DEFEATING BRAIN TUMOURS

Our strategy to double survival and halve the harm that brain tumours have on quality of life.

2015 - 2020
Our vision

Our vision is for a world where brain tumours are defeated.

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours, making a difference every day to the lives of people with a brain tumour and their families. We are committed to having the biggest possible impact for everyone affected by a brain tumour, to defending the most amazing part of the human body, so that the diagnosis of a brain tumour is no longer a death sentence.

We fight brain tumours on all fronts through research, awareness and support to save lives and improve quality of life.

- **We fund pioneering research** to find new treatments, improve understanding, increase survival rates and bring us closer to a cure.

- **We raise awareness** of the symptoms and effects of brain tumours, to reduce diagnosis times and make a difference every day to the lives of people with a brain tumour and their families.

- **We provide information and support** for anyone affected to improve quality of life.

The way we work is:

**Pioneering** We are relentless and courageous in the pursuit of our vision, seeking new ways to make a difference.

**Passionate** People are at the heart of our charity. We are passionate about finding a cure and ensuring that everyone affected has the highest quality of life and chance of survival.

**Collaborative** We will only achieve our vision by building networks, partnerships and a strong brain tumour community. We collaborate and value everyone’s contribution.

**Smart** We are focused and intelligent in our approach to defeating brain tumours.
Seizing the moment

Brain tumours are the biggest cancer killer of children and adults under 40. Over 55,000 people¹ are currently living with a brain tumour in the UK and most are coping with a reduced quality of life. Whilst survival has doubled across all cancers, ten year survival rates for brain tumours have improved little for adults in over 40 years.² This must change. We must transform outcomes and the quality of day-to-day life for those affected by brain tumours.

Over the past forty years the proportion of people who survived for ten years after a leukaemia diagnosis has increased more than sixfold.³ The proportion of people who survived for ten years after a brain tumour diagnosis has merely doubled.⁴ Insufficient improvements in survival rates from one decade to the next from a low starting point means that survival rates for brain tumours remain amongst the poorest of all cancers.² It is the case that the situation is better for children but at what cost? Quality of life for many children who have had a brain tumour is severely impaired and late effects are heart-breaking for far too many parents.

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

How is it that we can use our phone to pay for a sandwich, talk to a relative through a wafer thin screen on the other side of the globe, put a man on the moon, but it seems it is too difficult to organise the way we approach brain tumour research to make an impact on survival rates?

We know that, as charities and patient groups, we must also take some responsibility for the inadequate speed of progress. We have been disparate, too busy competing with each other rather than focusing on the end goal. Our gratitude at the kindness with which our loved ones have been treated has perhaps prevented us from asking the difficult questions or objectively funding only the most promising research.

This said, there are many hundreds of scientists, healthcare professionals, researchers, parents, family members and supporters of The Charity who have worked tirelessly over the past few decades to change outcomes. We are fortunate to build on that work and we are immensely grateful for it. We do recognise the complexities of the systems within which we all work but we also see the need to be co-ordinated, systematic, risk taking and, most importantly, courageous.

And, because of this, we think we are at a tipping point.

We can learn from a similar journey in the field of HIV and AIDS. With a recipe of advocacy, science and dogged perseverance combined with naivety and hope, the changes that were seen in the early days of drug development for HIV and AIDS mean that it is no longer a death sentence. They showed us that advocacy and persistence can change the research landscape and how the system works. We must learn from that. They still have some way to go but people are alive today because people like us acted.

Did something.

To understand the key issues better, we have listened to many people personally affected by a brain tumour. We are truly grateful to those who gave their time, experience, advice and expertise. They include people affected by a brain tumour, the global research community, healthcare professionals, the biotech and pharmaceutical industry, donors, other charities in the UK and overseas, our Trustees, staff and volunteers.

Their overwhelming message is that there are two priorities to address - the poor survival rate and the impact of brain tumours on quality of life. It is also clear that there must be a smarter way to achieve this.

So, this document shares our strategy for making these changes. Its aim is to enable those already involved, and others crucial to our strategy’s success, to unite around our vision for the future. This plan has driven our research strategy, how we will provide support and influence our partners, how much we raise and how we talk about what we do, and to whom, for the next five years.

Our strategy is necessarily and unashamedly ambitious but it is not only decades overdue, it is an essential step towards our vision for a world where brain tumours are defeated.

