

LOSING MYSELF

THE REALITY OF LIFE WITH
A BRAIN TUMOUR

Contents

A message from our CEO	2
Welcome	3
About the project	3
I feel like I've lost 'me'	4
My body is betraying me	7
It's taken my independence	10
I struggle to work	13
My family live with it	16
I've become isolated	19
I'm scared of dying	22
About us	24
Creating a better future together	25

A message from our CEO

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, raise awareness of the symptoms and effects of brain tumours, and provide support for everyone affected, to improve quality of life.

We are committed to making the greatest possible impact on the lives of everyone affected by this disease, to defending the most amazing part of the human body, and together defeating brain tumours. Our knowledge and experience show that only ambitious goals are adequate to the task of making real and lasting change, so that a diagnosis no longer means a death sentence. This aspiration is reflected in our organisational goals: to double survival within 10 years and to halve the negative impact that brain tumours have on quality of life.

It is with these goals in mind that we commissioned *Life with a Brain Tumour*, a landmark research project which investigated the real, lived experience of adults with a brain tumour and their experiences of treatment and care. It is the most comprehensive study of its kind.

This report, *Losing Myself: The Reality of Life with a Brain Tumour*, presents the project findings relating to the daily life of those living with a brain tumour – moving personal stories and stark statistics that demonstrate the extensive impact this disease has on how those affected go about their lives, day-to-day.

I would like to thank everyone who participated in this vital research for assisting us in our effort to achieve a deeper understanding of the needs of, and challenges faced by, our community. The accounts of daily life obtained in the study will be used to ensure policy makers, healthcare professionals and the public understand the realities of this disease. With this evidence we can make the change that is so desperately needed to improve life with a brain tumour today, tomorrow and in the future.

Sarah Lindsell
CEO



Every day 25 people in the UK are diagnosed with a brain tumour¹

That's 9,365 people diagnosed with a primary brain tumour every year²

Best estimates are that around 55,000 people are living with a brain tumour in the UK³

Welcome

The words 'brain tumour' tend to evoke thoughts of ending, dying and the absence of a life. Yet, for thousands of people across the UK a brain tumour is a part of living — an aspect of their present and future. Life with a brain tumour means going on, though often in dramatically altered circumstances. In this ground-breaking research project over a thousand people shared their stories of what it is like to live with a brain tumour.

People recounted a loss of identity due to personality changes, cognitive and communicative impairment, and being forced to abandon or change career. The decline in one's own physical or mental functions can

feel like a betrayal, obliging a person to rely on the care and support of others, and denying them the independence of adult life they once enjoyed. No longer being able to work and provide for the family, to socialise, or even help around the house, can have a devastating effect on relationships with loved ones. Living with a brain tumour also means coping with the dread of decline, fear of death, and anxiety about the wellbeing of those left behind.

The stories we've shared in this report illustrate the real-life needs, harms and hopes underpinning our goals to double survival within 10 years and halve the negative impact that brain tumours have on quality of life.

About the project

The *Life with a Brain Tumour* project was conducted by The Brain Tumour Charity in partnership with Alterline, an independent research agency.

In total 1,004 people completed the study questionnaire between 13 February and 13 March, 2015. Following the survey, 15 people took part in in-depth, face-to-face interviews and a further 25 kept reflective diaries over seven days.

1,004 people completed the questionnaire — the most comprehensive study undertaken of its kind, globally

The questionnaire used to collect the large-scale data was directly advertised to subscribers of The Charity's e-newsletter. It was also promoted on The Charity's website

and other communication channels, and by The Charity's volunteer and healthcare professional networks. The majority of respondents accessed the questionnaire online, with a small number completing it over the phone. Alterline also publicised the questionnaire on mainstream social media websites to reach people living with a brain tumour who had no association with The Charity.

Developed by Alterline alongside The Charity, the questionnaire covered many aspects of people's lives, reflecting experiences recounted in pre-survey scoping interviews with people with a brain tumour.

The quotations that appear in this report are transcriptions of words spoken by people who took part in the research; all photographic images likewise feature study participants, shown at the time of interview in their home or workplace.

1, 2 Based on 2011 statistics. Cancer Research UK. *Brain, other CNS and intracranial tumours statistics*. Available at: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-tumours#heading-Zero> [Accessed 29 October 2015]

3 brainstrust. *Living with a brain tumour*. Available at: http://www.brainstrust.org.uk/Uploaded/brain_tumour_infographic.jpg [Accessed 21 May 2015]



Stuart, 52, lives with his wife and two children in Cheshire. He was diagnosed with an anaplastic ependymoma in 2011. He was eventually forced to give up work due to the cognitive impact of the tumour, which impaired his memory and concentration. He would like to return to work, but is uncertain as to whether this is achievable.



I feel like I've lost 'me'

A fundamental difference between a brain tumour and a tumour in other parts of the body is the effect it can have on the mind and interaction with other people. Brain tumours frequently lead to the loss of the characteristics and faculties that make us who we are as individuals: personality, memories, cognition and the ability to communicate with others. Involuntary changes to an individual's personality and behaviour can make them unrecognisable to friends, loved ones, and even themselves, whilst those with speech, memory or concentration problems may find meeting new people stressful and embarrassing.



28% experience personality changes



1 in 2 experience memory problems



1 in 4 experience cognitive problems

Did you know?

A number of factors can cause changes in brain functioning, such as the location, size and grade of the tumour. Interventions intended to treat the tumour, such as radiotherapy and surgery, can also produce cognitive and behavioural symptoms as severe as those caused by the tumour itself.



“... My girls gave me a gift. It was a jar with ‘To a great mum’ on it, and inside there were ‘10 things we love about you’. Each little note had a phrase about me, ranging from how I ‘clean their messy rooms’ to ‘giving them healthy food’.

In most homes I imagine this moment would bring lots of ‘awws’ and hugs, but not in mine. The brain tumour has changed my personality. I no longer have feelings or emotions and get cross and angry at the slightest things.

Instead of saying thank you, I said ‘It would be nice to see actions rather than words’.”

Extract from Suzie’s diary — a 49 year-old woman with a high grade tumour

Becoming a different person

91% of participants in this study said that their tumour had affected their emotional or mental health. Brain tumours are the only type of tumour that directly impacts on personality, behaviour, cognition and communication — the essential features of individual identity. Nearly 3 in 10 people reported experiencing personality changes, such as depression, chronic feelings of anger, heightened emotions and disinhibition. One participant likened her personality fluctuations to Jekyll and Hyde; another said he felt as though part of his brain had ‘been deleted’. Such experiences are not what might be expected as a natural psychological reaction to the distress of a potentially life-threatening illness; they arise from physical changes to the brain caused by the tumour and don’t improve with emotional adjustment to the condition. When people speak in terms of the loss of part of themselves, that loss is very real.

“I feel frightened by how I behave sometimes. It’s like it isn’t really me.”

45 year-old woman with a low grade tumour

Losing your memories

As well as personality changes, over half of the people living with a brain tumour we spoke to reported experiencing memory problems. Participants described the distress and embarrassment of forgetting important details about their lives and the people in them, such as the fact that they are married, have moved house, or the names of their grandchildren.

