

LOSING MY PLACE

**THE REALITY OF CHILDHOOD
WITH A BRAIN TUMOUR**

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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 ten 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 the Life with a Brain Tumour project – the most comprehensive study of its kind. It will provide an extensive evidence base to inform improvements and innovations across the services provided by The Charity, and will be used to help us ensure policy makers, healthcare professionals and the public understand the realities of a disease that affects both the old and the young.

The public outputs from the project encompass three publications, including two sister reports on adult brain tumours, 'Losing Myself: The Reality of Life with a Brain Tumour' and 'Finding Myself in Your Hands: The Reality of Brain Tumour Treatment and Care'. This report, 'Losing my Place: The Reality of Childhood with a Brain Tumour', presents the project findings relating to the daily life of children and young people with a brain tumour and their families – moving personal stories and stark statistics that demonstrate the extensive impact this disease has in the early stages of life, when hopes should be many in number and fears few.

I would like to thank everyone who has participated in this vital research for assisting us in our effort to achieve a deeper understanding of the needs of, and challenges faced by, children, young people and their families.

Sarah Lindsell
CEO



Every year, around 400 children aged 0-14 are diagnosed with a brain or central nervous system tumour¹

Brain tumours claim more lives than any other childhood cancer²

Brain tumours are the largest cause of preventable or treatable blindness in children³

Welcome

Childhood is the dawn of human life – a period of gathering strength and expanding horizons, where sickness and decline are out of place. Yet every year hundreds of children and young people in the UK find the health and hopefulness of their youth interrupted when they are diagnosed with a brain tumour.

The polymorphous nature of a tumour in the brain means a terminal prognosis is far from automatic, though the survival rate is low compared to most other cancers. For many children and young people life goes on, but often in circumstances very different from the years of play, adventure, mischief and self-exploration every parent hopes their child will enjoy.

In this ground-breaking research, nearly 300 young people and parents shared their stories of what it is like to live with a brain tumour in childhood.

This report looks at the challenge of finding your place in the world as a child or young person with the serious and often life-threatening condition that is a brain tumour.

These contributions provide a unique insight into the suffering that childhood brain tumours cause for children, young people and their families – stories of courage and perseverance, when a child is forced to miss out on so much of what the world has to offer; when they are alone whilst others are making friends, hatching plans and falling in love; when they cannot keep up in school and life at home is forever changed; when they find they are facing death, before their life has really begun. It also examines the impact on the lives of caregivers and other family members – they too may face adjustment to a new position within the fabric of family and daily life that can be difficult to come to terms with.



¹ Based on the average in Great Britain for 2006-2008. Cancer Research UK. *Children's Cancer Incidence Statistics*. Available at: <https://www.thebraintumourcharity.org/get-involved/why-we-need-your-support/the-statistics-about-brain-tumours/> [Accessed 4 April 2016]

² Children with Cancer UK. *Facts and Figures*. Available at: <http://www.childrenwithcancer.org.uk/facts-and-figures> [Accessed 24 April 2016]

³ The Brain Tumour Charity. *The Statistics about Brain Tumours*. Available at <https://www.thebraintumourcharity.org/get-involved/why-we-need-your-support/the-statistics-about-brain-tumours/> [Accessed 24 April 2016]

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.

The children and young people's component of the study examined the lives of those aged 0 to 24 and their families. A total of 282 people participated in this, with 274 people responding to the survey, twelve undertaking in-depth qualitative interviews, and five completing a seven-day reflective diary. The survey took place between 26th November, 2015 and 22nd January, 2016, and the interviews and diaries were completed between 10th and 21st March, 2016.

The overall sample comprised three subsamples: young people aged 14-24, parents or carers of children and young people aged 0-24, and bereaved parents or carers of children and young people who were diagnosed between the ages of 0 to 24. Each sub-sample completed separate surveys based on a core question set common to all three. 43 young people aged between 14 and 24 years completed the survey, five participated in interviews and three completed reflective diaries. 164 parents or carers of children and young people aged 0 to 24 completed the survey on behalf of their child/ ward, seven participated in interviews and two completed online diaries. 67 bereaved parents or carers completed the survey on behalf of children and young people diagnosed with a brain tumour before the age of 25.

