SPEND YOUR YEAR WITH US

Our Annual Report 2015/2016
It is easy to talk about defeating brain tumours. The real challenge is to translate those words into effective action.

This report shows how The Brain Tumour Charity is rising to that challenge.

In 2015/16 The Charity once again invested millions in research, from a clinical trial for children affected by the deadliest form of the disease to a major new project aimed at reducing the time taken to diagnose adults in the UK.

The Charity’s Quest for Cures initiative has brought together some of the best researchers from around the globe to share their knowledge and expertise. Its New Ideas awards are funding cutting-edge projects that epitomise The Charity’s pioneering approach.

Major milestones in 2015/16 included publication of The Charity’s five-year strategy and its two landmark reports on life with a brain tumour, based on the largest ever survey of people living with the disease.

Between them, these three documents provide powerful evidence of both the need for change and The Charity’s unswerving determination to bring it about.

As chair of The Brain Tumour Charity, I am proud to say that determination shines through every page of this document. It has brought about the many achievements that are set out here and it will continue to drive progress towards a better future for all of those affected by a brain tumour.

Sir Martin Narey
Chair of Trustees, The Brain Tumour Charity

We speak out unashamedly at The Brain Tumour Charity about the need to do things differently.

We know that new ideas and a pioneering approach will propel us as quickly as possible towards our twin goals: to double brain tumour survival and halve the harm caused by the disease.

But we’re also passionate about working smartly – about focusing our efforts for maximum effect and minimum waste. There is no time to spare in our quest to cure brain tumours.

So it’s fitting that we’ve shared our most recent achievements in a way that’s both creative and useful.

We hope that over the next 12 months, you will take a minute or two each week to read about the progress we have made.

You will find within these pages information about every aspect of our work in 2015/16 and how it is helping people affected by a brain tumour, whether through our research funding or our drive to end diagnosis delays, our support for children and families or our campaign to improve NHS services for those living with the disease.

You will read about some of the people who have united with us, including fundraisers, volunteers and researchers – all of whom share our vision of a world where brain tumours are defeated.

We are inspired every day by their stories and their support. We hope you will be too.

Sarah Lindsell
CEO, The Brain Tumour Charity
Our strategy launch

With the launch in July 2015 of our strategy, Defeating Brain Tumours, we set out the path towards our twin goals: to double survival and halve the harm that brain tumours cause to quality of life.

We pledged to invest in research, to increase patient involvement in clinical trials and to improve the process of brain tumour diagnosis.

We promised to tackle differences in the quality of care offered to brain tumour patients and to improve life today for all of those affected by the disease.

Our strategy has united researchers, healthcare professionals and our supporters in pursuit of our vision: a world where brain tumours are defeated.

“We have made real progress in understanding how certain types of brain tumour form – but we need to go further, faster. Too many lives are being lost. We must do whatever we can, together, to speed up the search for a cure.”

Professor Richard Gilbertson, Li Ka Shing Chair of Oncology and Director of the Cambridge University Cancer Centre, who was appointed in February to lead our Grant Review and Monitoring Committee (GRAM).

My week in a nutshell

This week I’ll do these 3 things...

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3 Sign up to The Twilight Walk
thebraintumourcharity.org/thetwililightwalk

Something to celebrate...

My notes/doodle space

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It’s the weekend!

The Twilight Walk

In the autumn of 2015, hundreds of people whose lives have been touched by a brain tumour came together for The Twilight Walk.

Our flagship events for the brain tumour community took place in Windsor, York, Chester and Warwick and raised more than £220,000 to support our work.

Overall, 1,100 walkers of all ages united to complete the 10k routes in memory of a friend or relative lost to a brain tumour – or to achieve a personal goal in the face of their own brain tumour diagnosis.

Did you know?
The Twilight Walk will take place once again in 2016, on 2 October in Warwick, 9 October in Chester and 16 October in Windsor. For more information visit thebraintumourcharity.org/thetwililightwalk

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My week in a nutshell

This week I’ll do these 3 things...

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Something to celebrate...

My notes/doodle space

The Research Involvement Network

Patient-focused research is at the heart of our strategy to defeat brain tumours. Without it we cannot meet our goals of doubling survival and halving the harm caused by the disease. Yet research remains inaccessible to far too many of those affected.

That’s why last year we launched our Research Involvement Network. The RIN is open to anyone affected by a brain tumour who would like to play their part in supporting and promoting research.

RIN members contribute in a variety of ways – for example, by helping researchers to design patient-friendly studies or speaking publicly about their own experience.

didyouknow@thebraintumourcharity.org/RIN

Did you know?

Across the UK, less than 3% of people with a brain tumour take part in a clinical trial. Yet Professor Garth Cruickshank, one of our researchers at the University of Birmingham says, “Across all cancers, this figure is as high as 25% in some centres.” This is an achievement we aim to build on, alongside researchers, as we seek to learn more from all of those who are diagnosed with a brain tumour.

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My week in a nutshell

This week I’ll do these 3 things...

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Something to celebrate...

Suggest us as your company’s Charity of the Year
thebraintumourcharity.org/COTY

ICAP Charity Day

In 2015 we applied successfully to take part in the 23rd global Charity Day organised by financial services company ICAP.

Our high-profile supporters at the December event – former England rugby captain Lewis Moody, television presenter Matt Allwright and Earl Spencer – joined dozens of other well-known faces on the trading floors of ICAP’s London headquarters to help seal some of the day’s global deals.

We received £100,000 from ICAP towards our research into adult brain tumour diagnosis times in the UK, taking us a step further towards tackling the delays that affect too many patients with the disease.
Pushing for change across the UK

People with a brain tumour should receive the best possible care and treatment no matter where they live.

