it in the future.

In a separate study jointly led by Professor Clifford and Dr Louis Chesler, researchers discovered that taking an extra tumour sample when medulloblastomas relapse could identify subsets of patients who might be treatable with existing drugs.

Professor Clifford said: “It’s clear that new biopsies need to be taken when the disease returns to give doctors a clearer picture of the best and most appropriate treatment.”

Q&A with Dr Janet Lindsey Newcastle University



Dr Lindsey is one of the researchers we fund in Professor Steve Clifford's team at Newcastle University. The team focuses on finding new treatments for medulloblastomas and is part of our INSTINCT programme, which is investigating some of the deadliest childhood brain tumours.

Find out more about INSTINCT:
thebraintumourcharity.org/INSTINCT

Why did you become a researcher?

I became very interested in genetics and how changes in genes could have such devastating consequences, causing diseases like cancer. I wanted to help deepen our understanding of the processes involved so we can develop new treatments to combat the disease.

What excites you about your job?

There are always new results and techniques that allow us to perform research more efficiently. In the past we would take a long time to look at a single gene in a cancer cell but now we can look at all the genes relatively quickly and find the mutations causing the disease. I feel that we are making real progress.

Can you give us an idea of your typical day?

In the laboratory, I work with DNA from tumours or grow cancer cells so we can study them and look at ways of stopping their development. I also train postgraduate students, discussing the work they've done and teaching them techniques. Most days

we either have a team meeting about our results or a seminar from an external speaker on exciting developments in cancer research. I spend a lot of my day on data analysis, looking for differences between cancer cells and normal tissue.

What is the potential impact of your work?

Some types of medulloblastoma brain tumours are very resistant to current treatments and there is an urgent need to find new therapies. I am working on a particular type of medulloblastoma which has the poorest prognosis, looking for the defects that cause it and seeing if there are available drugs which could treat the tumour.

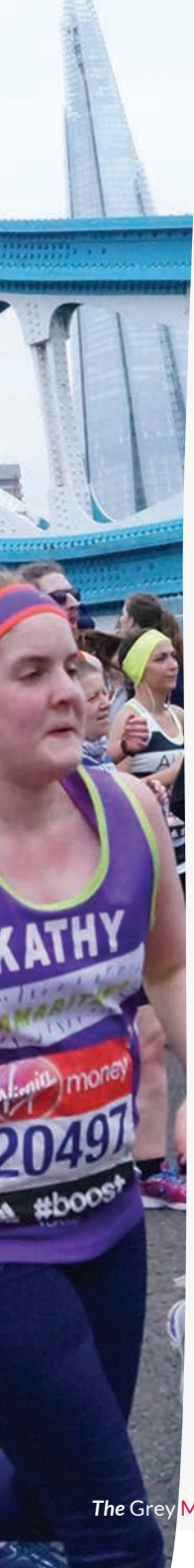
Why is more money needed for research?

If we can spend money on the new technologies available, we have the chance to make major breakthroughs in disease detection and treatment.

Running for research: a marathon hero



"I know mum would be proud of me."



This year we had a record 124 runners in the Virgin Money London Marathon, raising over £240,000 so far to help fight brain tumours. Robert is just one of our marathon heroes.

On 26 April, Robert Campbell achieved something that a few years ago would have seemed unthinkable – he ran the London Marathon and raised over £2,800 for The Brain Tumour Charity.

For the 25-year-old, it was further proof that he is back on track after his life was thrown off course when his mother Joan was diagnosed with a brain tumour in 2006.

From the moment Joan started her treatment, Robert struggled to cope. He watched his mother go through two operations – the first on his 16th birthday – as well as debilitating chemotherapy and radiotherapy.

“My mum ruled the roost at home. I was the youngest of five children and mum and I were very close,” says Robert, who lives in Barking, Essex.

“I dropped out of school before doing my A-levels and got a job in an office. But there was so much going on at home that I couldn’t cope with anymore pressure and I had to quit my job.”

Robert fell in with what he describes as ‘the wrong crowd’, turning to drink and marijuana to blot out his emotions.

“I wanted to escape,” he says. “After mum died in 2008, I just felt broken and couldn’t pull myself together.”

The turning point came three years after Joan’s death when Robert met his girlfriend, Jodie, and he stopped taking drugs. Now they’ve been together for four years and Robert is working again, in the ground maintenance team at Barking and Dagenham Borough Council.

Robert says he will always be grateful for the support of his family and friends, who know what a struggle he went through.

By running the London Marathon, with a fundraising target of £2,500, he wanted to help others in return – as well as proving how far he has come.

“I’m putting the pieces of my life back together and regaining my self-respect,” says Robert.

“I want to give something back by raising awareness and money for research to help other people affected by brain tumours and stop more people suffering my heartache. I hope I can help save lives.

“I know mum would be proud of me.”

Apply for a place in next year’s London Marathon or choose from runs all over the country: thebraintumourcharity.org/runs

New funding for pioneering research

During December 2014, we launched and began to implement *A Cure Can't Wait: Our Research Strategy*, which is part of our overarching strategy for the next five years.

In addition to the research we are already funding, *A Cure Can't Wait* represents a further investment of at least £20million to help us achieve our goals – doubling survival and halving the harm that brain tumours have on quality of life.

Researchers have already been applying for grants across four of the schemes we announced in our research strategy, with more funding calls scheduled to open later this year.

Visit thebraintumourcharity.org/researchstrategy to keep up to date.

Creating a centralised biobank

Applications under review

A key to unlocking new brain tumour treatments is through access to patients' tumour samples. However, we know that routine collection of tissue for research isn't a reality yet. We also know that many of those affected are prepared to gift their tumour samples so others can benefit in future.