No longer thinking straight

Nearly two-fifths of participants reported struggling to concentrate and 1 in 4 cited cognitive problems. One female participant described difficulty remembering what she is trying to say during conversations; another reported forgetting ‘even the simplest words’, undermining her motivation to speak at all. Poor concentration, an inability to multitask or process information quickly, and memory problems, all impact negatively on the ability to retain control of one’s own life. One male participant reported being unable to manage his medication because he felt he could no longer trust himself with the task.

Losing the ability to speak

1 in 5 people reported having speech problems as a result of their brain tumour. People told us of the embarrassment and anxiety that comes from living with aphasia, or speech disorders. One female participant explained that she felt she could never say what she meant: ‘I am never quick enough and can often throw in the wrong word, which is totally irrelevant in a sentence’. Others described feeling stupid, fearing that others would pity them, or think they were ‘thick’ or ‘drunk’. The data show that the impact of such difficulties is considerable, both in terms of the practicalities of communication, and the confidence and self-esteem of the individual.



“I’m probably one of the only people who was chuffed to be told there was a blob in my head.”

Emma was diagnosed with an epidermoid tumour on her brain stem in 2011, after years of experiencing symptoms that were wrongly attributed to mental illness. She lives with her husband of 14 years and two teenage children in Liverpool, and works as a carer advocate for The Brain Charity, formerly Neurosupport.

“My brain tumour completely changed my personality. I was misdiagnosed with mental health problems at a young age, and was given a diagnosis of everything from post-traumatic stress to postnatal depression. I also had a very long history of bipolar disorder. When I was diagnosed with the tumour I was scared but relieved. I’m probably one of the only people who was chuffed to be told there was a blob in my head.

Before surgery, when I had my brain tumour, my confidence was at rock bottom. I was extremely anxious and my mood was always very low. I was very isolated and insular. I would go out to work and then go straight to bed when I got home. I didn’t even have eye contact with my children, meaning that I

completely lost touch with being a mum. I also found it incredibly hard to make friends or communicate with others.

I did not just suffer from personality changes, I also used to hallucinate dinosaurs flying over the streets of Liverpool and genuinely believed they were real. Once the hallucinations passed, I knew I couldn’t tell anyone in case I got locked up. What I didn’t realise was that the hallucinations I was experiencing were temporal lobe seizures; my brain tumour was swelling and putting pressure on certain areas of my brain. Even though going for brain surgery was a scary idea for me, it was my chance for a cure.

Since surgery I’m so much better. I’m confident, I can communicate with people, and my kids are so much happier. They say ‘We prefer this mum; this mum’s awesome’. My brain tumour made me a completely different person and the person I am since having it removed is a much better one!”

Emma, 36, from Liverpool

Michael, 47, lives with his wife and three teenage daughters in Glasgow. He has struggled with epilepsy since having surgery to treat his tumour and finds living with the resulting seizures more distressing than the tumour itself. Whilst medication has helped, fear of the sudden onset of a seizure can cause him periods of ongoing anxiety in daily life.

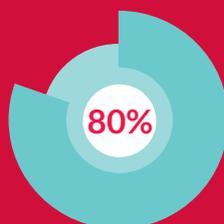


My body is betraying me

Brain tumours may occur in any part of the brain and can therefore affect the full range of physical functions. The majority of people with brain tumours experience physical symptoms of some sort, such as fatigue and headaches, whilst many endure others, including mobility problems, pain, sensory impairment and seizures. Brain tumours limit the control people have over their body, reducing their capacity to function normally and live life to the full.



29% have mobility problems



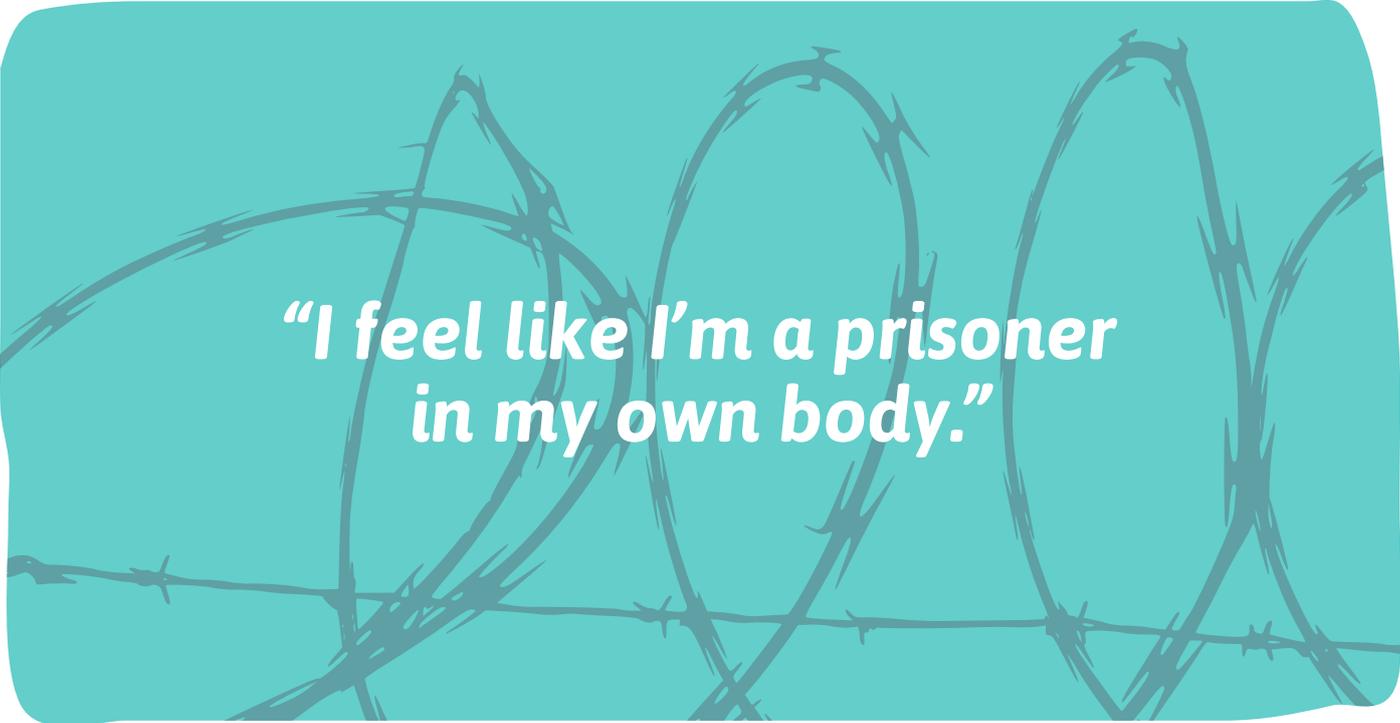
80% of those with mobility problems have been moderately or severely affected by them



3 in 5 people experience fatigue

Did you know?

A brain tumour can cause raised intracranial (inside the skull) pressure. This can lead to various physical symptoms, such as headaches, changes in vision, seizures, nausea and fatigue.



**“I feel like I’m a prisoner
in my own body.”**

Colin, a 23 year-old man with a low grade tumour

Feeling exhausted all the time

3 in 5 people we spoke to reported fatigue and, of those, 40% said they were severely affected by it. The impact of fatigue on a person’s capacity to cope with daily life can be devastating. Unlike an acute sleep deficit, the exhaustion caused by a brain tumour cannot be eliminated with an increase in sleep, and the depletion in energy levels can limit a person’s ability even to deal with basic, routine tasks. One participant said that she ‘has no energy whatsoever’ and would ‘stay in bed all day’ if she could.