In March 2016 we published a manifesto for each of the devolved nations ahead of elections to the Scottish Parliament, the Welsh Assembly and the Northern Ireland Assembly.

Our manifesto made recommendations to all political parties, including:

• A focus on brain tumours as part of all devolved nations’ cancer awareness campaigns;
• Promotion of our HeadSmart campaign to raise awareness of childhood brain tumour symptoms;
• Access to neuro-rehabilitation services for all children and young adults diagnosed with a brain tumour;
• Action to reduce the high proportion of brain tumours diagnosed through accident and emergency departments;
• Allocation of a clinical nurse specialist or key worker to every brain tumour patient.

Our manifesto launch events brought together politicians and people directly affected by a brain tumour, helping to raise awareness of the disease and the steps we know are necessary to improve services and outcomes.

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Family Days

When a child is diagnosed with a brain tumour, family relationships suffer. Parents and siblings often feel isolated. We bring together families affected by a childhood brain tumour in places where they can have fun. Last year we held four Family Days across the UK, welcoming a total of 180 people who took part in activities including kayaking, climbing, rafting and sensory walks.

“Coming to a family day makes me feel like I’m normal, because I’m not the only kid with a brain tumour. I don’t have to explain anything to anyone here because they know what it’s like. They get it.”

George, 14, who is living with a brain tumour

“Being supported and understood by someone else who has been through it means everything.”

Harry, Young Ambassador for The Brain Tumour Charity
The Brain Tumour Charity, in our view, is the most dynamic, thoughtful and effective UK charity leading the charge in the field of brain tumour research.rob

Spurred on by his son’s incurable brain tumour diagnosis, Rob Ritchie brought together a team of friends and colleagues from Goldman Sachs to climb the equivalent of Mount Everest in the Alps – on skis.

They generated an astounding £2.9 million in donations, allowing us to begin planning in 2016 the largest single investment worldwide into low grade childhood glioma research.

A film about the team’s gruelling expedition and the impact we will make with the money they raised, narrated by television newsreader Alistair Stewart, will help us to inspire further major fundraising efforts.

Watch the film: thebraintumourcharity.org/everest
Tasha’s legacy

A severe shortage of brain tumour tissue for research is one of the major hurdles we are working to overcome. Bereaved families have told us they feel frustrated at the lack of information they were offered about brain donation after the death of a loved one but we also know it can be very hard for healthcare professionals to raise the subject.

When our Young Ambassador Tasha (pictured below) lost her battle with a brain tumour in December 2015 at the age of 24, her parents Graham and Shona honoured her wishes by donating her brain – a decision which researchers said would help to revolutionise their understanding of diffuse intrinsic pontine glioma (DIPG), the type of tumour which killed Tasha. With Graham and Shona’s backing, we shared their story to help give others the confidence to talk about tumour tissue donation.
“I am very, very lucky to have made a full recovery.”

Carol Rutherford

We have heard from countless people with a brain tumour over many years about their struggle to secure a diagnosis. Among them was Carol Rutherford, who sought medical advice at least five times before she collapsed and was diagnosed with a brain tumour the size of a fist.

Last year, researchers funded by The Brain Tumour Charity began a project to piece together systematically the factors that affect diagnosis times for adults in the UK.

Alongside stories like Carol’s, their work will provide the clinical evidence we need to help bring about early and accurate diagnosis for all of those with a brain tumour.
My week in a nutshell

This week I’ll do these 3 things...

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3 Watch a Jake animation at thebraintumourcharity.org/jake and share it on social media

Something to celebrate...

My notes/doodle space

Jake

“In a really difficult time of uncertainty, Jake is someone children can relate to. He has a reassuring way of getting across some scary subjects and helps take some of the fear away.”

Parent of a young brain tumour patient

We created our animated character, Jake, to help children and families faced with a brain tumour diagnosis.

In a series of short films available freely on our website, Jake explains to children what to expect at different stages of their treatment - for example when they have a scan, surgery, radiotherapy or chemotherapy.

We built on Jake’s success throughout 2015/16 by adding new films about the impact on children of a brain tumour diagnosis in a parent or sibling.

Our films have now been viewed more than 10,000 times. Watch them here: thebraintumourcharity.org/jake

Did you know?

Our animation videos and our children and family services were part-funded by BBC Children in Need, who supported our work in 2015/16.

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A benchmark for brain tumour care

“At the initial appointment with the GP, nothing was explained other than that I should get an appointment from the neurologist. The following weeks were agony with worry and stress, as I heard nothing from anyone.”

Jane, diagnosed with a low-grade brain tumour

Last year we began work on a document setting out the optimum adult care pathway for people diagnosed with a brain tumour. This will highlight the basic standard of care that all patients should receive, from the point of diagnosis through treatment and end-of-life care planning.

In January 2016 we brought together a steering group of healthcare professionals, patients and carers from across the UK to shape the document.

We plan to launch the optimum adult care pathway in the autumn of 2016 as we continue our quest to secure equal access to the best treatment and care for all those diagnosed with a brain tumour.

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My week in a nutshell

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“It’s vital that we get behind The Brain Tumour Charity’s invaluable work for those who are affected and those who could be in the future.”

Steve Backshall, TV presenter, naturalist and explorer

New ways of thinking

Progress towards more effective treatments for brain tumours has been too slow for too long.

In September 2015 we announced our New Ideas Awards to encourage innovation in the field of brain tumour research. We asked researchers to come up with novel approaches that could fundamentally change our understanding of brain tumours, in relation to either diagnosis or treatment or both. The teams who have successfully bid for grants of up to £100,000 each under our New Ideas Award will begin working on their projects in 2016/17.