To enable us to learn from every patient, we are building on existing central tissue banking for paediatric cancers by funding a centralised biobank of adult brain tumours. The biobank will ensure tissue samples are accessible and available so that top researchers have a comprehensive resource that will allow key questions to be answered sooner.

“

“If I'd known that scientists could have used Alex's tumour tissue to save other people's lives then I would definitely have agreed to it.”

Jeannette Bolt from The Brain Tumour Charity
Alex Bolt Fund

Investigating early diagnosis for adults

Applications closed, grant due to be awarded later this year

Our HeadSmart campaign to raise awareness of the signs and symptoms of childhood brain tumours has reduced diagnosis times from over 14 weeks to 6.7 weeks since it launched in 2011. HeadSmart has saved lives and helped to reduce long-term disabilities, and we believe that diagnosing adult brain tumours early could have a similar impact.

We will fund research to investigate the diagnostic pathway for adults with a brain tumour in the UK. This research will generate evidence to understand the impact that an earlier diagnosis may have on outcomes, and will provide the foundation needed for a symptom awareness campaign for adults.



"I was treated for several seizures before my brain tumour was finally diagnosed. If I had been scanned when I had the first seizure, my epilepsy and the weakness down my left side might not be so bad. I also now suffer from anxiety. Earlier diagnosis is massively important."

Sophie O'Hagan

Quest for Cures: building elite research teams

Applications open

This scheme will build international and interdisciplinary research teams to accelerate discoveries and get them to patients faster. Teams will be drawn from institutions all over the world and formed of the most talented and promising researchers.

We are keen to facilitate collaborations between researchers who may not previously have worked together in order to explore new ways of enhancing our understanding of brain tumours. Our aim is to create teams with a broad range of skills across different fields, allowing us to address some of the critical issues that could lead to a step change in the search for cures.

New Ideas Awards: finding novel approaches

Applications open

Our New Ideas Awards will help develop novel and innovative approaches that could fundamentally change the understanding, diagnosis and treatment of brain tumours. We are seeking original concepts that may eventually lead to significant improvements in clinical outcomes, including quality of life, for patients with brain tumours.

Rather than supporting the development of existing research, the New Ideas Awards will open avenues of investigation that have not been tried before. Successful applicants will have one year to test their idea and the results of their research could pave the way for larger scale projects.



Focus on clinical trials

One of the aims of our new strategy is to ensure that those affected by brain tumours can contribute to research and clinical trials. Taking part in clinical trials can give patients faster access to treatments, better care and the opportunity to play a part in defeating this disease.

To help accelerate change, we have committed to increasing our investment in early-phase clinical trials. We also host a worldwide clinical trials database with up-to-date information about trials for new brain tumour treatments. Access the database at thebraintumourcharity.org/clinical-trials-database

Q&A with Ken Harper

Ken Harper had a glioblastoma brain tumour removed in April 2014. He had further surgery this March and is now on a clinical trial led by Professor Garth Cruickshank at Queen Elizabeth Hospital Birmingham.

How did you find out about your clinical trial?

My wife Marj and I went to the Birmingham Information Day organised by The Brain Tumour Charity. We heard Professor Cruickshank talk about a clinical trial that injects tiny beads during surgery which deliver chemotherapy directly to the brain. We noted down the name of the trial, thinking we would follow up later, but coincidentally a research nurse at Queen Elizabeth Hospital phoned the very next day to ask if I wanted to get involved! I didn't hesitate to accept the offer.

Why do you think clinical trials are important?

On Easter Saturday my daughter Victoria got married. To be honest, I didn't think I'd still be here for the wedding but I gave a speech and my family said I nailed it! Clinical trials are essential to giving brain tumour patients more of life's best moments because we cannot get better treatments without them. I've got my fingers crossed for my trial that the researchers will find some progress. **The trial may not provide 100% of the solution but it might provide 1% – and that's worth doing.**

What would you say to other patients about clinical trials?

For me, it was an obvious choice to go on a clinical trial. I'm giving myself the best possible chance by testing a new treatment, while making a difference to vital research.

The latest from our Young Ambassadors

Having all been affected by the diagnosis of a brain tumour, our Young Ambassadors are helping to spread the word and make an impact for other young people nationwide.

Later in 2015 they will be representing The Charity at Information Days, Paediatric

Information Days and Way Ahead Days for newly diagnosed patients. They will also be travelling to the European Parliament in Brussels this autumn to raise awareness of brain tumours amongst MEPs and explain our work.



To enable the group to build their skills ahead of a busy rest of the year, we held two days of training in February at our HQ. We asked Laura, one of the Young Ambassadors, to report back on how the days will help in her role.

“Firstly, we took part in training sessions with two of The Charity’s corporate partners, dunnhumby and CTN Communications.

“The sessions aimed to help us speak as concisely as possible when representing The Brain Tumour Charity and included an invaluable workshop on how to talk confidently in front of a group of people.

Most of us were definitely a little shy about this beforehand!

“It was particularly helpful to gain a better understanding of conveying The Charity’s message successfully, given that we have all been personally affected by this devastating disease and talking about why we chose to become Young Ambassadors can be quite emotive.

“That evening we went to have pizza together, which was followed by an impromptu game of hide-and-seek!

“On Saturday we had training about using social media to encourage supporters

to engage with us. Social media is a great way to give others a glimpse into some of the incredible work that The Charity does and, in turn, brings about more greatly deserved support.