“I am just so tired, not just when I do things, but every single day. I work so hard to ignore this but it drains my system. I have little energy for anything other than work.”

58 year-old woman with a high grade tumour

Losing control of your body

Nearly 3 in 10 study participants reported mobility problems, 80% of whom said that they were moderately or severely affected by them. Meanwhile, 38% of respondents told us they experienced problems with balance. People are rendered bed-bound or wheelchair-dependent by their tumour; others use a walking aid or require assistance to leave the house and get about in public. Participants in the study spoke of living in fear of falling, saying that falls were unpredictable, whilst some

worried about people thinking they are drunk when they struggle, stumble or fall in public.

*“It means I’m stuck inside
and either chair-bound
or bed-bound.”*

54 year-old woman with a high grade tumour

Feeling ‘imprisoned by pain’

Pain is a significant feature of life with a brain tumour for many, with nearly 6 in 10 experiencing headaches prior to diagnosis, 43% saying they currently endure them, and 21% currently experiencing other pain. The degree of pain and incapacity endured as a result of chronic headaches, migraine and accompanying nausea can be completely debilitating, confining people to bed to ‘sleep it off’ or to recover from drowsiness caused by strong pain relief. One participant described constant head pain: ‘I go to bed with a headache and wake with one’; another reported having migraines ‘24/7’.

Losing your sight

Nearly 3 in 10 participants said that their sight had been affected as a result of their tumour. Loss of peripheral vision or depth perception can cause collisions, falls, knocking things over and the impairment of the manual dexterity required to safely use kitchen implements or tools. Sight loss may mean that a person can no longer read, or may be so severe as to require walking aids, making mobility outside the home difficult and potentially dangerous.

Having epileptic seizures

Nearly a quarter of participants in this study reported experience of seizures. A seizure is a frightening experience, involving involuntary movement, loss of control of bodily functions or even loss of consciousness. Reports of fear and anxiety about the onset of seizures were common. Their unpredictability, and the possibility of occurrence whilst out in public or in front of one's children, can cause considerable insecurity, and loss of peace of mind and self-confidence. One participant described being 'ambushed' by seizures; another said they made her feel 'scared to be alone'.

"Seizures have made me lose all my confidence. They make me scared to be alone and I have huge anxiety problems."

55 year-old man with a low grade tumour



38% have balance problems



28% have visual problems



1 in 4 experience seizures



"My tumour is a growth defect. It's been there since birth, but we don't know what triggered it and made it start to grow. I've always had issues with my balance. For example, if I'm sleeping on my back and turn over, it feels as if I'm free-falling. I now realise these balance problems are due to the tumour."

Sunil, 45, lives with his wife and three children in Preston. He now works as a maths teacher in a secondary school, but prior to his diagnosis he held the post of assistant head teacher. As the tumour is located around his cerebellum, Sunil experiences difficulties with balance.

Joanne, 47, lives in Warrington with her husband. Her driving licence was revoked for two years when she received her diagnosis, due to the high grade of the tumour. With successful treatment it was reinstated but subsequently revoked once more when the tumour returned. Passionate about the freedom driving gives her, she has described losing her licence as the single most emotionally damaging aspect of her condition, making her reliant on others to go about her daily life.



It's taken my independence

Whilst the effects of a brain tumour vary in range and severity, the net result for many is a loss of the autonomy that defines a person as a fully independent adult. The personal toll of adapting to a new way of living, dependent on the support of others, can be high indeed. Loss of one's driving licence leads to an increased reliance on others that can feel frustrating and burdensome for all involved. Those who find they require assistance with personal care may feel their dignity and self-respect has been undermined by their condition.



3 in 4 lose their driving licence at some point



61% have difficulty with domestic chores



2 in 5 have difficulty with personal care

Did you know?

A study which looked at individuals with two specific tumour types found that the frequency of seizures, reduced mobility and the difficulty of performing daily activities all lead to lower self-reported quality of life, with 1 in 5⁴ people no longer able to live independently.

4 Habets E.J., Taphoorn M.J., Nederend S., Klein M., Delgadillo D., Hoang-Xuan K., et al. Health-related quality of life and cognitive functioning in long-term anaplastic oligodendroglioma and oligoastrocytoma survivors. *J Neuro-oncol.* 2014; 116 (1): 161-168.



“... At 8:15 my dad arrives take me to work. I am a teaching assistant at a local school — dad has agreed to take me as, since my seizures, I am not allowed to drive.

I hate being reliant on him, but the bus station is nearly 2 miles from where I live, and I have to get my daughter to nursery.

Poor dad... He says he doesn't mind, but I do worry that the daily journey will soon become wearing, and what will I do then?”

Extract from Harriet's diary — a 41 year-old woman with a low grade tumour

Becoming reliant on others

Living with a brain tumour can make routine day-to-day tasks and self-care more challenging, and may increase dependence on other people for help and support. Over a third of respondents said their brain tumour had led to changes in where they are living, changes to their home, or meant that they need more support to live independently. Difficulty with domestic chores was reported by 6 in 10 and nearly three-quarters said they had lost their driving licence at some point, or had voluntarily relinquished it. One participant described the loss of his licence as leaving him 'trapped at home in my small world'. Nearly 20% of those who said they had made changes to where they live or need more support to live independently have had to move in with a friend or family member because of their condition.

“I feel like I'm a burden. I'm no longer the capable man I once was.”

64 year-old man with a high grade tumour

Losing your dignity

39% of participants reported having difficulty with basic aspects of their personal care, such as washing themselves and getting dressed. One female respondent said she 'hated the indignity' of this and described assistance with eating as being 'fed like a baby'. Another said he felt like he was 'no longer the capable man he once was'.

Being a burden to loved ones

Being confined to the role of care-receiver is a widespread source of distress for people who have become dependent on the support of others. One female respondent described feeling 'inadequate, worthless, a burden, unloved and unlovable'. Another said she did not want a relationship; that it was easier to be alone because 'no-one else should be burdened with this'.

“Showering is extremely difficult. My wife gets a bowl of water and washes me from head to toe.”

56 year-old man with a high grade tumour



1 in 3 have made changes to where they live / need more support to live independently



For 1 in 5 of those who had made changes, this involved moving in with a friend or family member



“My three year-old son sat next to me while I had a seizure. He stroked my head and told me that ‘everything would be OK’.”

Karl lives in Barnsley with his wife and two young children. He was diagnosed with an astrocytoma in 2009 and experiences seizures and chronic fatigue. Once employed as a regional manager for a British Gas training company, he is now unable to work. Instead he dedicates himself to fundraising and awareness-raising activities and helping others living with brain tumours in whatever way he can.

“The brain tumour has impacted my life and independence in so many ways. We have had to move house; I’m not earning anymore; my wife has to do all the driving, and she also does everything for the kids because I’m not able to help. It’s changed my life across the whole spectrum of everything. I don’t feel like me anymore. It’s as though I’ve lost ‘me’ as a provider to my family.

One of the main reasons we moved to our current house is because my mum and dad

live in a bungalow around the corner. They are a two-minute run from here, in case anything happens to me. My parents are always checking in on me. It’s awful. I hate having to be checked on at 36 years old.