Did you know?

Whilst survival has doubled on average across all cancers in the last 40 years, ten-year survival rates in adults with brain tumours have improved little.4


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Something to celebrate...

My notes/doodle space

My week in a nutshell

This week I'll do these 3 things...

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3 Take on a personal challenge
   thebraintumourcharity.org/challenges

It's the weekend!

Ocean Valour's
record-breaking row

After losing his father to a brain tumour, Tom Rainey was determined to help spare others the pain his family has endured.

Tom described our support in the wake of his father's diagnosis as 'a port in an otherwise unweatherable storm'. In May 2015, he and fellow adventurer Lawrence Walters set out to row across the Atlantic in aid of The Brain Tumour Charity.

The pair broke four world records and raised more than £100,000 – an inspirational feat that is helping us to make a difference for those affected by a brain tumour.

"Keep going because I promise you, you will succeed. Any dream you have, just smash it."

Tom (left in the photo above)
My week in a nutshell

This week I’ll do these 3 things...

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My notes/doodle space

Something to celebrate...

HeadSmart: Sharing our success

In November 2015, our HeadSmart campaign to raise awareness of childhood brain tumour symptoms was the subject of a paper in the journal Neuro-Oncology.

The paper, by researchers at our partner institution The Children’s Brain Tumour Research Centre at Nottingham University, confirmed that the campaign had halved the time taken on average to diagnose a childhood brain tumour in the UK – from 14 weeks to less than seven.

The paper attracted national media coverage for HeadSmart, helping to raise further awareness as we seek to cut that average diagnosis time to below four weeks.

Our Young Ambassadors Jessica and Lauren Pearson were featured on BBC News talking about the impact of the campaign along with Professor David Walker, co-director of the CBTRC and HeadSmart’s leading clinician.

Did you know?

Brain tumours account for one-quarter of all childhood cancers. While five-year survival rates have risen to more than 70%, 62% of long-term survivors of childhood brain tumours are moderately or severely disabled.

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My week in a nutshell

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It’s the weekend!

Empowering families

“It’s important for us to learn as much as we can about our son’s condition.”

Shirleen, whose son Theo is living with a brain tumour

Theo was diagnosed with an inoperable brain tumour at the age of two. After an 18-month course of chemotherapy, he is doing well – but he will need further treatment at some stage.

In May 2015, he and his family attended our Paediatric Information Day in Birmingham where they were able to learn more from expert speakers about clinical trials, treatment options and Theo’s educational needs.

The day also offered families like Theo’s the chance to meet others affected by a childhood brain tumour, helping them to feel less isolated.

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Tackling late diagnosis

People with a brain tumour are more likely to be diagnosed via a hospital A&E department than those with any other type of tumour.

Patients whose cancer diagnosis happens in this way are less likely to survive and more likely to experience long-term health problems than those whose disease is picked up at an earlier stage through a GP referral.

Last year we announced funding for research led by teams in Edinburgh and Cambridge into the delays that affect adult brain tumour diagnosis and what can be done to tackle the problem.

With their findings we aim to build on the success of our successful HeadSmart campaign, which raises awareness of the symptoms of brain tumours in children.

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Connecting carers

Even the strongest relationships can come under enormous strain when ill health leaves a family member or friend in need of long-term care.

In addition to the physical and emotional challenges of coping with any debilitating condition, those caring for someone with a brain tumour may have to deal with distressing personality changes which leave a much-loved partner or parent behaving more like a stranger.

Last year we launched our Facebook support group for carers, in recognition of the unique difficulties they face. Posts are visible only to members of the group, so they can share their experiences freely and build online networks.

90% of people with a brain tumour have become more reliant on others.


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“I love going into The Charity to help out as a volunteer. This award isn’t just for me, it’s also for The Brain Tumour Charity and the other volunteers.”

Paul, winner of the Healthcare Volunteer of the Year award for his achievements with The Brain Tumour Charity

Our volunteers

After 22 years of military service, Paul left the Army in 2002 when he was diagnosed with a slow-growing brain tumour.

Along with hundreds of others, he gives his time and energy voluntarily to The Brain Tumour Charity to help us achieve our common goal: defeating brain tumours.

Whether it is with our Farnborough team or at one of our fundraising events around the UK, our volunteers – many of them personally affected by a brain tumour – drive us further and faster than we could travel alone.

Did you know?

Last year our volunteers sent out more than 7,000 packs of Christmas cards, helping us to raise more than £55,000 in sales from our seasonal shop.
My week in a nutshell

This week I’ll do these 3 things...

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Something to celebrate...

Seeking new treatments

Last year we co-funded two university posts in partnership with the Medical Research Council, which oversees government spending on medical research.

Both are designed to allow a researcher with an existing medical qualification and experience of treating patients to take a further degree specialising in brain tumours.

- In Bristol, Dr William Singleton is investigating new ways of delivering immunotherapy and chemotherapy treatments to highly aggressive brain tumours in children and adults;
- In Nottingham, Dr Jason Adhikaree is working on a new cancer vaccine with the potential to treat glioblastoma, the most common malignant brain tumour in adults.

These clinical research training fellowships aim to speed up the development of more effective brain tumour treatments, helping us to reach our goal of doubling survival.
### My week in a nutshell

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### My notes/doodle space

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**My brother has a brain tumour**

Following the success of our animated films about Jake, a young boy who shares his experience of brain tumour diagnosis and treatment in a child-friendly way, we created a new set of characters in 2015 to help families affected by the disease.

In *My Brother has a Brain Tumour*, Lily talks about the impact on family life after her brother Noah is diagnosed with a brain tumour.

Showing families they are not alone is a key part of our drive to improve life for all of those affected by a brain tumour.