The questionnaire used to collect the survey 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 by The Charity's volunteer and healthcare professional networks and on Facebook. All respondents accessed the questionnaire online.

Most of the statistics reported in this publication are based on the aggregation of responses from all three sub-samples in the survey, including responses given by parents on behalf of young or deceased children. However, in order to simplify reporting, the findings are described as if the child or young person responded themselves in every case. In some places the responses from the three sub-samples are reported separately, where age and role-specific descriptions are necessary, and this is made clear in the text. In all cases statistics describe only those to whom the question asked was applicable, and exclude those who answered 'not sure' or 'prefer not to say'. Where age is reported this refers to the age of the child in question at the time the survey was completed, or their age at death.

The quotations that appear in this report are exact transcriptions of words spoken by participants in the study. With the exception of case studies, which appear alongside photographs of the contributors, any names associated with quotes have been changed to protect anonymity. The designation of the tumour grade of these contributors is based on the principle that 'low grade' refers to grade 1 and 2 tumours and 'high grade' to grades 3 and 4.



Josh, 16, lives with his mum, dad and two brothers and sister in Birmingham. He was diagnosed with a low grade astrocytoma when he was 18 months old, and underwent surgery immediately. He temporarily lost his vision, and when it returned he remained partially-sighted – he lacks forward vision in one eye and lateral vision in the other. In order to help his friends understand how he sees the world, his parents bought some safety goggles, and taped over the parts where he doesn't see. Josh explained that rather than seeing darkness in those areas, he simply sees nothing: "With things interpreted with the brain it's sort of like, what it doesn't see, it doesn't use."

A different childhood, an uncertain future

The brain is the only vital organ with core functions that continue to develop after a child is born, all the way through to adult life. When a tumour develops in the brain during childhood, it inhibits the interaction with the world that is crucial to this development process. It thereby interrupts progress towards independence. From chronic fatigue, nausea and pain to delayed puberty, cognitive impairment, and loss of mobility, the difficulties caused by a brain tumour replace energy and exploration with caution and care. 'What do you want to be when you grow up?' becomes a challenging question.



70% of children/ young people said they had difficulty doing things outside of the house



Nearly two-thirds of under 16s⁴ said they missed out on playing with other children



89% of children/ young people whose education had been affected said they had had to take time off

⁴ Based on those children and young people who said they felt they had missed out on at least one activity other people their age enjoy.

“My son cannot be left alone in case he falls over. He can stand and walk a few steps but his balance is poor. He cannot pick his teddy bear up off the floor if he drops it. He cannot dress himself, or go to the toilet himself. He cannot manage steps or the stairs.”

Parent, son aged 5 with a high grade tumour

Being young and being ill

The range of symptoms caused by brain tumours can be extremely debilitating for a child or young person and may limit their ability to participate fully in everyday life in many different ways. The parents of a healthy child expect to face the challenge of keeping up with a young body powered by boundless energy. However, the reality for the family of a child with a brain tumour is often quite different. The most commonly reported symptom in this study was fatigue. Of those who said they had symptoms, 63% said they currently experienced fatigue and more than 7 in 10 said fatigue impacted their daily life ‘quite a lot’ or ‘a lot’.

Further difficulty is caused by physical disablements – 55% respondents with symptoms reported some degree of difficulty with balance, coordination, moving or walking. Of these, nearly 7 in 10 said it affected daily life ‘quite a lot’ or ‘a lot’. Meanwhile, 39% of respondents with symptoms reported problems with vision, over a third reported nausea and/ or vomiting, and nearly 1 in 5 said they experienced seizures. Treatment regimens can cause additional symptoms and trauma, and may be terrifying for children too young to understand what is happening to them and why.