“The training was something that I know each of us will remember for a long time. Being able to make a difference as Young Ambassadors is a perfect example of something good coming from something that could have easily changed our lives for the worse. We really hope that this will give some assurance and hope to those affected by a brain tumour.”

Surviving Terminal Cancer



We know that survival rates for patients diagnosed with an aggressive brain tumour have barely improved in the last 40 years, and we are determined to start a conversation amongst researchers and patients on the fastest ways to change this.

On Wednesday 4 February, World Cancer Day, we supported the premiere of a film called *Surviving Terminal Cancer* at the British Film Institute in London. The film challenges the orthodox approach to improving cancer treatments by telling the story of three long-term brain tumour survivors who researched and devised their own treatment programmes.

It features Ben Williams, Richard Gerber and Anders Ferry, who all identified pharmaceutical drugs and naturally-occurring agents which unconnected trials have found may act individually to block specific cancer pathways. Against doctors' advice, the three took many of these simultaneously as a "cocktail" while undergoing the standard treatment offered to patients like them.

After the film showing, which was attended by 400 of our supporters, Professor David Walker from The University of Nottingham chaired a panel discussion including the three patients whose stories are presented by the film, as well as international brain tumour experts. The film was additionally premiered at the Lincoln Centre in New York two weeks later.

Surviving Terminal Cancer was written and directed by entrepreneur Dominic Hill, who lost his brother-in-law to a glioblastoma in 2010. He says: "Patients facing the worst diagnosis known to man should not also have to be victims of man-made problems and paralysis.

"I have made this film to try and disseminate critical information to future patient populations about the invisible barriers they will face beyond their biological diagnosis, that preclude in most cases their access to the treatments at the front of the innovation curve."

Watch *Surviving Terminal Cancer* at thebraintumourcharity.org/surviving-terminal-cancer



“

“Thank you for allowing us to attend the premiere and share this special evening. We hope this thought-provoking film will pave the way for more creative and successful treatment of terminal diagnosis. It was a privilege to shake Ben Williams’s hand and be in the company of such inspirational and determined survivors.”

Caroline Fosbury from The Ella Fosbury-Hill Fund, one of our Supporter Groups

Taking action

All too often, people affected by a brain tumour are missing out on promising new treatments due to delays in getting them from the laboratory to the clinic. In light of the Surviving Terminal Cancer film, we launched an e-petition calling on the government to ensure innovative therapies get to brain tumour patients faster.

In particular, the e-petition focused on the Early Access to Medicines Scheme (EAMS) and the adaptive pathways approach, which are existing UK and European initiatives to speed up access to new treatments. We believe that greater investment in EAMS will mean that patients can access drugs going through the clinical trials process, and that government support for adaptive pathways will help to accelerate the drug development procedure.

We are delighted that our e-petition received over 15,000 signatures, meaning that we are guaranteed to get a formal response from the Department of Health in the next few months. Thank you to everyone who helped to make our voice heard.

Keep checking our website to find out what you can do to make change happen after we hear back from the government.

HeadSmart



Saving children's lives: Darcey's story

Our HeadSmart campaign raises awareness of the symptoms of childhood brain tumours to drive down unacceptable diagnosis times. Since the launch of the campaign, we have reduced the average time it takes to diagnose a childhood brain tumour from 14 to 6.7 weeks, saving lives and minimising long-term disabilities. headsmart.org.uk

Earlier this year, Chrissy Fletcher told us: "If I hadn't read the HeadSmart symptoms card, I have no doubt whatsoever I would have been burying my little girl. I cannot thank The Brain Tumour Charity enough."

Chrissy's six-year-old daughter Darcey had been suffering from severe headaches so she took her to the GP and the hospital. Doctors told Chrissy that Darcey was suffering from migraines or a virus, but she was so concerned that she then booked an appointment with the family optician.

At the optician, Chrissy was given a HeadSmart symptoms card and she realised that her daughter could have a brain tumour: "When I read the card the optician gave me, Darcey had every single symptom except epilepsy."

She immediately took Darcey to hospital where an MRI scan was finally carried out. The scan revealed a brain tumour the size of an orange, which was removed within 24 hours.

Darcey is now being monitored with regular scans and is recovering well, but doctors say that if they had not diagnosed her when they did, she would have died within a week.



Know the symptoms on-the-go
Text SMART to 81400 for your free mobile symptoms guide.



HeadSmart heroes

Our HeadSmart Community Champions, volunteers and corporate supporters play a vital role in spreading the word far and wide.

Two volunteers in the Midlands, Tracy Jones and Karen Wand-Riley, have recently been working with councils and Directors of Public Health in several of their surrounding counties to get symptoms cards out to all schools, GP surgeries, opticians, pharmacies and A&E departments.

We are also delighted to have formed a new partnership with a communications consultancy called Salix and Co. The company is going to be helping us by reaching and influencing decision makers in the health, education and social sectors.

Visit thebraintumourcharity.org/teamheadsmart to get involved.

As part of our research strategy, we are preparing to award funding for a study that will investigate how early diagnosis could make a difference for adults. This will provide the evidence for an adult brain tumour symptom awareness campaign, which would build on the success of HeadSmart.

Read more about the research on page 11.

Securing accurate diagnosis

In addition to driving early diagnosis of brain tumours, we are committed to making sure that patients are diagnosed accurately, as identifying the correct tumour type allows them to receive the most appropriate and effective treatment.

Accurate diagnosis can be life-changing for patients. Our supporter Gideon Burrows found out that he had an oligodendroglioma brain tumour with a certain genetic make-up that means radiotherapy is more effective. He says: "This information gave me peace of mind, armed me with knowledge and gave me just that little extra hope."