[thebraintumourcharity.org/lily](http://thebraintumourcharity.org/lily)

“The video shows me that I am not alone - there are other kids who have brothers and sisters with brain tumours and sometimes we get treated differently to them.”

Sibling of a young brain tumour patient

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My week in a nutshell

This week I’ll do these 3 things...

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Like HeadSmart on Facebook
facebook.com/headsmartcampaign

Raising awareness, saving lives

“HeadSmart saved my little boy’s life.”

Rosalind, whose son was diagnosed with a brain tumour at the age of three

After Daniel’s behaviour changed and he began vomiting occasionally, his complaint of a headache one morning triggered alarm bells.

His mum Rosalind recalled a Facebook post about our HeadSmart card, listing common signs of a childhood brain tumour.

Daniel was referred to a paediatrician but before his appointment he was diagnosed with a brain tumour via A&E. Two years on, following surgery, Daniel is doing well.

In August 2015 his story was featured in national media, helping us to raise awareness of HeadSmart and the importance of early and accurate diagnosis.

Something to celebrate...

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Finding Myself in Your Hands: The Reality of Brain Tumour Treatment and Care

We are passionate about improving services for brain tumour patients. To make that happen, we need more than words. We need to prove that change is necessary.

That's why last year we surveyed more than 1,000 people living with a brain tumour about every aspect of their NHS treatment and care.

The results of the survey underpinned our report, Finding Myself in Your Hands: The Reality of Brain Tumour Treatment and Care, which was published in January 2016 and received widespread national attention.

The evidence we uncovered in our survey will be crucial as we fight for equality of access to the best treatment and care for everyone with a brain tumour.

Read the report: thebraintumourcharity.org/finding-myself

31% of brain tumour patients visited healthcare professionals at least five times before their diagnosis.11


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The Lewis Moody Foundation was set up by the former England rugby captain and his wife Annie to touch the lives of families affected by serious illness.

As well as raising more than £260,000 in 2015/16 for The Brain Tumour Charity’s research projects, Lewis and Annie helped to create precious memories for children and parents affected by a brain tumour through their support for our Family Days.

Their experiences inspired them to work with our team on similar days out for families with a parent diagnosed with a brain tumour.

“Lifting the spirits of families going through challenging times, seeing them able to communicate, off-load and share their stories, is humbling and the impact is instant.”

Annie and Lewis Moody, November 2015
My week in a nutshell

This week I’ll do these 3 things...

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Buy a bandana and #WearItOut
thebraintumourcharity.org/wearitout

It’s the weekend!

#WearItOut

On March 4, 2016 our annual Bandanas for Brain Tumours Day united thousands of people affected by a brain tumour, including our research community.

Hundreds of our supporters across the UK chose to #WearItOut and share their pictures on our social media, reaching more than twice as many people as in the previous year and improving awareness of brain tumours.

We raised £80,000 towards our research into early diagnosis.
Before this week is over, I will...

Mummy has a Brain Tumour

A brain tumour diagnosis often throws up more questions than answers. If you’re a parent, one of the first is likely to be: “What shall I tell my children?”

Last year we added a new film, Mummy has a Brain Tumour, to our series of family-friendly animations explaining the disease and its effects.

The film is told through the eyes of Charlie, who explains how his parents broke the news of his mum’s diagnosis and what happened afterwards.

By talking straightforwardly about the effects of a brain tumour – including tiredness and personality changes – Charlie is helping other families cope in stressful circumstances.

thebraintumourcharity.org/charlie

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Losing Myself: The Reality of Life with a Brain Tumour

We hear every day about the frustrations and challenges faced by those diagnosed with a brain tumour. We want to help make their voices heard, so that others – including healthcare professionals – have a better understanding of their lives.

Our survey last year of more than 1,000 people living with a brain tumour uncovered some difficult truths about the problems which unite them.

As we reported in our subsequent publication, Losing Myself: The Reality of Life with a Brain Tumour, these include fatigue, financial problems and feelings of severe isolation.

The report received national media coverage and gives us a powerful evidence-based tool as we strive to halve the harm caused by brain tumours.

thebraintumourcharity.org/losing-myself

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A pioneering partnership

“The Brain Tumour Charity and its leadership are real visionaries.”

Professor Chas Bountra, chief scientist of the SGC at the University of Oxford

In March 2016 we announced our partnership with the Structural Genomics Consortium (SGC), an international group of researchers using cutting-edge science to accelerate the discovery of potential treatments for incurable diseases such as brain tumours.

We will fund two research posts at the SGC. The aim is to discover the shape of proteins which play a part in causing brain tumours, paving the way for the development of drugs that ‘lock on’ to specific parts of those proteins and change their behaviour.

Crucially, any findings with potential benefit are shared immediately and freely with other researchers around the world - regardless of whether they are part of an academic organisation or a pharmaceutical company.

Our agreement with the SGC is a pioneering and collaborative step towards our key goals – to double survival and to halve the harm caused by brain tumours.

“The Brain Tumour Charity is driving real change to tackle this devastating disease.”

Mel Giedroyc, TV presenter

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My week in a nutshell

This week I'll do these 3 things...

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My notes/doodle space

Something to celebrate...

Amelia, Pride of Britain

“Amelia, we think you are probably the bravest person we have ever met.”

Simon Cowell on our young fundraiser Amelia

Millions of people saw ten-year-old Amelia receive a Daily Mirror Pride of Britain award for her fundraising achievements.

Amelia lost her dad Peter to a brain tumour in February 2015, shortly before her younger brother Josh was told he had a life-threatening condition which puts him at risk of having a stroke.