So, today, we hold ourselves to account for the lack of progress in improving survival rates. We recognise that to make progress we need to work together, relentlessly, until we have better answers and people with brain tumours live, and enjoy that life.

Sarah Lindsell, CEO
April 2015

A wider perspective

The external context in which The Brain Tumour Charity seeks to eradicate brain tumours will have a significant impact on our activities and the success of our plans. We must consider the opportunities, and manage the risks, that arise from political, economic, health and social pressures and from charity competition and advancing technology over the next five years.

With relentless pressure on government funding coupled with rising patient expectations of care, health policy is becoming more open to innovation. In this environment, we can be pioneers in enabling progress in brain tumour services, research and treatment, initiating and facilitating the united voice for change at a policy level. Historically there has been very little cross-sector working between not-for-profits, the pharmaceutical and biotech industry and academia, nor a collective voice to call for change. We can foster the growth of such a voice.

Policy makers are exploring innovative ways of tackling health issues, social problems and empowering communities. Whilst this is promising, continued economic uncertainty means that we need more effective and better value solutions to health issues.

Healthcare budgets are being squeezed and patients in some countries are being denied basic cancer drugs and treatments. We can help carve out a greater proportion of available funding for brain tumours. We can also work collaboratively and innovatively to improve the value that can be gained from limited funding.

Technology has transformed our economy and the ways in which we learn and live, enabling quick and easy communication regardless of location. We can use these developments to help us broaden and improve our communications and enhance the way we provide information and support, whilst taking care not to lose sight of any of those less technically inclined.

The brain tumour voluntary sector is populated by numerous small charities and only recently have the charities started merging and working together in a more collective way, particularly globally. It is clear from the history of advances in other cancers that it is only when charities collaborate that real progress in survival rates is seen. The Brain Tumour Charity is currently the leader in its sector and as such we have a responsibility to enable this change.
Together creating a better future

Whilst survival has doubled across all cancers, survival rates for brain tumours in adults have improved little in over 40 years: 60\(^6\)\(^\text{a}\) of people diagnosed with a malignant brain tumour will not survive one year and just 19\(^\text{a}\)\(^\text{b}\) of adults will survive for five years or more.\(^3\) That means that more than 5,000 people lose their lives every year.\(^6\)\(^\text{b}\) In addition, brain tumours reduce life expectancy by an average of 20 years, the highest of any cancer.\(^7\) Despite these facts, less than 2% of the £500million invested in cancer research in the UK every year is spent on brain tumours.\(^8\) We must improve survival rates through the funding of high quality research and the efficient translation of the results into new treatments.

Brain tumours are different from other cancers – they affect the part of the body that makes you the person you are. They can directly affect your character, feelings and ability to use all other parts of your body. This is why people with a brain tumour and their families do not simply focus on survival but on their quality of life. Over 55,000 people\(^9\) are currently 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.\(^10\)

The daily impact that brain tumours have, as well as the trauma of diagnosis, must be understood more widely. We must reduce the harm caused not only to the lives of those living with this disease, but on their carers, families and friends.

In addition to these two key issues, we have also identified areas of particular concern where improvement would contribute to better survival and quality of life:

- **Late and inaccurate diagnosis**
  - UK diagnosis times must be reduced further across all age ranges, and diagnosis must become more accurate, to maximise treatment options and therefore improve the chances of recovery with a better quality of life.

- **Inconsistent NHS experience**
  - The overall consistency and quality of the NHS experience for brain tumour patients must be improved in the UK.

- **Lack of support**
  - We must extend our information and support services to everyone who needs help with navigating the system and enhancing their quality of life.

Now is the time to challenge the status quo, to seek innovative answers and to push the boundaries of scientific knowledge about brain tumours.

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\(^7\) 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.

\(^8\) National Cancer Research Institute. NCRI Cancer Research Database [Internet]. Available from: bit.ly/NCRI_research_database


Defeating brain tumours are the BIGGEST CANCER KILLER of children and adults under 40.

62% of children who survive a brain tumour will be left with a life-altering, long-term disability.

91% of people who survive a brain tumour find that it affects their emotional or mental health.

62% of people with a brain tumour find that it affects their emotional or mental health.

A world where brain tumours are defeated.