The research we have already funded has led to new state-of-the-art tests that detect biomarkers and genetic mutations in glioma brain tumours to give a more accurate diagnosis. Also, thanks to Professor Peter Collins, a number of hospital laboratories in the UK and worldwide now routinely test for the BRAF fusion gene to determine whether a tumour is a pilocytic astrocytoma.

Find out more about what we are doing to secure accurate diagnosis at thebraintumourcharity.org/researchstrategy

Building connections to better care

We are dedicated to ensuring that every person with a brain tumour has the same access to the best care, wherever they live and whatever their tumour type or age.

Every day we work with healthcare professionals all over the UK who provide innovative, high quality care for those affected. We know that we can only drive improvements for patients if we share knowledge and expertise at each opportunity, so we build connections wherever we can.

We would like to share two examples of best practice from clinical nurse specialists: Anna and Jo. They help to run programmes in different parts of the country to enhance all-round quality of life for people diagnosed with a brain tumour. Anna and Jo regularly exchange experiences and ideas with a wider network of healthcare professionals across the country to provide first class holistic care.

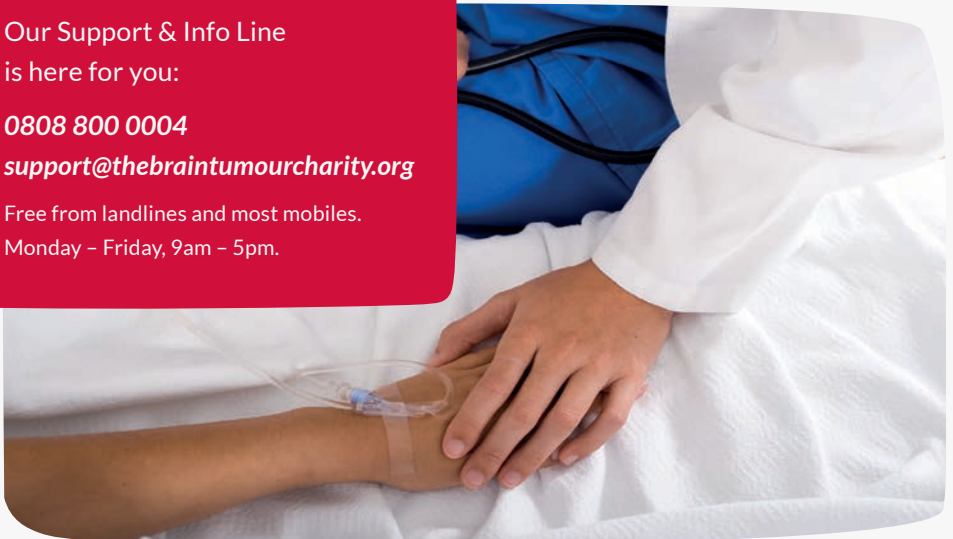
Need to talk?

Our Support & Info Line is here for you:

0808 800 0004

support@thebraintumourcharity.org

Free from landlines and most mobiles.
Monday – Friday, 9am – 5pm.



Anna Crofton

Lead Clinical Nurse Specialist
at The Walton Centre, Liverpool.
Runs a holistic needs clinic

What does 'holistic needs' mean and what does your clinic do?

Living with a brain tumour can be very traumatic. Not knowing what to expect, dealing with symptoms daily and not understanding the physical and psychological feelings can cause distress. Holistic needs assessment is designed to make sure all aspects of the patient's life are considered, not just the clinical side. It helps people identify their individual concerns about all sorts of aspects of living with a brain tumour and allows healthcare professionals to guide and signpost to the right level of support.

In our holistic needs clinic, we cover physical, emotional, job and money worries along with treatment issues, practical issues, spirituality and family matters.

How does your holistic needs clinic make a difference?

Our clinic has been well-received by patients. Sometimes its role is to explain that many symptoms, such as fatigue, are normal. These types of symptoms can feel alien and just to know that it is okay to feel fatigued can help relieve stress and anxiety.

Why is it important to share expertise?

The sharing of experience and best practice between healthcare professionals is at the heart of improving patient experience.

Jo Johnson

Lead Neuro-Oncology Clinical Nurse
Specialist at St George's Hospital, London.
Helps to run an integrative medicine clinic

What does 'integrative medicine' mean and what does your clinic do?

Integrative medicine concentrates on the treatment of the whole person and focuses on wellness and health rather than treating disease. At St George's NHS Foundation Trust there is a flourishing integrative medicine service led by Dr Kavita Prasad.

I am now working closely with Dr Prasad to provide an integrative medicine clinic for patients with brain tumours. This clinic supports the teaching of the stress management and resilience training (SMART) programme, which originated at the Mayo Clinic in the USA.

How does your integrative medicine clinic make a difference?

We explain ways for patients to cope with the trauma of diagnosis and deal with the stress associated with having intensive treatment and a life-limiting disease. Our clinic's impact and the role it plays in the holistic treatment of brain tumours will be formally assessed as part of an upcoming research study.

Why is it important to share expertise?

It is vital that knowledge and insight gained from projects such as these is shared by healthcare professionals. This enhances care and has a positive impact on the patient experience and perception of their disease.

Vicki Browne

“Cherish every moment and make happy memories”

In five years, Vicki Browne lost her husband and had two brain tumours. Yet she is back in her role as a presenter on The Jewellery Channel and is helping to raise awareness for The Brain Tumour Charity.

Two years after her husband suddenly died from a heart attack at the age of 42, Vicki Browne found out she had an astrocytoma brain tumour in the area of the brain which controls speech.