She went on to raise thousands of pounds for causes including The Brain Tumour Charity, helping us to invest in vital research and support for families like hers, whose lives are changed forever by a brain tumour.

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Before this week is over, I will...

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It’s the weekend!

Bandanas for Brain Tumours

Our supporters are as passionate as we are about raising awareness of brain tumours and the need for early diagnosis.

On Bandanas for Brain Tumours Day in March 2016, we shared the stories of just some of those whose symptoms could have been picked up earlier.

Among them was Louis, who lost vision in his right eye after surgery to remove a late-diagnosed tumour. Louis and his family are determined to help spare others a similar experience and we were privileged to welcome them on board as we launched Bandanas for Brain Tumours Day.

“After our experience with Louis, we wanted to help raise awareness of brain tumours. Supporting Bandanas for Brain Tumours Day was a great opportunity for our whole family to do that.”

Darren, Louis’ dad

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“Research gives us hope that our children will not be affected by this devastating disease.”

Mark, diagnosed with a low grade brain tumour.

My week in a nutshell

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It's the weekend!

A landmark achievement

This will allow us to invest more than ever before in vital research and support those whose lives have been affected by a brain tumour.

As well as working so hard to inspire donations from others, our fundraisers across the UK help to spread the word every day about our vision and our goals.

We are profoundly grateful to every one of them for uniting with us in pursuit of our goal: to defeat brain tumours.

Did you know?

Gifts in Wills make up less than 3% of our income. Last year we shared with our supporters the stories of some of those who have chosen to leave us a legacy, to show how even a small donation of this kind can make a big difference to our work.

£10m

The total amount we raised in 2015/16.
My week in a nutshell

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It’s the weekend!

Shaping services

We believe everyone diagnosed with a brain tumour should have access to a clinical nurse specialist (CNS) - someone who understands the disease and can act as a single point of contact with the rest of a patient’s care team.

Last year, our survey of more than 1,000 people living with a brain tumour found that those with access to a CNS were likely to report fewer severe symptoms and experience better mental and emotional health than those without.

The survey, which underpinned our report, Finding Myself in Your Hands: The Reality of Brain Tumour Treatment and Care, was featured prominently in journals including Cancer Nursing Practice and the British Journal of Nursing.

It has provided us with powerful evidence as we continue to work towards equal access to the best treatment and care for all brain tumour patients.

Did you know?

Overall, 32% of brain tumour patients who took part in our survey said they had no single named point of contact, such as a clinical nurse specialist, within their healthcare team.13

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Our new website

In September 2015 we launched our new website. Improvements included:

- Clearer signposting towards our information and services;
- More accessible information about the research we fund;
- Better coverage of brain tumour policy and research developments globally.

Use of the website has increased significantly following these changes. In March 2016, for example, the number of sessions recorded was 23% higher than during the same month in 2015.

We put in place a system that allows us to track the number of times each of our factsheets is downloaded, so we can respond to the needs of our community.

The changes we introduced have helped us reach out more effectively to everyone affected by a brain tumour, enabling us to improve lives today.

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My week in a nutshell

Something to celebrate...

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£1.1m

The amount of income generated by our Supporter Groups in 2015/16.*

United against brain tumours

Our Supporter Groups are set up either in memory of someone who has lost their life to a brain tumour, or by a fundraiser who is living with the disease. All of the money they raise is invested through The Brain Tumour Charity into vital research, support services and raising awareness.

In 2015/16, 27 new Supporter Groups were created, taking the total number to 245.

* This figure includes all money raised directly by Supporter Groups as well as that generated by individuals associated with Supporter Groups in events such as the London Marathon.
Virgin Money London Marathon

“It’s been very inspiring to run for The Brain Tumour Charity – to be part of a group of people who are running for someone they love and so determined to make a difference.”

Xavier, co-founder of Peak (a brain training app developer) and one of our 2015 London Marathon runners

Between them, our 118 runners in the 2015 Virgin Money London Marathon raised more than £250,000, as well as enhancing awareness of our cause through local and national media coverage of their efforts.

Thanks in part to their inspirational stories, we attracted a raft of new runners to enter the Virgin Money London Marathon in 2016 – helping us to sustain the fundraising we rely on to work towards defeating brain tumours.

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Information Days

Our Information Days in London, Manchester, Brighton and Glasgow offered an opportunity for people living with a brain tumour and their families to learn more about treatments, coping strategies and support services.

More than 260 people heard from speakers including neurosurgeons, clinical nurse specialists, carers and those personally affected by the disease.

More people attended our London Information Day in June 2015 (91) than any similar event we have hosted.

We held Paediatric Information Days in Southampton, in partnership with University Hospital Southampton NHS Foundation Trust and in Birmingham, in partnership with Birmingham Children’s Hospital NHS Foundation Trust. More than 35 families came along to hear from experts in the field of childhood brain tumour treatment and care.

“I know first-hand, from the incredible support The Brain Tumour Charity gave my family during my dad’s illness, how important it is for families to have that network.”

Tom Daley
Building global teams

Collaboration is key in the hunt for more effective brain tumour treatments.

In September 2015 we announced our Quest for Cures initiative to bring together brain tumour researchers from at least two institutions in the UK or globally.

These grants were designed specifically to support laboratory-based research that has the potential to lead quickly to benefits for patients.

Our funding of up to £1.5 million for applicants under Quest for Cures enabled scientists and clinicians to share expertise and ideas, accelerating progress towards a cure.

Did you know?

Most of our grants are awarded for research initiatives lasting more than 12 months, so we need to know that our funding is sustainable from one year to the next. That’s why last year we took steps to show how simple it is for supporters to leave a legacy gift to The Brain Tumour Charity, and what a difference that can make to our future.