1. A CURE CAN’T WAIT
2. DOUBLE SURVIVAL WITHIN 10 YEARS
3. EARLY AND ACCURATE DIAGNOSIS
4. UNITED IN OUR BATTLE TO DEFEAT BRAIN TUMOURS
5. SMART COMMUNICATIONS
6. SUSTAINABLE FUNDING
7. A HIGH PERFORMING TEAM

Goal 1

Smart

Pasionate

Smart

Defeating brain tumours 2015 - 2020
Brain tumours reduce life expectancy by on average 20 YEARS.

With a brain tumour, 6% of people with a brain tumour find that it affects their mental health.

Of the cancer research funding in the UK is spent on brain tumours, less than 2%.

The components of success:
- A lean and scalable organisation
- Learning organisational culture
- Collaborative approach
- Pioneering thinking
- The way we work

Goal 2: Every patient is a research patient

Priority 4: Equal access to the best treatment

Priority 5: Improving life today

Vision: A world where brain tumours are defeated.
The goals

We are committed to having the biggest possible impact, for everyone affected by a brain tumour in the UK. We are determined to defeat brain tumours. We have set ambitious goals as we know these are the only way we will see a real and lasting difference for people with a brain tumour:

- **Double survival within 10 years in the UK**
  Our goal is to halve the average years of life lost to a brain tumour from 20.1 to 10 years by 2025.

- **Halve the harm that brain tumours have on quality of life in the UK**
  Our goal is to halve the harm caused by brain tumours by 2020, from a baseline measure which we will agree with clinicians and patient groups by the end of 2015.

To reach our goals, we have established key priorities to direct our activities, engage the brain tumour community and make the changes vital for success. Here we set out these priorities and how we will address them by 2020.

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

- **62%**
  Children surviving a brain tumour who are left with a life-altering, long term disability.

- **91%**
  Adults reporting that their brain tumour affects their emotional and mental health.

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When I was diagnosed with a brain tumour at the age of 16, I was given no hope. The doctors told my parents I would live for a year, at most. Seven and a half years later, I’m still here. I’ve learned to cope without my sight after surgery damaged my optic nerves and I’ve achieved things that once seemed impossible, like studying for a university degree and living with my fiancé in our own home.

Two months ago, a scan showed that the tumour is back. I was told for the second time to fear the worst. But I’m not ready to give up. I will never accept there is no hope.

That’s why I’m so passionate about supporting The Brain Tumour Charity and its goals – to double survival and to halve the harm caused by brain tumours.

The charity is offering something precious to everyone affected by a brain tumour: hope.

Tasha Floyd
A cure can’t wait

We will invest in forward-thinking, outcomes-orientated and patient-focused research. We will bring about global collaboration to speed up the time it takes to turn discoveries into treatments and cures. Our research strategy takes its name from this priority – a cure can’t wait – and sets out how we will:

- Accelerate research progress through centralised collection of, and access to, brain tumour samples, creating a national biobank.
- Seek to diagnose brain tumours earlier and more accurately for both children and adults.
- Increase understanding of the genetics and biology of tumour development to identify effective new treatments.
- Translate laboratory discoveries into new and effective treatments that increase survival and quality of life.
- Enhance care and quality of life for everyone affected by a brain tumour, including patients and carers.

Our target:

- Invest a further £20million through our research strategy from 2015 to 2020.

Read in full A Cure Can’t Wait: Our Research Strategy at: thebraintumourcharity.org/researchstrategy

"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."
Every patient is a research patient

We will make sure every patient is able to contribute to research and clinical trials, as this gives them faster access to treatments, better care and the opportunity to help defeat this disease. To make this happen, we will:

- Empower patients to ask about and become involved in research, including clinical trials, tissue banking, trial design and qualitative research.

- Increase the number of, and access to, clinical trials by investing more money in trials, helping the most promising trials recruit patients and engaging professionals to promote patient participation in clinical trials.

- Establish a global, open access brain tumour registry, ensuring that it is patient led yet medically verified.

Our target:

- 70%, at least, of patients living with a brain tumour are contributing to some form of research by 2020.

Brain tumour patients who are taking part in a clinical trial,\textsuperscript{15} compared to an average of 7% for all cancers.\textsuperscript{16}

Andrew Brodbelt, consultant neurosurgeon and clinical director of neurosurgery at The Walton Centre NHS Foundation Trust.