“While I was live on air I just couldn’t get my words out properly,” says Vicki. “I called gems by totally the wrong name.”

After an operation in 2011 to remove her brain tumour, she had routine MRI scans every three months which showed a second small astrocytoma in July 2013. This was removed in another operation in January 2014.

For seven weeks, Monday – Friday, Vicki had chemotherapy and radiotherapy at the Royal Marsden Hospital in London. Then for six months she had chemotherapy for three nights a week.

Even during her chemotherapy, Vicki insisted on getting dressed up. “Looking good and my sparkle made me feel better,” she says. “I wanted to be as positive as I could and cheer the other patients up, too.

“Losing my long, dark hair was hard as it’s always been a big part of my personality. My son Louis was really supportive. He gave me a big hug and told me ‘You rock bald, mum!’”

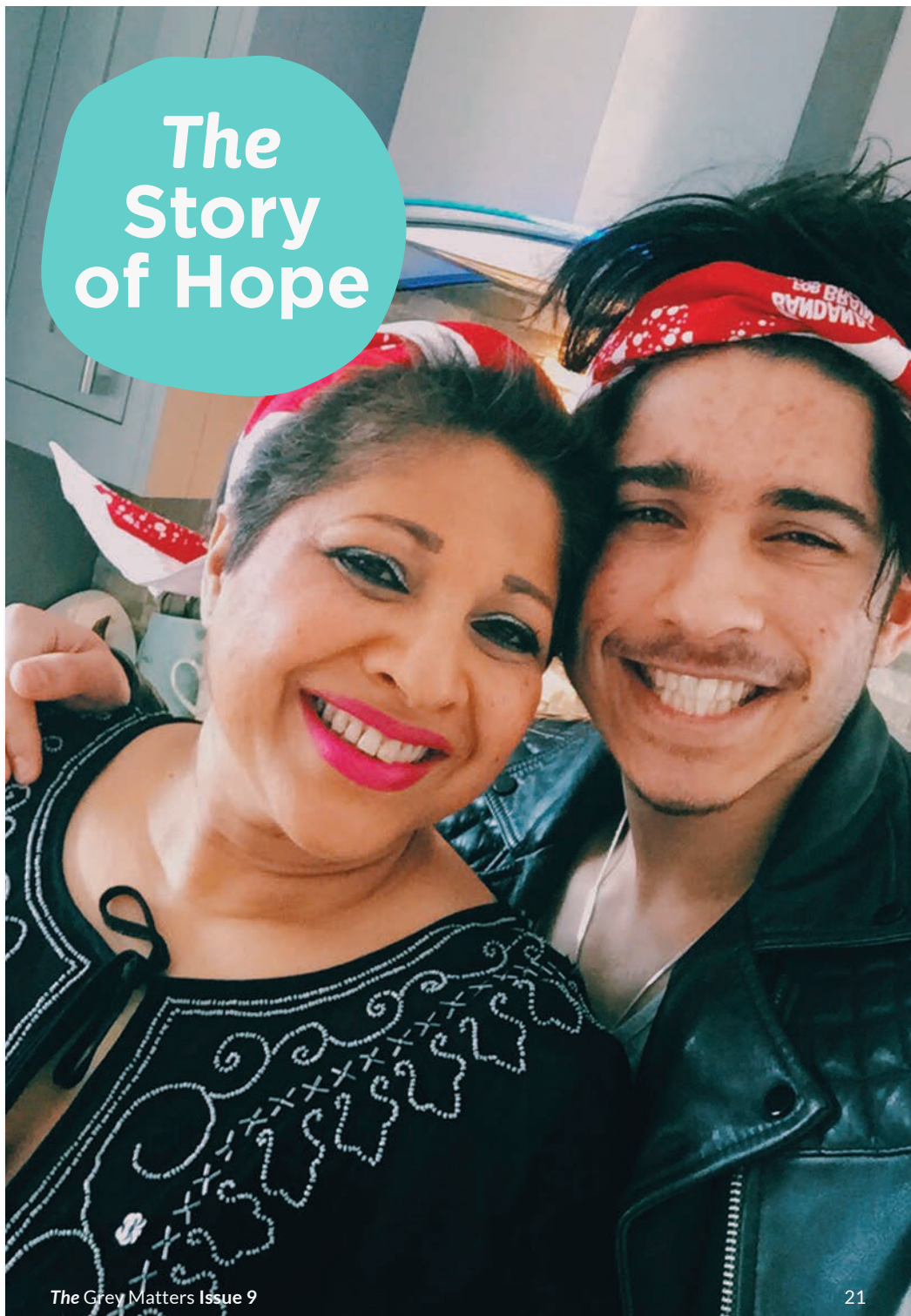
Vicki made her comeback to The Jewellery Channel in January this year after 12 months off, and refused to wear a wig. “I wanted to make a stand and help The Brain Tumour Charity raise awareness,” she says. “I was proud of how I looked. It showed I’d been ill but that I was still standing and looking forward to the future.”

She also wore a bandana on air in support of Bandanas for Brain Tumours and student Louis, 20, wore one too.

“I want people to know there’s always hope,” Vicki says. “I have a wonderful son and we make as many happy memories together as we can. And I count my blessings for my friends and family who’ve been there for me.

“Despite everything I’ve been through – or maybe because of it – I live life to the full and cherish every moment.”

The Story of Hope



Where did you wear yours?