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Trialling new treatment options

One of the key obstacles to treating brain tumours more effectively is the difficulty of delivering drugs across the blood-brain barrier.

Last year we co-funded research by Professor Susan Short at Leeds University into the use of viruses which destroy cancer cells without killing healthy cells.

Early results show these viruses can reach tumour cells in the brain via a simple injection into the patient’s bloodstream.

Professor Short and her team are now trialling these injections in people diagnosed with glioblastoma, the most common form of malignant brain tumour in adults, helping us progress towards our goal of improving survival.

Less than 3% of brain tumour patients take part in a clinical trial, compared to an average of 7.5% of patients across all cancer types.

This week I’ll do these 3 things...

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Spread the word about HeadSmart: thebraintumourcharity.org/headsmart

My notes/doodle space

My week in a nutshell

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It’s the weekend!

HeadSmart: reaching out across the UK

In 2015/16 we sent out more than 295,000 of our pocket-sized HeadSmart cards, which list the main signs and symptoms of childhood brain tumours.

This took the total number of HeadSmart cards distributed in the UK to almost two million, improving awareness of brain tumours in children and helping our progress towards early and accurate diagnosis of the disease.

Key achievements included distributions to:

- All GP practices in Northern Ireland;
- All schools in Bournemouth;
- 40 schools, 20 GP surgeries and the main hospital on the Isle of Wight.

We also produced a new Welsh language version of the HeadSmart card.

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This week I’ll do these 3 things...

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Listening, learning, sharing

In January 2016 our report, *Finding Myself in Your Hands: The Reality of Brain Tumour Treatment and Care*, received widespread national media attention.

The report was based on a survey of more than 1,000 brain tumour patients which found that:

- Women were more than twice as likely as men to wait over a year for a diagnosis after first seeking medical advice for their symptoms;
- Patients in low-income households were more likely than those in better-off households to see a doctor more than five times and to wait for more than a year between their first visit and their diagnosis.

Our findings were reported by newspapers including *The Times*, *The Guardian*, *The Independent*, *The Daily Mail* and *The Sun*, raising valuable awareness of our drive to secure equal access for all brain tumour patients to the best treatment and care.

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**My week in a nutshell**

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**Brainteaser**

*Can you turn this fish around by moving only three matches?*

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**A trusted voice**

A brain tumour diagnosis opens up a world no-one wants to visit.

To help reassure those affected that they are not alone, last year we produced support and information videos on subjects including:

- Being a carer
- The side effects of a brain tumour
- Depression
- Seizures

By sharing the stories of others who have found a way to cope with problems like fatigue and the loss of their driving licence, we are working to reduce patients’ sense of isolation and improve their lives today.
International collaborations and partnerships

No-one working alone will defeat brain tumours.

That’s why last year we continued to build productive partnerships with other organisations in the UK and around the world.

We forged links with the US National Brain Tumor Society and other not-for-profit bodies around the globe, as well as continuing to co-fund research with charities including Cancer Research UK, Children with Cancer UK and Great Ormond Street Hospital Children’s Charity.

By pooling our knowledge and expanding our global networks, we maximise our impact for the benefit of all those affected by a brain tumour.
My week in a nutshell

This week I’ll do these 3 things...

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The Alex Bolt Fund

“Your fundraising efforts will help me and my team find better treatments for children, starting today.”

Professor Chris Jones of the Institute of Cancer Research on the work made possible by our Supporter Group, The Alex Bolt Fund

When Alex Bolt died from a brain tumour at the age of just 16, his family pledged to do all they could to help others diagnosed in the future.

Last year, thanks in part to a 6th successful golf day and gala dinner at Wentworth hosted by former England cricketer Darren Gough, the total amount raised by The Alex Bolt Fund for The Brain Tumour Charity since 2011 passed £600,000.

Money from The Alex Bolt Fund directly supports two research posts at the Institute of Cancer Research.
My week in a nutshell

This week I’ll do these 3 things...

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Follow @BrainTumourOrg on Twitter

Making waves


Our spokespeople appeared on broadcast outlets including BBC News, the Today programme and numerous local and regional radio stations.

By enhancing our digital and offline reach during 2015/16 and beyond, we continue to raise awareness of our work and inspire support for our goals.

Between 2015/16, our Twitter followers increased from 8,422 to 11,531 and our Facebook followers increased from 17,417 to 23,655, over a 30% rise on both social media sites.
My week in a nutshell

My notes/doodle space

This week I’ll do these 3 things...

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29%

Quality of Life

We are working to halve the harm caused by brain tumours.

To achieve that goal, we need to understand what most affects the quality of life experienced by brain tumour patients.

In 2015 we announced plans to fund research projects focusing on this issue, with suggested topics including:

- Symptom management
- Treatment side effects
- Emotional and mental health
- Relationships

Our funding call was for projects lasting up to three years, with grants of up to £300,000, which will help to improve life for brain tumour patients at any stage from diagnosis onwards.

29% of people living with a brain tumour feel severely isolated.\(^{16}\)

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\(^{16}\) The Brain Tumour Charity. Losing Myself: The Reality of Life with a Brain Tumour [Internet]. 2015. Available from: https://www.thebraintumourcharity.org/losing-mysel
Trialling new treatments for childhood brain tumours

In April 2015 we granted funding for a clinical trial into potential new treatments for diffuse intrinsic pontine glioma or DIPG, a highly aggressive and incurable childhood brain tumour.

The five-year trial, which we are co-funding with Cancer Research UK, will involve 150 children diagnosed with DIPG. Each patient will be given one of three existing anti-cancer drugs, depending on an analysis of their tumour and its molecular make-up.

All of the children will undergo radiotherapy in combination with their targeted drug treatment.