I am petrified to take my kids out on my own, too. Both of my kids have had to learn what to do if I have a seizure. My daughter has had a mobile phone since she was seven, which she always takes with her if I take her out on my own. She knows to ring 999, and we have taught her that she needs to tell the paramedics that her dad has a brain tumour and is having a fit. One time my three year-old son sat next to me while I had a seizure. Instead of being frightened, he stroked my head and told me that ‘everything would be OK’ while the paramedics were stabilising me. It’s like the roles have reversed.”

Karl, 36, from Barnsley

Tracey, 53, lives with her husband in a village in the Peak District, and has three grown-up daughters. She is employed as a secretary in a law firm, but has been unable to work since undergoing surgery for her brain tumour. Over a year since the operation, she continues to experience chronic fatigue, preventing her from doing a full day's work at the office.



I struggle to work

The negative effects of a brain tumour on employment and career prospects are often far-reaching and profound, affecting individuals, their partners and families. Many people find they have to give up work entirely, change job, or reduce their hours and duties. If a partner acts as a carer, their career may also be affected. Financial difficulties as a result are common, adding to the stress and vulnerability of illness. The loss of identity and purpose provided by work can also have a deeper emotional impact, undermining self-worth and hope for the future.



3 in 4 have had their / their partner's working life affected



28% have had to give up work entirely



1 in 2 experience financial difficulty

Did you know?

People who are unable work because of their tumour can apply for Statutory Sick Pay (SSP) and receive £88.45 per week for up to 28 weeks. SSP equates to just over a third of the earnings of a full-time employee on minimum wage (approximately £250 per week)*.

*Correct as at June, 2015.

“We had to live on Statutory Sick Pay of £75 a week with five kids.”

Helen, a 44 year-old woman with a low grade tumour

Career curtailment

Of those who said their working life or that of their partner had been affected by their brain tumour, 43% said they had had to give up work entirely and a further 22% said they had reduced their working hours. Few found their professional lives untouched by the condition, with over three-quarters saying either their own or their partner's working lives had been affected. Those who are able to continue working may find that they are no longer able to sustain their career paths as their symptoms limit their capacity to cope with the demands of their job, damaging both their professional prospects and self-esteem. This can be particularly upsetting for younger people, who are still at the stage of planning and building a career: 46% of those who said their brain tumour had impacted on their, or their partner's, education, reported that this had meant having to reassess their education plans or career aspirations.

“Working created my identity and that has gone, leaving me empty and invaluable.”

60 year-old man with a high grade tumour

Losing your purpose in life

Living with a brain tumour can mean giving up the job you love. Work is often integral to a person's identity, a fact reflected in the accounts we received from those whose tumour had limited or terminated their capacity to function professionally. One respondent observed that no longer

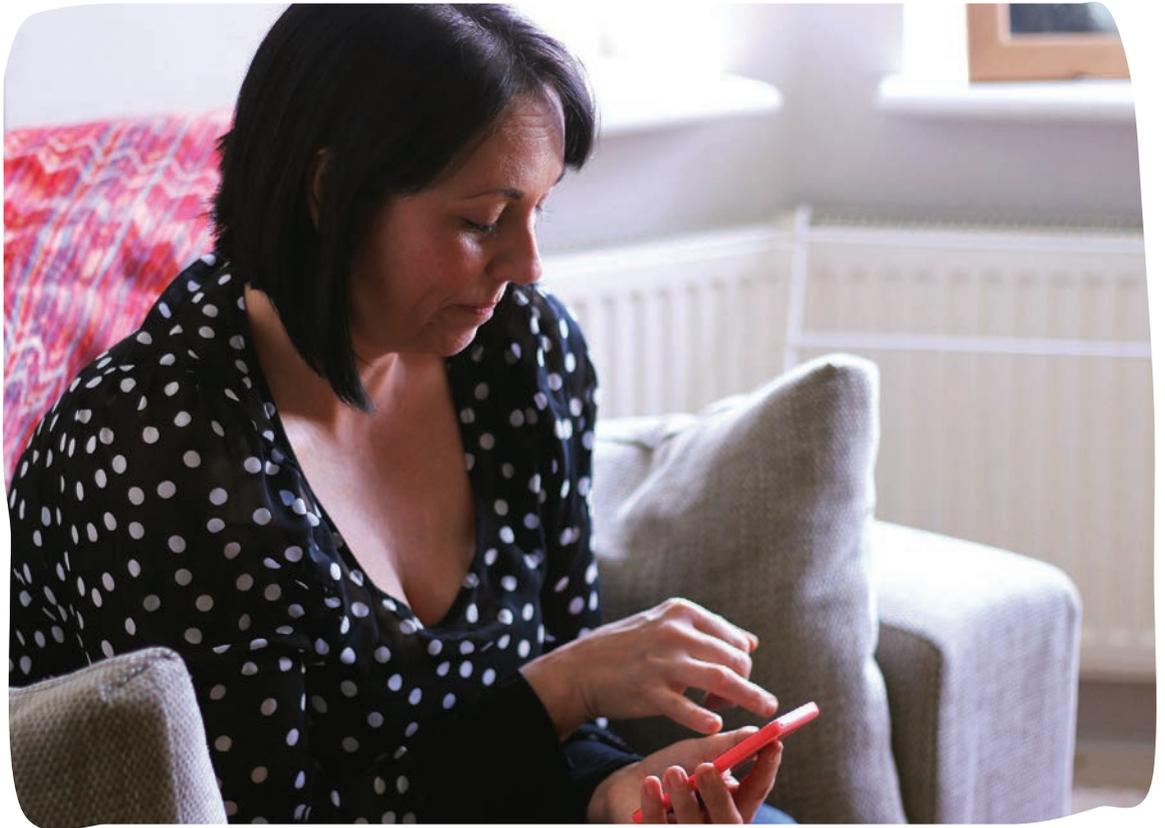
being able to work had not only taken away her purpose in life, but also meant no longer having things in common with others: 'talking about work or what I was doing at the weekend'. Another respondent who had been forced to give up his job observed that 'working made me who I am'.

Financial difficulties

Nearly half of the people we spoke to have experienced financial difficulty. Respondents described having to use savings to survive, becoming dependent solely on their partner's income, asking for support from family and friends, claiming benefits and applying for financial aid. At the same time as experiencing a loss of income people may be faced with additional monthly costs, such as travel to the hospital, parking charges, prescriptions and extra childcare. In extreme cases people have been forced to sell their homes, whilst others recounted spiralling debt since diagnosis. The stress and anxiety this causes may aggravate the very symptoms that necessitated the change of employment status.

“I had to quit my job as I simply couldn't do the work because of the diminution of cognitive skills, and a lack of energy and stamina. I now feel very deflated with no job, no driving licence and little ambition.”

60 year-old man with a high grade tumour



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

Tasmin is a single mother of four children and lives in Cheshire. She was diagnosed with a meningioma in 2013 and underwent a craniotomy. She is a midwife but has struggled with work and finances since the onset of her tumour.

“When I was first diagnosed with my brain tumour it was as though my life flashed before my eyes. I’d just got a new job and was really enjoying it. It’s so difficult when you are faced with your own mortality.