Thank you so much for an incredible Bandanas for Brain Tumours Day on Friday 6 March. Thousands of you came together to wear our bandanas all over the country, as well as holding bandana days. You have helped to spread the word, unite our community and make change happen as fast as possible. We raised an incredible £88,092 and you shared more #Wearitout photos with us than ever before.

View all the photos at bit.ly/wearitout-2015-photos



Wear it out!



The Supporter Groups

We have more than 200 Supporter Groups, all dedicated to raising funds and awareness on a long-term basis. Groups are set up inspired by someone living with a brain tumour or in memory of a loved one. They are a great way to bring friends, family and colleagues together in the fight against brain tumours.

Setting up a Supporter Group is easy and we're here to help every step of the way.

Find out more:

supportergroups@thebraintumourcharity.org

01252 749043

thebraintumourcharity.org/supportergroups

Taking care of business

One of the ways our Supporter Groups make a difference is by using their networks to create connections with companies that might otherwise be unaware of our cause.

Beth Worrall from The Barbara Wood Fund is an employee of dunnhumby, and nominated The Brain Tumour Charity for her company's charity scheme. We won the staff vote and dunnhumby went on to raise over £90,000 for us over two

years, as well as sharing business skills and donating items for The Brainy Bag, which we give to children with a brain tumour.

Groups can also be chosen as charity partners in their own right, and we are delighted that The Silas Pullen Fund is being supported by Catlin UK. In February the company handed over a cheque for £10,000 ahead of a year-long partnership.

Local businesses too are often happy to get behind Supporter Groups in their area. For example, ASDA Biggleswade selected The Colin Nugent Fund for their green token scheme and raised £50. The Fund has additionally been getting local shops and pubs to display collection tins.

The Maisy Rose Project

Thank you to everyone who has raised money for The Maisy Rose Project, a Supporter Group set up in memory of one-year-old Maisy, who lost her life to a brain tumour. The group presented us with a £58,767 cheque and is continuing to raise funds for our childhood brain tumour research.

Welcome to our new groups

The DJG Cancer Fund

**The John Clover
Memorial Fund**

The Alex Cripps Fund

The Jack Bray Fund

**The Holly Locke
Memorial Fund**

The Steven Strange Fund

**The John "Louis"
Armstrong Fund**

The Molly's Magic Fund

The Beautiful Minds Fund

The Lee Howell Fund

**The Catherine Lynn
Smith Fund**

The David Webb Fund

The Jennifer Amy Fund

**The Amanda
Shannon Fund**

The Julie Kember Fund

The Jamie Maciver Fund

**The Dr Louise Coast-Smith
Memorial Fund**

The

TWILIGHT WALK

We are delighted to announce that The Twilight Walk is back! As well as joining together to help stamp out brain tumours in Windsor, Chester and Warwick, this year we'll also be walking in the beautiful city of York.

Our magical 10k walks at dusk follow breathtaking routes lined by volunteers to show you the way and cheer you on at every turn. Everyone in the family is welcome and we'd love to have your friends and colleagues on board too.

In 2014, over 1,000 amazing walkers took part and raised more than £220,000 – enough to fund four years of pioneering research. Please join our united community and walk with us this autumn so we can make an even bigger impact!

Karen runs a Supporter Group to raise money in memory of her husband Kevin, who lost his life to a brain tumour.

She says: "I am proud to have taken part in both of the previous Windsor walks and I am planning to be there again this time. Signing up for The Twilight Walk is a really good way of getting together with friends and family of all ages to try to raise funds and awareness.

"When I turned around at the end of the Long Walk last year and saw just how many people were walking together – so many of them affected in one way or another by something as terrible and devastating as a brain tumour – I felt very emotional.



"I did the walk with friends and it was lovely to spend the time remembering Kevin and chatting about him."



Windsor

Sunday 20 September

Back for a third year, our route through the town centre boasts Windsor Castle, the Long Walk and the River Thames.



Chester

Sunday 27 September

Our Chester walk explores a unique Roman past, crosses the Queen's Park Suspension Bridge and tackles the city walls.



York

Sunday 4 October

We'll be walking York's scenic streets for the first time, alongside landmarks including York Minster and Clifford's Tower.



Warwick

Sunday 11 October

Walk right through the world-famous Warwick Castle and take in parks, gardens, historic buildings and the majestic River Avon.

Sign up
now!

Sign up and start your fundraising now at thebraintumourcharity.org/thetwilightwalk

Volunteers at The Twilight Walk make sure it's an incredible night from start to finish. Register to be part of the team at bit.ly/twilightvolunteering



Image:

The Everest in the Alps team



Image:

School friends Toby (left) and Ben waiting to cheer their dads, Rob Ritchie and Rob de Laszlo, across the finish line.

Everest in the Alps raises over £3million

In March, a team of 14 climbed the equivalent height of Mount Everest on skis in the Swiss Alps to raise money for The Brain Tumour Charity.

Over four days, the team took on 13 ascents of up to 2,500m, burnt approximately 40,000 calories and tackled 28 hours of uphill ski-touring.

Everest in the Alps was led by Rob Ritchie, a Managing Director at Goldman Sachs, whose son Toby is recovering from 18 months of chemotherapy after the diagnosis of an inoperable brain stem tumour at the age of five.

With the support of Rob's colleagues at Goldman Sachs, the team has raised more than £3million, which is the largest single donation we have ever received for research into childhood brain tumours.

Our Chief Executive, Sarah, said: "This money will have a profound impact on paediatric brain tumour research.

"It will allow us to accelerate progress towards better understanding of the disease and more effective treatments, so that families in future are spared some of the trauma the Ritchies have suffered.

"We are immensely grateful to the team for their astounding physical and fundraising efforts."