A research team led by Dr Darren Hargrave at Great Ormond Street Hospital will compare the results of the trial with those achieved using the standard DIPG treatment of radiotherapy alone, with the aim of making progress towards one of our key goals: improving survival.
Alfie’s legacy

“We know how much brain donations are needed to drive forward research. We find some comfort in knowing that a part of Alfie is still here helping others.”

Zoe and Danny, who lost their son Alfie to a brain tumour

Alfie died in 2014 at the age of six, less than a year after he was diagnosed with an incurable brain tumour called diffuse intrinsic pontine glioma (DIPG).

Determined to bring hope to other families facing a DIPG diagnosis in future, his parents made the pioneering decision to donate Alfie’s brain for research. They also set up a Supporter Group, Alfie’s Journey Fund, which in 2015/16 reached a milestone £50,000 in funds raised for The Brain Tumour Charity.

Their donations are helping us to move further and faster towards effective treatments for children like Alfie.
Creating support networks

Few parents know the shock of being told: “Your child has a brain tumour.”

And few parents know personally the impact that diagnosis can have on every aspect of life – from family relationships to workplace choices, from financial decisions to sleeping habits.

That’s why last year we launched our Facebook support group to unite parents and carers of children who have been diagnosed with a brain tumour.

Members can share their fears, seek support and offer solidarity within a secure online environment, helping to improve the lives of families affected by a brain tumour.


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Young Ambassadors: pressing for change

In February 2016, eight of our Young Ambassadors travelled to Brussels to call for more action to defeat brain tumours.

The group – all of whom have either been treated for a brain tumour or have lost a close relative to the disease – met Emma McClarkin, Member of the European Parliament for the East Midlands, to discuss their experiences.

Along with our CEO, Sarah Lindsell, they also visited the office of the European Cancer Patient Coalition (ECPC).

By sharing with policymakers and campaigners their experience of brain tumours and the impact of the disease, our Young Ambassadors helped garner support for every part of our strategy – from our work towards early and accurate diagnosis to our call for greater global research collaboration.
My week in a nutshell

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It's the weekend!

Offering quality information

We produced eight new factsheets about brain tumours in 2015/16, taking our total to 46.

In addition, we revised five of our existing factsheets as part of our ongoing efforts to ensure the information in all of our publications is accurate and up to date.

Once again we were awarded the Information Standard quality mark, following a process of review by neuro-oncology experts and a panel of patients and carers.

By providing clear and accurate information, we helped give patients and their families the knowledge and confidence to make their voices heard.
My week in a nutshell

This week I’ll do these 3 things...

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Something to celebrate...

My notes/doodle space

CTN Communications

The benefits of our 2015 partnership with CTN Communications were many and far-reaching. CTN provided us with valuable media training, equipping more of our team with the skills necessary to raise awareness of brain tumours, and worked with us to produce a unique video promoting Bandanas for Brain Tumours Day 2016 to help unite our community.

“CTN and The Brain Tumour Charity are a similar size and both punch well above their weight. From media training to creating engaging films, CTN are delighted to have the opportunity to help increase the impact of The Charity’s communications.”

Donna Burtchaell, Account Director

Did you know?

Our successful partnerships during 2015/16 included Bluecube, the technology services company which provides us with IT support free of charge, and recruitment consultants Hays, whose staff raised more than £200,000 for us in total over two years.
My week in a nutshell

**MON**

**TUE**

**WED**

**THUR**

**FRI**

It’s the weekend!

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**Brainteaser**

9 1 7 3 5
8 5 4 6 2 1
3 6 8 4
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7 2 4 1 6 8
6 9 7
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**It’s the weekend!**

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172 cycled across all terrains in the UK and around the world

1,031 ran in marathons, half marathons and other events

**The TWILIGHT WALK**

1,100 walked together to stamp out brain tumours in The Twilight Walk

9,397 joined us to #WearItOut for Bandanas for Brain Tumours Day

338 trekked up mountains, through deserts and across the UK

1,359 organised their own fundraising events across the UK

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Since 1996 we have been at the forefront of the fight against brain tumours. We know how vital it is to find a cure. Laboratory-based research is essential, but on its own is not enough. That’s why we fund every phase of research.

WE WORK with researchers to find the cause of brain tumours, to diagnose the disease more accurately and to understand what prevents early diagnosis.

WE INVESTIGATE new ways to find a cure and support clinical trials to improve treatment and care.

WE COLLABORATE with leading researchers across the world, as well as Cancer Research UK, to ensure we maximise all opportunities.

Alongside research, we do everything we can to improve life for those affected.

WE HELP people affected by a brain tumour every day through our Support & Information Service.

WE CAMPAIGN for early and accurate diagnosis. Our HeadSmart campaign has halved the average diagnosis time for childhood brain tumours in the UK.

Our VISION is a world where brain tumours are defeated.

Our GOALS are to double survival within 10 years and halve the harm caused by the disease to quality of life.

With YOUR HELP we can go further, faster.

Please, pass this page on to one person who can lend us their support – whether it’s as a fundraiser, a volunteer, a corporate partner or a researcher.

Share with them the difference we are making together.

THANK YOU

OVER 55,000 people are currently living with a brain tumour in the UK.

This year, over 5,000 will lose their lives to a brain tumour.

Of those who survive, most will have a reduced quality of life.

The brain tumour charity.

20. HeadSmart was developed in collaboration with the Children’s Brain Tumour Research Centre at The University of Nottingham and the Royal College of Paediatrics and Child Health.
Our finances

The Charity’s incoming resources jumped by 43% to £10,272,063 from £7,158,946.

Underlying income, which excludes exceptional income, was £7,382,114, an increase of 3% over the previous year.