I had to take time off work to have surgery, but my contract meant I could only have two months’ full pay and two months’ half pay. After that I would have to rely on sick pay of a hundred and something a month. I was expecting to be as right as rain after a couple of months, but obviously I was quite naïve about that.

After surgery I still had all my normal outgoings and, because my income was

so reduced, I was left in quite a lot of debt. I couldn’t afford to stay off work, and so I decided to go back just three months after surgery. I knew I wasn’t really fit enough to return, but financially I needed to.

When I went back to work I was so tired. The tiredness you experience after you have had a craniotomy is unbelievable. I only did three hours in the morning, doing simple things like answering phones, but after those three hours I had to go home and sleep for three days. It made me really ill.

Even when I was on the phased return, I was still on reduced wages. The debt I had got into throughout the period of treatment just got worse when I returned to work, as I still couldn’t afford to pay for my normal outgoings. I am now going through a charity that helps with debt management, because it has got really bad.”

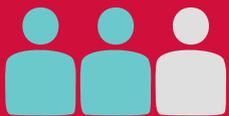
Tasmin, 38, from Cheshire



Keith, 51, lives on his own in Liverpool, around the corner from his partner, Alison. Having a brain tumour has had a significant impact on their relationship. Where once he was a regular at social engagements, even quiet meals out with Alison are now rare. Alison has adapted to Keith's new, more reclusive, nature but still finds this change in the character of their relationship difficult at times. [Read more on page 21](#)

My family live with it

A brain tumour seldom impacts solely on the life of an individual. Partners and family members live with the condition, affecting their emotional health and damaging or even destroying relationships. Many find that the physical or psychological effects of their illness have consequences for the quality and intimacy of their relationship with their partner. Children and grandchildren are affected when an adult family member becomes a recipient, rather than a giver, of care. Distress, conflict, and a sense of loss may result from changes in relationship roles or in the personality of the individual.



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



72% have had physical intimacy affected



1 in 2 are playing with their children / grandchildren less or have stopped completely

Did you know?

Studies show that it is the personality and cognitive effects of brain tumours that place most strain on relationships, particularly where they cause behaviour change, and that interventions to manage challenging behaviour and increase caregiver knowledge can make a positive difference⁵.

5 Ownsworth T., Goadby E., Chambers S.K. Support after brain tumor means different things: family caregivers' experiences of support and relationship changes. *Front. Oncol.* 2015; 5: 33. doi: 10.3389/fonc.2015.00033



“Mother’s Day... not that you would know in my house. I’m 36 and live on my own. When I say ‘live on my own’ I forgot to mention my kids, all five of them.

Mother’s Day for me was two cards, a clay penguin, three chocolates in a handmade paper basket, and a laundry basket with enough washing to sink a ship – I kid you not.

When I woke, I wandered into the kitchen to see an extra two children and the leftovers of a sleepover – carnage basically,

I looked at my cleaning schedule. It’s a new addition, post brain tumour, so that I don’t overload myself with chores and knacker myself.”

Extract from Rachel’s diary – a 35 year-old woman with a high grade tumour

Married to a stranger

Two-thirds of respondents told us that their relationship with their partner had been impacted negatively, whilst nearly three-quarters reported effects on physical intimacy. In some cases the strain may cause relationship breakdown; where a relationship is sustained, it may be altered in every aspect.

“I split from my partner of five years following diagnosis. It put so much strain on our relationship and we were unable to deal with it.”

39 year-old woman with a low grade tumour

Intimacy may be compromised when a person becomes dependent on their partner for care, with one respondent reporting that his wife had ‘become his mother’. Meanwhile the distress of personality changes can be overwhelming: one participant described feeling ‘married to a stranger’; another told us that his wife had divorced him because of his personality change.

“I felt I was married to a stranger and had to relearn how to love again.”

57 year-old woman with a low grade tumour

A different kind of childhood

Over half of the people we spoke to told us that their condition had had a negative impact on their relationships with their children or grandchildren. Witnessing the symptoms of a brain tumour can be particularly traumatic for young children, whilst older children may find themselves taking on caring or domestic duties and experience anxiety about the health of their parents. One respondent observed that this had made her children ‘grow up a little bit quicker’; another felt that her child had ‘never really recovered emotionally’ from witnessing her illness as a toddler. Reports of missing out on family life as a consequence of chronic pain were common.

“I try my hardest to be strong but fatigue can hit me all of a sudden. I can’t even stand up and cook my kids their tea. I feel like such a failure.”

50 year-old woman with a low grade tumour



1 in 2 have seen a negative impact on their relationship with their children / grandchildren



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

Dafydd lives in a farmhouse in North Wales with his wife, Lyn. They have been together for nine years. He was diagnosed with a glioblastoma in 2013, after experiencing muscle wasting and spasms. He was partially paralysed during a biopsy and has since been unable to walk. He requires around-the-clock care from nurses and his wife.

“Being diagnosed with a brain tumour was horrific. It was something I didn’t expect; that I didn’t want. I was given a couple of tests and then was told I was having a biopsy. I walked into hospital but then after the biopsy I never walked again.

The brain tumour and its after-effects have impacted me and Lyn in different ways. We have been through so many emotions together in the last 18 months: fear, shock, despair, sorrow and grief, but also love.

Our relationship is totally different from what it used to be. We can’t even sleep in

the same bed anymore. I sleep downstairs in a hospital bed, but she sleeps with a baby monitor next to her so she can still hear me snoring, or come and help me if I shout her.

I was always a very loving person. I used to give Lyn hugs all the time, but I just can’t do that anymore. I can’t look after her; instead she has to look after me. If I want to go to bed, I have to ask my wife to get me in using the hoist. If her tyre blows, I can’t help her replace it. In a way my wife has become my protector. She has looked after me so well; I just couldn’t have done it without her.

I keep thinking maybe it’s been a bad dream; maybe we will wake up. It took us so many years to find each other, and it’s a match made in heaven. We just had so many plans but they have all had to change.”

Dafydd, 62, North Wales



Gary, 45, lives in Glasgow with his wife, two children and his cat. He underwent a craniotomy to debulk his meningioma. He found that for friends and family who were initially supportive, life goes on, and people soon drifted away, leaving him isolated. He compared the experience to a funeral: people gather in numbers to mark the event, but once this initial formality is over, the bereaved is left alone. The solitude Gary endured during this distressing period of his life led to feelings of depression and anxiety.

I've become isolated

A brain tumour diagnosis, and the ensuing symptoms, can cause lasting damage to the social fabric of a person's life in a way that reflects the unique impact of brain tumours. Fear and incomprehension of changes to the individual, and the poor probability of their recovery, may lead friends and acquaintances to withdraw. Meanwhile the person living with the tumour may retreat from social and leisure activity due to mobility problems, fatigue, pain and difficulties with cognition or communication. The resulting loneliness or boredom can markedly diminish quality of life.



70% feel awkward in social situations



61% participate in less social activity



29% are severely isolated

Did you know?

The role of family and friends is vital in the fight against brain tumours. Studies have shown that people who are socially isolated when diagnosed with cancer are more likely to die from the disease than those with strong social networks^{6,7}.