At the finish, Rob Ritchie said: "After months of planning and four intense days, we are all elated to have achieved our goal and raised so much money.

"Skiing into Verbier and seeing our families and friends there to meet us was something none of us will forget."

You can read about Everest in the Alps as it happened and see the amazing photos from the challenge at everestinthelps.com

Everest in the Alps has raised an unprecedented sum of money but, in one way, it is not unusual. Every day we hear from our amazing fundraisers about the tough targets they set themselves. They haul themselves out of bed in the middle of winter to train for a 10k run. They sign up for a skydive, when the mere thought terrifies the living daylights out of them. They shave their heads, cycle across continents and take on The Twilight Walk with hundreds of others affected by brain tumours. It may not be Everest but it is often a 'personal Everest' and every single pound raised goes straight to our vital work. Start your fundraising journey at thebraintumourcharity.org/fundraising

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

The Joseph Foote Ball took place in March, raising £290,000. Held at the Hilton Metropole in Birmingham, 750 guests attended the evening, which included performances from Rebecca Ferguson and Jake Quickenden. This was the sixteenth annual ball in memory of Joseph Foote, who sadly lost his life to a brain tumour aged nine.

Volunteer Julie Norman has been a Collection Box Volunteer since October 2013. In this time she has placed over 230 collection boxes in local businesses in the Solihull area and has raised over £3,400 so far. Julie supports The Charity as she lost her mum to a brain tumour.



In January we held the inaugural Cameron Buchanan Gala Dinner at The Merchants' Hall in Edinburgh, with over 100 people attending and raising just under £30,000. The night was hosted by Cameron Buchanan MSP, who is living with a brain tumour, and consisted of a champagne reception, auctions and entertainment from David John.



Sophie Morris, who is living with a brain tumour, has raised over £31,400 by bringing together the local community of St Ives in Cambridgeshire to hold various fundraising activities. On Bandanas for Brain Tumours Day, schools, businesses, families and local postmen and women all played their part. See photos at bit.ly/sophie-morris-bandana-day

Seventeen runners, including two students from Bath University, took part in the Bath Half Marathon. Alex raised £1,804 inspired by his father, who is living with a brain tumour, and Jimmy ran in memory of a school friend, raising £782.



The Peace and Loaf restaurant in Newcastle raised £220 for The Kuly Ral Fund by holding a Bandana Day.

Caroline, Ross and Sue from Devon cycled and successfully completed the 31 mile Tarka Cycle Trail in memory of Ross's father, Ken. Mali the dog accompanied the team all the way and together they raised £441.

The Lawn family and friends from East Kilbride hosted their Too Good To Be Forgotten ceillidh fundraiser in memory and celebration of Irene Lawn. The event raised £18,000.

Cambridge based Nick, Paddy and Dan took part in Row For It! inspired by Nick's friend, who died from a brain tumour. They rowed a 26.2 mile marathon on a rowing machine and raised £2,580.

A team of 26 colleagues at Thames Water raised £3,800 by running the Reading Half Marathon in support of colleague Mark Day, who is living with a brain tumour. Mark also took part in the run.



On Bandanas for Brain Tumours Day, Friday 6 March, Danielle McGriskin was awarded a Points of Light award by the Prime Minister for her dedication to fundraising. Danielle runs The Danielle McGriskin Fund, which has raised £136,000 so far for The Brain Tumour Charity. The Fund also organised for Belfast City Hall to be lit up for a night in support of Brain Tumour Awareness Month.

Tammy Henn and friend Mandy Jerrison organised a Bavarian themed night at Darlaston Sports and Social Club in support of Tammy's husband Stephen, who is living with a brain tumour. The money raised will be match-funded by Npower, doubling the total to £1,288.

When Peter from Morpeth was diagnosed with a brain tumour, he decided to focus his energy on raising funds and awareness. He chose to take part in a series of runs throughout the 12 days of Christmas, raising £8,500. Peter was supported by his friend and brother-in-law, Ben Dunderdale, and together they are planning their next challenge for 2015.



To mark 10 years of running for charity, Richard Dade from Norwich has challenged himself to 10 challenges throughout the year, including the Silverstone Half Marathon, the Virgin Money London Marathon, the Great North Run and the Three Peaks.

Give hope and life to future generations

Leaving a gift in your Will to The Brain Tumour Charity will help fund vital research to find better treatments and ultimately a cure. After looking after family and friends, a gift of any size will help us create a world where brain tumours are defeated.

It's not difficult to make or change a Will

Caroline is a solicitor and prepares Wills for a living. She knows from personal experience that the diagnosis of a brain tumour is life-changing.

I was widowed when my husband died from the disease, leaving me with two small children. Writing and updating your Will is very important to give you peace of mind and security for your family in the long term. I would like to challenge the idea that this process is difficult, complicated and expensive.

These are points you should consider before visiting your chosen solicitor or professional Will writer:

1. What happens if I don't make a Will?

If you are married then the likelihood is that your estate will pass to your spouse. However if you are not married then your partner will not automatically inherit. It's not worth taking chances – the best thing to do is to make a Will.

2. If my circumstances change should I update my Will?

To make sure that your Will protects the right people in your life, we normally advise that it should be reviewed every 5 – 10 years.

3. Who will care for my children?

You can use your Will to appoint guardians for your children so think about who you would want to look after them.

It's easy to add The Brain Tumour Charity to your Will. You can complete the codicil (a document that is used to change a Will that has already been made) attached to this newsletter if you already have a Will, or use the suggested wording on the back of the form if you are planning to write or rewrite your Will.