Income in the year included exceptional restricted income of £2.9 million generated by one of our major donors. The scale of income from this source is not expected to recur each year.

All of our services are free of charge for anyone affected by a brain tumour. This, coupled with our research and awareness work, is only possible thanks to our dedicated supporters, as we receive no government or statutory funding and rely 100% on voluntary funding.
Highlights

Thanks to every one of our supporters, 2015/16 was a landmark year for The Brain Tumour Charity. Your fundraising efforts enabled us to invest further in groundbreaking research and support more people affected by a brain tumour, as well as stepping up our campaign to raise awareness of the disease.

So whether you ran, cycled or trekked, organised your own unique event or joined us as a corporate partner, you helped us to raise an incredible £10 million last year in pursuit of our vision: a world where brain tumours are defeated.

Here’s a taste of what we achieved together in 2015/16.

April 2015
More than 200 supporters ran the Virgin Money London Marathon in aid of The Brain Tumour Charity, raising over £250,000 for our work.

May 2015
We held two Paediatric Information Days for families affected by a childhood brain tumour, in partnership with healthcare providers.

June 2015
We announced funding for new research into the delays that affect adult brain tumour diagnosis in the UK.

July 2015
We published Losing Myself: The Reality of Life with a Brain Tumour, the first in a series of reports based on our unique survey of more than 1,000 people living with a brain tumour.

August 2015
The Ocean Valour duo, Tom Rainey and Lawrence Walters, arrived in the UK after a record-breaking transatlantic row that raised more than £100,000 for our research into brain tumours.

September 2015
We announced two major research initiatives: Quest for Cures, to enable researchers from around the globe to share their expertise, and New Ideas, to encourage innovation in brain tumour research.

October 2015
The Twilight Walk united 1,100 people to #WalkWithUs in Warwick, Windsor, York and Chester, raising more than £220,000.

January 2016
We launched Finding Myself in Your Hands: The Reality of Brain Tumour Treatment and Care, the second report to come out of our groundbreaking survey of more than 1,000 people living with a brain tumour.

March 2016
Thousands of people across the UK joined forces to #WearItOut! on Bandanas for Brain Tumours Day, raising awareness of the disease and funds for research into diagnosis delays.

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Thanks

In addition to our thousands of dedicated supporters, we are grateful to many companies, charitable trusts and foundations, both in the UK and internationally, which are having a significant impact across all areas of our work. These investments are making it possible for us to fund the best research to help find a cure, support everybody affected by this devastating disease and raise awareness of brain tumours to save lives.

Trusts
Allergan International Foundation
BBC Children In Need
Carly Bush (Lovett) Fundraiser Ltd
McClay Foundation
Peter Culverhouse Memorial Trust
P F Charitable Trust
Rowan Bentall Charity Trust
ShareGift – The Orr Mackintosh
Stafford Trust
The Adrian Swire Charitable Trust
The Barcapel Foundation
The Gentlemen’s Night Out
The Light Fund Company
The Sir James Reckitt Charity
The Sobell Foundation
UPS Foundation
William Brake Charitable Trust

Co-funding Partners
Action Medical Research
Cancer Research UK
Children with Cancer UK
Great Ormond Street Hospital Children’s Charity
Medical Research Council
Katy Holmes Trust
Naseem Manx’s Brain Tumour Charity
OSCAR’s Paediatric Brain Tumour Charity
Pippa Jones Little Treasure Trust

We also extend our huge thanks to our high profile supporters who have worked with us and helped us generate greater awareness of The Charity. A special thank you to:
Alastair Stewart OBE
Caroline Lucas MP
Chris White MP
Dr Chris Jones
Dr Paul Brennan
Emma McClarkin MEP
Jonny Wilkinson CBE
Lewis Moody MBE
Lorraine Kelly OBE
Marc Silk
Margaret Rose, Mayor of Marlborough
Mel Giedroyc
Mr Sorin Bucur
Professor Barry Pizer
Professor Denise Sheer
Professor Susan Short
Sir Colin Brian Blakemore FRS, FMedSci, FBPhS
Steve Backshall
Tom Daley

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Tesco Supply Chain
Thomson Airways Birmingham
Venn Group
Voip Unlimited
XL Catlin Insurance Company Ltd

Chief Executive Officer
Sarah Lindsell
Company Secretary
Angela Deacon

Governance
The Charity has an independent Grant Review and Monitoring Committee (GRAM) and is also supported by over 300 international reviewers from around the world who undertake peer review assessments of research grant applications and make recommendations to the GRAM.

Name
Professor Roy Rampling
(Chair; until January 2016)
Professor Richard Gilbertson
(Chair; from January 2016)
Karen Ackling
Professor Martin van den Bent
Professor Steven Clifford
(until August 2015)
Professor V Peter Collins
(until August 2015)
Dr Antony Michalski
Peter Moreton
Dr Simone Niclou
Professor Martin Taphoorn
Professor Susan Short
Professor Chris Twelves
Dr Ian Waddell

Institution/lay member
Glasgow and Western Infirmary
Cambridge University Cancer Centre
Erasmus University,
The Netherlands
University of Newcastle
Great Ormond Street Hospital for Children
Luxembourg Institute of Health,
Luxembourg
Medical Centre Haaglanden,
The Hague, The Netherlands
University of Leeds
University of Manchester
St Jude Children’s Research Hospital

If you’d like to know more about The Brain Tumour Charity and the work we do, please get in touch:
thebraintumourcharity.org
01252 749990
enquiries@thebraintumourcharity.org

Registered office:
Hartshead House, 61-65 Victoria Road,
Farnborough, Hampshire GU14 7PA