\textsuperscript{15} National Cancer Research Institute. NCRI Brain Tumour Clinical Studies Group Annual Report 2013/2014 [Internet]. Available from: bit.ly/NCRI_brain_tumour_report


“Every person who is diagnosed with a brain tumour should have the opportunity to take part in a research project. This can help to optimise their own treatment and enhance our understanding of these tumours so we can more quickly improve treatments for the future.”
Early and accurate diagnosis

We will work to reduce diagnosis times and improve accuracy of diagnosis so that brain tumours are treated earlier, with the best possible treatment at the right time. To make this happen, we will:

- Continue to develop our HeadSmart early diagnosis campaign for childhood brain tumours.
- Commission research to understand the routes to diagnosis for adults and the impact of earlier diagnosis.
- Create and launch a public early diagnosis campaign for adults using evidence-based research and learning from our HeadSmart campaign.
- Improve accuracy through promoting biomarkers and molecular testing as part of diagnosis.

Our targets:

- Increase public awareness of HeadSmart from 15% to 30% by 2020.
- Reduce average diagnosis times for children and young people to five weeks by 2017.
- Measure the average diagnosis time for adults by 2017 and halve this by 2020.

Heather Dearie was diagnosed with an acoustic neuroma more than a year after she first consulted a GP about her symptoms.

"Earlier diagnosis would have made a dramatic difference to me. By the time my tumour was removed, the surgery I needed was very damaging - I still have muscle weakness in my face and no peripheral vision. A brain tumour should never be the last thing doctors consider."
Equal access to the best treatment and care

We will work to ensure every person with a brain tumour has the same access to high quality treatment, care and information regardless of postcode, age or tumour type. To make this happen, we will:

- Develop an optimal patient pathway for treatment and care and use it to propose a quality standard and call for change through the UK.
- Work to improve the NHS experience of patients with brain tumours by seeking improvements in information and services, highlighting inequalities and funding service innovation.
- Share knowledge and best practice, through providing information and support as well as platforms for professional networks and peer to peer support.
- Improve data availability and outcome measurement for brain tumours.

Our targets:

- Establish a Patient Pathway quality standard for brain tumours, with 90% of patients following it by 2020.
- Improve the NHS experience of adults with brain tumours, taking it from the bottom 4 to the top 4 cancer types by 2020, as reported by the National Cancer Patient Experience Survey.

Anna Crofton is a clinical nurse specialist at The Walton Centre, the UK’s only specialist neurosciences NHS Trust.

“Every patient with a brain tumour needs to be certain they have access to the best possible treatment and care. It is traumatic enough to cope with a brain tumour diagnosis – the struggle should never be harder simply because of your age or where you live.”

Improving life today

We will provide information and support to help every person to navigate the system and improve their quality of life. To improve life today we will:

- Map the patient pathway for treatment, care and research and all systems that significantly affect quality of life including social care, welfare, education and employment.

- Develop information and support materials and resources, on and offline, for each stage of a patient’s and carer’s journey.

- Commission research on the impact of brain tumours on the lives of patients and families, identifying the needs of those affected and developing our range of services according to those needs.

- Prioritise our services according to the impact they can have on quality of life and collaborate with others to help deliver information and support.

Our targets:

- Double the number of people we support each year until 2020.

- Ensure that at least 90% of those using our services tell us that their quality of life has improved and they feel more in control of what is happening.

Fiona Woodfield’s ten-year-old daughter Madeleine was diagnosed with an epidermoid cyst in her brain in 2013.

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The support we received from The Brain Tumour Charity after Madeleine’s diagnosis has made a huge difference to our lives. They understood what we were going through and helped us practically and emotionally, so that we feel much more confident about the future.
United in our battle to defeat brain tumours

We will lead and facilitate a community that works collaboratively. We value everyone’s contribution. Every day, we witness the impact of a diagnosis on people’s lives and this makes us committed to finding a cure. It is imperative we do this as part of a community of people affected by and working against this disease. Only by working as one, will we make change happen. To build this community we will:

- **Develop further co-funding partnerships** with research institutions, charities, industry and other organisations, both in the UK and internationally.

- **Encourage global collaborations** between researchers, enabling those affected by brain tumours to participate in research and service development and become actively involved as ‘experts by experience’.

- **Demonstrate the impact of living with a brain tumour** to create a common sense of purpose and understanding.

- **Strengthen the brain tumour community** by partnering with other organisations with whom we share a common purpose and values, and drive consolidation in the not-for-profit brain tumour sector.

Experience ongoing symptoms including personality changes, pain, memory problems and cognitive problems.19

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

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Bhavna Emery Jones was diagnosed with a highly aggressive brain tumour in 2013. Since then she has taken part in several fundraising events for The Brain Tumour Charity.