⁶ Kroenke C.H., Kubzansky L.D., Schernhammer E.S., Holmes, M.D., Kawachi I., et al. Social Networks, Social Support, and Survival after Breast Cancer Diagnosis. *J Clinical Oncology*. 2006. 24(7): 1105-1111. Available at <http://jco.ascopubs.org/content/24/7/1105.full> [Accessed 29 May 2015]

⁷ Lutgendorf S. K., De Geest K., Bender D., Ahmed A., Goodheart M.J., Dahmouh L., Zimmerman M.B., et al. Social Influences on Clinical Outcomes of Patients with Ovarian Cancer. *J Clinical Oncology*. 2012; 30(23): 2885-2890. Available at: <http://jco.ascopubs.org/content/30/23/2885.full> [Accessed 29 May 2015]

“Many people I considered friends are gone. It looks like they followed the path of life as I took the path of death.”

Katie, a 45 year-old woman with a low grade tumour

Drifting apart from friends

Two-thirds of respondents said that they felt their brain tumour had had a negative impact on their friendships, and nearly 3 in 10 reported feeling severely socially isolated. Some find their friends cannot cope with their new circumstances, behave differently around them, or withdraw entirely. Making new friends requires the mobility, energy, and the cognitive and communicative dexterity that a brain tumour impairs. 7 in 10 respondents said they felt awkward in social situations. One participant told us she had lost people who were friends for more than 20 years.

“I struggle to get my words out. I get them the wrong way round but don’t realise until people look at me strangely.”

48 year old-woman with a tumour

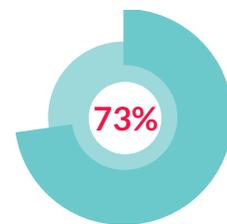
Giving up the things you enjoy

Many people living with a brain tumour find they can no longer take part in leisure activities, with nearly three-quarters of people in this study telling us they had given up, or reduced, their participation in sport or exercise. Previously nurtured skills or hobbies may become impossible to pursue due to loss of physical function or concentration, and pain or fatigue. For some, life with a brain tumour is so confining that they no longer feel like they

are living. One female respondent said ‘It took my life without killing me’. Another told us it had left her with ‘nothing but lying in bed’.

“I miss simple things like walking the dog. Or just popping out to the pub or shops. I have become very lethargic and couldn’t care less about some things, even though I don’t want to be like this.”

60 year-old man with a low grade tumour



73% have given up sport / exercise or reduced what they do



2 in 3 have felt a negative impact on their friendships



“I just close the curtain and stay inside my house. Alison calls it my ‘cave’.”

Keith lives in Liverpool with his dog. His mum and his partner of several years, Alison, both live around the corner. He was diagnosed with an oligodendroglioma in 2005 and, following an awake craniotomy, had no problems for 7 years until the tumour began to grow. This tumour required radiotherapy and he hasn't been able to work since finishing the treatment in October 2012.

“It was the radiotherapy that hit me hard and all I did was sleep and walk the dog. It absolutely wiped me out.

When someone has been inside your head and messed about for eight hours, your attitude to everything changes. You become insecure and insular. There have been times when I wouldn't get dressed, have a shower or shave, let alone go out.

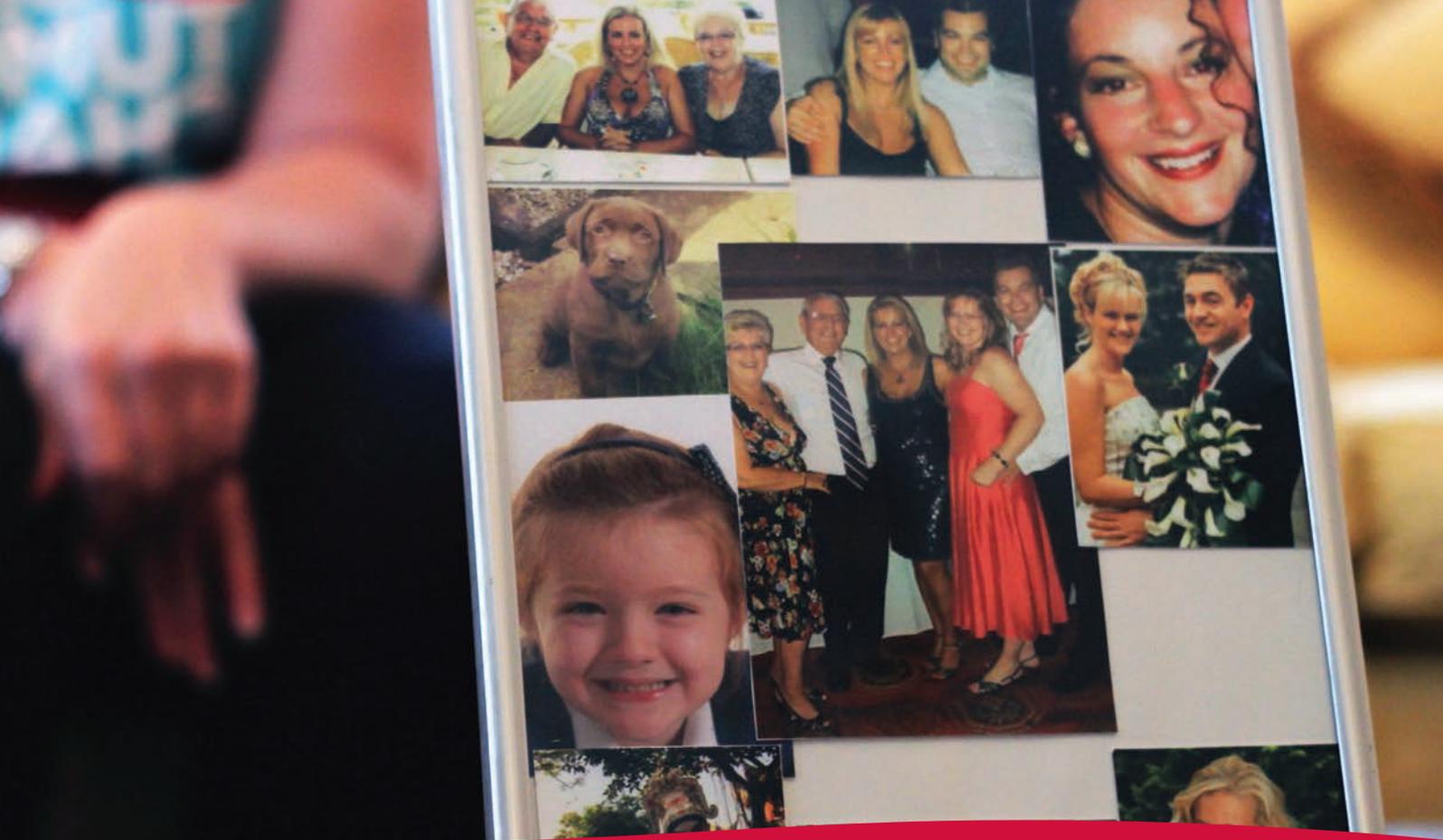
I have very dark days where I just close the curtain and stay inside my house. Alison calls it my ‘cave’; I retreat inside the cave and I never

want to leave. You wake up one minute and you want to make all these plans, but then the next minute you're thinking ‘But what about this? What about that? What about my tumour?’. We have been ready to go out, dressed and by the door, but then I'll suddenly decide I don't want to go out anymore. Nobody can change my mind. I'll just go upstairs and go to bed, or close the curtains and stay inside. I know it affects my mood too: my mum always says ‘When I'm good, I'm very, very good, but when I'm bad, I'm horrid’.