Why we need more gifts in Wills

Compared to many other charities, we receive very few gifts in Wills.

We need to change this so we can give hope and life to future generations.

A comparison of recent charity income through gifts in Wills:

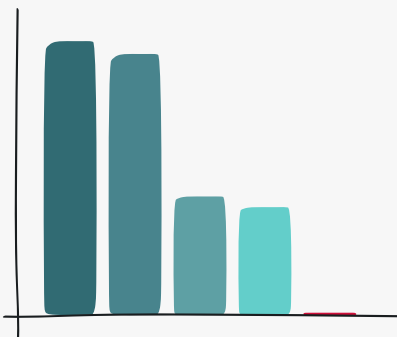
Age UK: £20.1million

The Donkey Sanctuary: £20million

Multiple Sclerosis Society £9.1million

Parkinson's UK: £8.3million

The Brain Tumour Charity: £12,000



Did you know that you can leave just 1% of the remainder of your estate to The Brain Tumour Charity after your family and friends have received what you left to them?

Find out more at thebraintumourcharity.org/legacy

4. Who is going to inherit my estate?

Usually, this will be your spouse or partner. You can also provide for your children if anything should happen to both of you.

5. Do I want to leave any specific gifts?

In your Will you can pass on a fixed amount of money, a percentage of your estate or an item which you own. You could consider leaving a gift to The Brain Tumour Charity to support their work.

6. Who do I want to appoint as my executor?

The executor is the person who will take charge of your affairs and should be somebody that you trust.

7. How much will it cost?

The cost could start at around £200 plus VAT for two new Wills but it's worth approaching several firms.

When my husband and I did our Wills, we left small gifts to the charities which supported him. I would always encourage clients to leave a gift to The Brain Tumour Charity, however small, as this could help someone with a brain tumour survive.

Caroline Wallis

Partner with Boyes Turner LLP solicitors in Reading

How to use the codicil and suggested wording for your Will

A gift of any size in your Will helps to give us the long-term, sustainable funding we need to make a difference for future generations.

If you would like to add a gift to The Brain Tumour Charity to your existing Will, you can easily do so by using the codicil on the other side of this page. Your codicil must be signed and dated by you, in the presence of two adult witnesses who are not family, to make sure your gift is legally recognised. It's a good idea to send a copy of your Will and codicil to a trusted friend and indicate where the original is being kept.

If you are writing a Will for the first time or rewriting your Will because it's outdated, you can take the wording below to your professional Will writer or solicitor, who will make sure a gift to The Brain Tumour Charity is included. We have provided suggested wording below for two types of gifts you could consider:

We recommend that you seek the guidance of a solicitor or professional Will writer when you are writing your codicil or Will so that your intentions can be fully carried out.

**Any questions?
We're here to help**

**legacy@thebraintumourcharity.org
01252 749043**

1. A residuary gift is when you leave a percentage of what's left over after your family and friends have been looked after.

I give all or [insert %] share of the residue of my real and personal estate which I can dispose of by Will in any manner I think proper to The Brain Tumour Charity, Registered Charity No. 1150054 (England and Wales) SC045081 (Scotland), of Hartshead House, 61-65 Victoria Road, Farnborough, Hampshire, GU14 7PA to be applied for its general purposes and I direct that the receipt of the Honorary Treasurer or the proper officer for the time being of The Brain Tumour Charity shall be a complete discharge to my executors.

2. A pecuniary gift is when you leave a specific amount of money.

I give the sum of [insert amount in numbers and in words] to The Brain Tumour Charity, Registered Charity No. 1150054 (England and Wales) SC045081 (Scotland), of Hartshead House, 61-65 Victoria Road, Farnborough, Hampshire, GU14 7PA to be applied for its general purposes and I direct that the receipt of the Honorary Treasurer or other proper officer for the time being of The Brain Tumour Charity shall be a complete discharge to my executors.

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 impact of our work.

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



Codicil

Please complete this codicil form if you would like to add a gift to The Brain Tumour Charity to your existing Will. See the other side of this page for more information about how to use the codicil form and what to do if you don't already have a Will.

I (full name) _____

of (address) _____

_____ (postcode) _____

declare this to be a First Second Third
codicil to my Will, dated and made the day/
month/year _____
_____ (date of original Will)

I give (please tick as appropriate):

all the residue of my estate
 a ____% share of the residue of my estate
 the sum of £ _____

_____ (in figures and in words)

the following specific item(s), free of the
expense of delivery, namely (please name and
describe the items): _____

I wish that donations are given in lieu
of flowers at my funeral

to The Brain Tumour Charity, Registered Charity
No. 1150054 (England and Wales) SC045081
(Scotland), of Hartshead House, 61-65 Victoria Road,
Farnborough, Hampshire, GU14 7PA for its general
charitable purposes and I direct that the receipt(s) of
the Treasurer or duly authorised officer for the time
being of The Brain Tumour Charity shall be sufficient
discharge of my Executor/Trustees.

The gift(s) I leave to The Brain Tumour Charity
are done so in loving memory of my late
_____ (son, daughter, mother,
father, friend etc.), _____
_____ (full name).

The gift(s) I leave to The Brain Tumour Charity
are done so in support of _____

_____ (name of Supporter Group)

In all other respects I confirm my Will and any
other codicils thereto.

Signature: _____
Date: _____

Signed by the aforementioned in our presence
and witnessed by us in the presence of him/her
and each other

Witness one

Name _____
Address _____
_____ Postcode _____

Occupation _____
Signature _____

Witness two

Name _____
Address _____
_____ Postcode _____

Occupation _____
Signature _____