"My diagnosis was devastating for me and my family. However, my attitude from day one was ‘bring it on’. There are so many people fighting this battle. By uniting, sharing and supporting we are stronger – and we can win."
Components of success

We have clear goals and a set of values to guide how we will achieve them. Our success will be built on:

**Smart communications**
We need compelling, engaging and targeted communications to raise national brand awareness and enhance our pioneering and collaborative reputation. We will focus on these key areas - our digital presence, the media, awareness campaigns and high profile endorsements.

**A lean and scalable organisation**
We are keen to stay lean and efficient, remain entrepreneurial and build for scale, whilst keeping our personal approach. We will maintain our ratio of charitable to non-charitable spend at 80:20, set objectives and targets for our activities and measure performance continually.

**A high-performing team**
We will continue to attract, grow and keep a positive, productive team. We will support leaders at every level of the organisation as they define clear goals and build a shared vision of the future, encouraging autonomy and forward thinking. We will involve the right people with the right skills in each project and work collaboratively as a unit. We will learn openly from mistakes, celebrate success and apply these principles to our wider team of volunteers, advisors and board.

**Learning organisational culture**
We will embrace a learning culture to increase knowledge, competence and performance. We will do this through structured and peer-to-peer learning experiences, encouraging staff development through innovative working practices and creative thinking.

**Sustainable funding**
Our strategy is ambitious and to achieve our goals we will need to increase significantly our investment in our charitable objectives. We will implement a sustainable and scalable fundraising plan that doubles our income to £12million per year by 2020, diversifying our income streams and offering flexible ways for people to support us. We will explore opportunities and models of working with biotech and pharmaceutical companies and actively seek opportunities for co-funding partners.

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Raj had surgery to remove a brain tumour at the age of two. The tumour recurred last year and he was treated with NHS-funded proton beam therapy.

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“It is so important to improve the understanding and treatment of brain tumours. We have had outstanding care for Raj but more research and awareness is desperately needed, for the sake of everyone affected.”

Suki, Raj’s mum
Resources and finance

Our aim is to apply our resources as efficiently and effectively as possible. We only fund activities that drive us forward in achieving our goals. To do this, we need to understand and challenge the way we do things, work collaboratively across functions to simplify end-to-end processes and maximise their effectiveness. We will measure performance against pre-defined targets and benchmarks, to confirm our activities are meeting our expectations. Underpinning our spending is the development of our sustainable and stretching fundraising plan.

The chart below depicts how we anticipate our resources will be applied during the next five years, as we deliver our exciting and ambitious goals.
Conclusion

The Brain Tumour Charity’s unique position gives us a critical role in accelerating brain tumour research. We can help significantly improve survival rates and quality of life. At the same time, we need to improve the lives of those affected by a brain tumour today. We are acutely aware of how complex and challenging both of these goals are but we will work ceaselessly to achieve them.

This is both a privilege and a considerable responsibility, which we seek to share with all who understand the need for change – our partners, donors, those who are living with this truly devastating disease and the families who have lost loved ones. We cannot do this alone. Please join us and help us make these vital changes. There is more information on the many ways you can get involved on our website at thebraintumourcharity.org

Our strategy is for everyone to share, discuss, shape and implement – it is a working document. It will change over the next five years, as we learn and become smarter in our efforts. We welcome your feedback at comms@thebraintumourcharity.org
About us

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours, making a difference every day to the lives of people with a brain tumour and their families.

We fund pioneering research to increase survival and improve treatment options. We raise awareness of the symptoms and effects of brain tumours to get earlier diagnosis and to help families cope with everything that the diagnosis of a brain tumour brings.

We provide support for everyone affected so that they can live as full a life as possible, with the best quality of life.

We are committed to having the biggest possible impact for every person affected by a brain tumour, to defending the most amazing part of the human body, so that getting the diagnosis of a brain tumour no longer means a death sentence.

We believe that fighting brain tumours on all fronts through research, awareness and support is the only way to save lives, reduce long-term disabilities and help everyone with a brain tumour and their families.

We are members of the Association of Medical Research Charities, The Information Standard, The Helplines Partnership and the Fundraising Standards Board.
The Brain Tumour Charity was established in 2012 following the merger of the Samantha Dickson Brain Tumour Trust (est 1997) and Brain Tumour UK (est 1997, later merging with Joseph Foote Trust).