I worked in a pub from the age of 19 to 30, before being diagnosed with a brain tumour. I'd be out seven nights a week, and I was the life and soul of the party. Now Alison is lucky to get me to go out for a meal with her; I go to my mum's house and to Alison's house, and that's it.

This is my life at the moment. Without Alison and my mum, I'd be doing nothing.”

Keith, 51, from Liverpool



I'm scared of dying

The low survival rate of those diagnosed with a brain tumour, compared to other cancers, makes fear of dying a key consideration in understanding the reality of life with a brain tumour, crossing the boundaries of tumour type, grade and terminal or non-terminal prognosis. The chronic and life-changing nature of symptoms, and the lack of control that people feel over their condition, may heighten awareness of bodily fragility and mortality in a way that can be difficult to articulate. Anxiety about physical and mental decline, and the uncertainty of the timeframe of a terminal prognosis, can place individuals and their loved ones under enormous strain.



58% of survey respondents are scared of dying



1 in 5 survey respondents have been given a terminal prognosis



55% of people who have a terminal diagnosis haven't been given a choice of end of life options

Did you know?

Brain tumours reduce life expectancy by around 20 years — the greatest reduction of any cancer⁸. In total, over 5,000 people lose their lives to a brain tumour each year⁹.

⁸ Burnet N.G., Jefferies S.J., Benson R.J., Hunt D.P., Treasure F.P. 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.

⁹ Based on 2012 statistics. Cancer Research UK. *Brain, other CNS and intracranial tumours mortality statistics*.

Available at: <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/brain/mortality/> [Accessed 21 May 2015]

“It’s strange to think that my cat will outlive Dad.”



Phillip, a 43 year-old man with a high grade tumour, overhearing his son talking to his wife

Living ‘in a world of uncertainty’

21% of the people we spoke told us they had been given a terminal prognosis, however 58% of all survey respondents said they were scared of dying because of their brain tumour. It is hard to feel reassured about living with a disease that is so difficult to treat and whose effects can be so debilitating. One female participant described how unhelpful well-intentioned positive remarks of family members can be: ‘When I tell people, they usually say everything will be fine...in my head I’m thinking: how do you know everything is going to be fine?’ Another likened it to having ‘a ticking time bomb living in my brain’.

“Dying is a major worry for me...How will James manage? How will the kids manage without their mum?”

33 year-old woman with a low grade tumour

Not talking about dying

Of those with a terminal prognosis, 42% said they were not comfortable talking to those around them about dying, despite the fact that for the most common type of malignant brain tumour, the prognosis is less than two years¹⁰. For some this is a coping mechanism, allowing them to focus on living for today; another factor may be the desire to shield loved ones from what one female participant termed ‘the reality of the situation’. The data showed that men were less likely to feel

comfortable talking about dying than women, suggesting that gender roles impact on how people deal with the prospect of death. One male participant with a terminal prognosis told us ‘I have to pretend to be strong and nonchalant, especially to friends and my family’; another said ‘It’s actually very hard to tell people how you really are when they ask’.

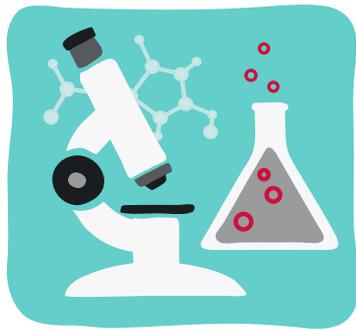
What happens at the end

The range and unpredictability of the effects of a brain tumour, compared to other cancers, make the progression towards death and the circumstances of dying a particularly acute source of anxiety. Dread at the possibility of a protracted, severely disabling, or painful decline can have a damaging impact on quality of life. One female participant described multiple scenarios she feared: ‘That I deteriorate suddenly. Or that I linger on, but am cognitively damaged and confused, and don’t know my own family’. Indeed, the uncertainty surrounding the manner of dying also causes anxiety about what friends and family may be forced to endure. One female participant told us ‘I fear for my kids seeing me differently and worry this will be very hard for them’. Another said she feared ‘A long painful, slow death that will put huge strain on my loved ones’.

“I try and live every day as if it were my last.”

45 year-old woman with a low grade tumour

10 Brodbelt A., Greenberg D., Winters T., Williams M., Vernon S., Collins V.P. Glioblastoma in England: 2007–2011. *European J Cancer*. 2015; 51: 533–542 Available at: <http://www.ejca.com/article/S0959-8049%2815%2900003-9/pdf> [Accessed 30 May 2015]



About us

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 greatest possible impact on the lives of everyone affected by this disease, to defending the most amazing part of the human body, and together defeating brain tumours.

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, increase treatment access and improve understanding of those living with the disease every day
- We provide information and support for anyone affected to help improve quality of life.

Our goals

We are committed to having the greatest possible impact for everyone in the UK affected by a brain tumour. It is with this in mind that we have set ambitious goals

to bring about real and lasting change, so that a diagnosis no longer means a death sentence.

- **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.

Questions?

If you have been affected by a brain tumour or are worried by any of the findings in this report, please get in touch with our team. We offer an inclusive Information and Support Service for everyone affected by a brain tumour – patients, family, friends and colleagues.

0808 800 0004
(Free from landlines and mobiles)

support@thebraintumourcharity.org

We rely 100% on voluntary donations to fund our vital work. If you would like to make a donation, or want to find out about other ways to support us, including fundraising, getting your company involved, leaving a gift in your Will or giving in memory, please visit us at **thebraintumourcharity.org**, email **fundraising@thebraintumourcharity.org** or call us on 01252 749043.





Creating a better future together

Whilst survival has doubled across all cancers, survival rates for brain tumours in adults have improved little in over 40 years: 60% of people diagnosed with a malignant brain tumour will not survive one year and just 19% of adults will survive for five years or more¹¹. This means that more than 5,000 people lose their lives every year¹². In addition, brain tumours reduce life expectancy by an average of 20 years, the highest reduction of any cancer¹³. Despite these stark statistics, less than 2% of the £500 million invested in cancer research in the UK every year is spent on brain tumours¹⁴. 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. This is why people with a brain tumour and their families do not simply focus on survival but on their quality of life. Of those currently living with a brain tumour in the UK, most 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 disability¹⁵. 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 to 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.

We will address these issues through our five year strategy *Defeating Brain Tumours*, summarised overleaf. Read the strategy in full at thebraintumourcharity.org/defeatingbraintumours

11,12 Cancer Research UK. *Brain, other CNS and intracranial tumours survival statistics*. Available at: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-tumours/survival#undefined> [Accessed 19 May 2015]

13 Burnet N.G., Jefferies S.J., Benson R.J., Hunt D.P., Treasure F.P. 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.

14 National Cancer Research Institute. *NCRI Cancer Research Database*. Available at: <http://www.ncri.org.uk/what-we-do/research-database/> [Accessed 25 May 2015]

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

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 find that it a emotional o



PASSIONATE

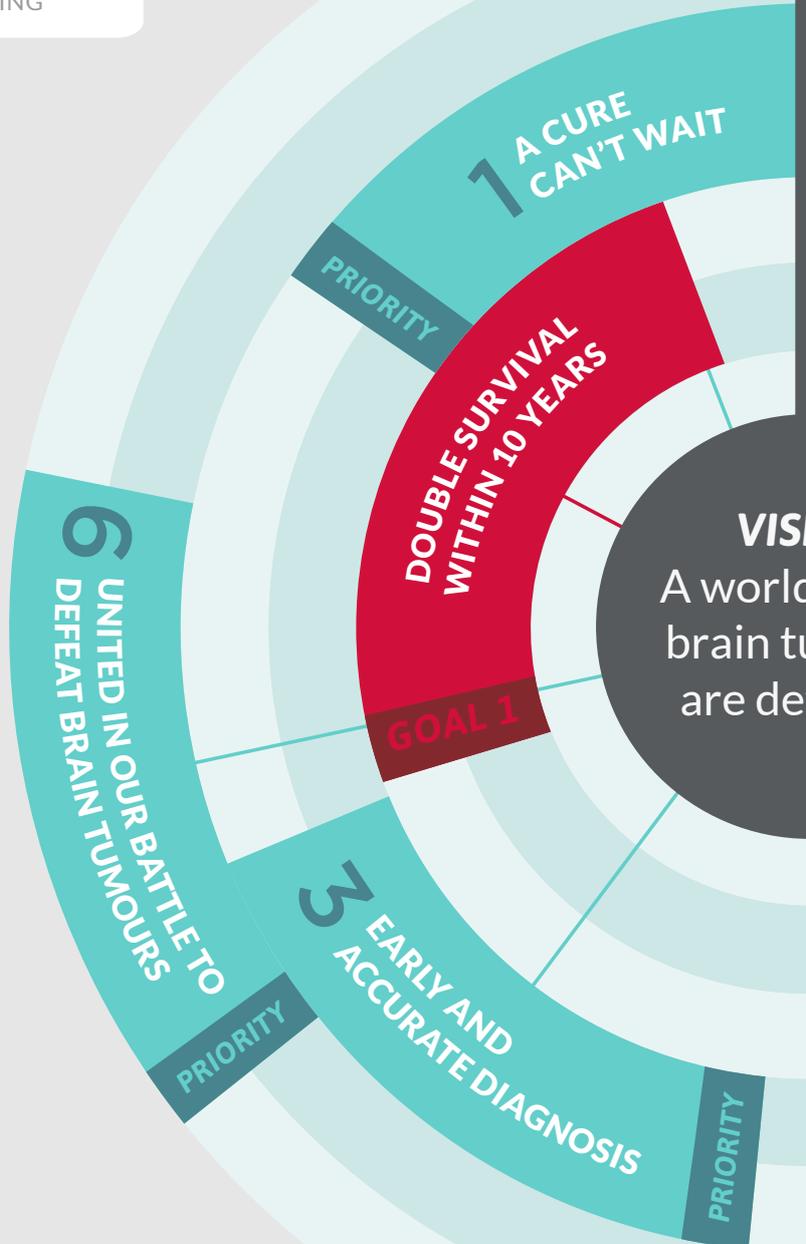
SUSTAINABLE
FUNDING

SMART
COMMUNICATIONS

A HIGH
PERFORMING TEAM



SMART



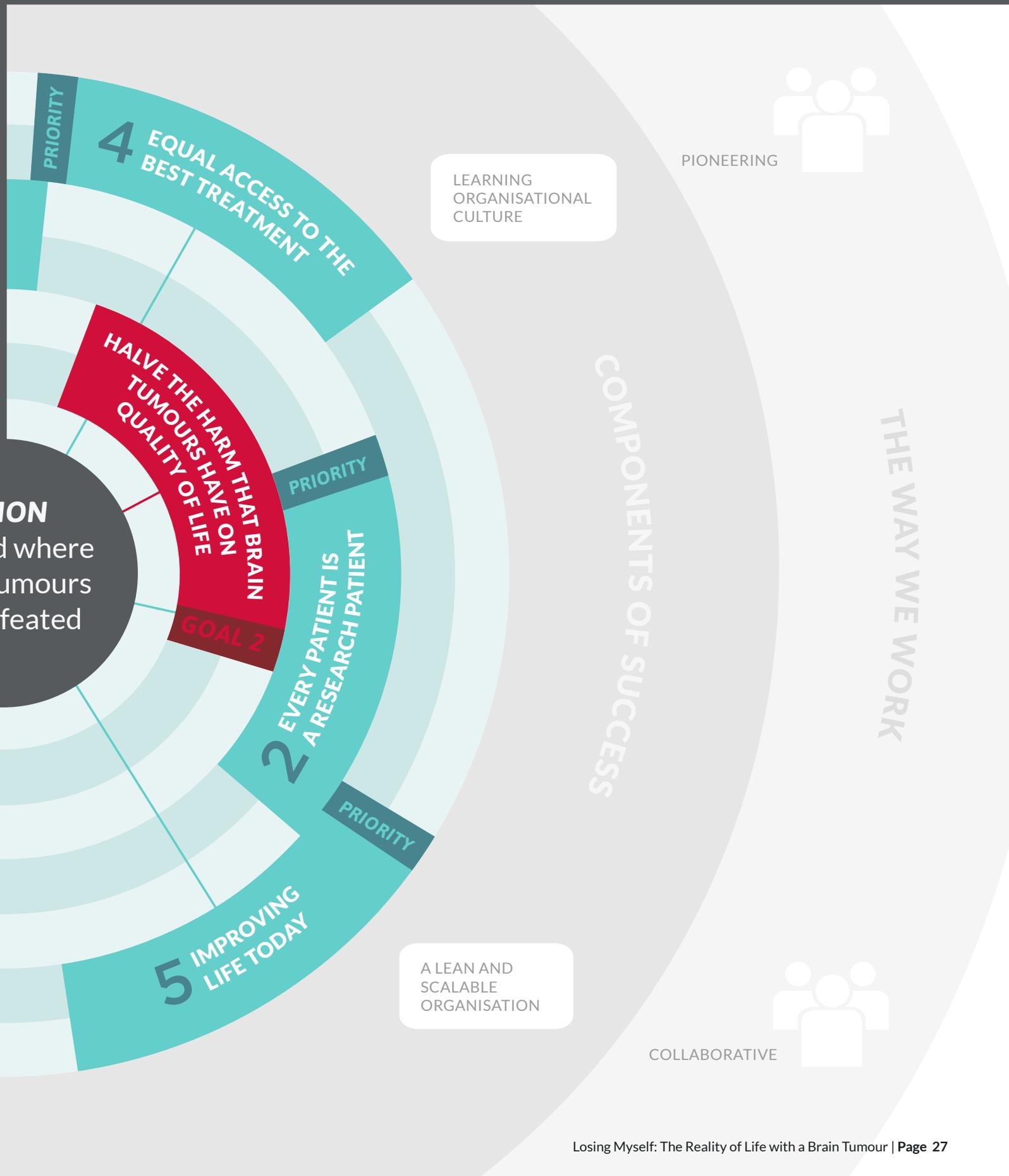
%

with a brain tumour affects their mental health

LESS THAN 2%

of the cancer research funding in the UK is spent on brain tumours

Brain tumours reduce life expectancy by on average 20 YEARS



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In partnership with:

alterline

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