Getting about and missing out

The kinds of barriers these symptoms present to ordinary childhood were amply recorded in the course of this research. 70% of respondents reported that they had at least some difficulty doing things outside of the house, with nearly two in five saying this was ‘very difficult’ or ‘impossible’. Nearly two-thirds said they had at least some difficulty doing things around the home, and nearly a quarter said this was ‘very difficult’ or ‘impossible’.

“It was like a form of torture for him not to be able to do the things he loved to do.”

Parent, son died aged 7 from a high grade tumour

85% of those who reported missing out on activities said that, compared to other children their age, they missed out on playing sport or physical games, nearly half said they missed out on hobbies or interests, and nearly two-thirds of under 16s missed out on playing with other children. People described a simple feeling of not being able to be just a ‘normal’ or ‘typical’ person of their age, and the loss of the possibility of having independence from their parents – indeed, just over half of over 16s who reported missing out on something said they missed out on driving, and 54% of respondents said they cannot live as independently as other people their age.



“I can struggle socially as all I’ve known is first school, middle school, cancer, adult life with side effects of cancer...and when people talk about different life experiences, I find it hard to participate in conversations. I didn’t have the early teens years where you experience different styles and sort of find out who you are for the first time and experience new social experiences. I missed out on that and sometimes it can really show and I don’t know how to react.”

Extract from Pippa’s diary — a 21 year-old female with a high grade tumour

Difficulty finding your place

Amongst those who said they had missed out on participating in activities other people their age enjoyed, socialising with friends was the second most frequently missed activity, reported by 7 in 10 respondents, whilst just over 6 in 10 said they had missed out on participating in group activities, such as after-school clubs, Scouts/ Guides or university societies. Full social and physical participation is made difficult in many and varied ways by the symptoms young people with brain tumours contend with.

“Loss of vision meant she often felt lonely at first as she couldn’t find her friends in the playground.”

Parent, daughter aged 7 with a high grade tumour

Loss of vision or hearing, and impairments to cognitive processing, speech and memory may all add to a child’s difficulty finding their place in both their social world and physical world. Losing the capacity to engage with daily life in an unbridled or spontaneous way can cause frustration for both the child themselves and their parents, and may inhibit a child’s progression towards developmental milestones. Some mature at a different rate from their peers and/ or have learning disabilities which mean that they cannot keep up with children of their own age, or do not share their interests.

Not being able to follow a conversation with more than one person or having difficulty seeing your friends in the playground can make the landscape of a child’s world stressful and difficult to navigate.



70% of children and young people miss out on socialising with friends⁵

Such barriers present their own challenges during adolescence and into early adult life when social allegiances and ‘being there’ take on a heightened significance. One participant in her early twenties described not being able to go out with friends in the evening to a bar or pub, because she cannot understand what people are saying when there is background noise. Another teenager told us that she no longer goes out as much as she used to, both because of tiredness and because her friends are scared that she will have a seizure.

⁵ Based on those children and young people who said they felt they had missed out on at least one activity other people their age enjoy.

“I am currently in college and am struggling. It frightens me that I will never succeed in what I dreamt about doing. It is a struggle to retain information. I also worry about having a family down the line after going through chemotherapy and radiation.”

Female, aged 20 with a high grade tumour

Disrupted education

Living with a brain tumour during childhood and early adult life frequently leads to interruptions in education. Nearly 90% of participants who said their education had been affected reported having to take time off because of their tumour or treatment. Nearly 2 in 5 reported missing coursework or exams. Absence alone can mean a child faces a struggle to catch up on returning to school, and over half of respondents whose education had been affected said they had fallen behind classmates. Nearly two-thirds of respondents said they or their child had needed extra help and support with their education, and 41% said they felt they had not done as well in coursework or exams as they could have.

In addition to the academic difficulties caused simply by being absent, a child's attainment may be compromised because of disruption in brain functions necessary for learning. Loss of memory or processing capacity, difficulty with concentration, personality changes, as well as fatigue and sensory impairment can all make life in the classroom and the exam room much more difficult than it was before.



Nearly two-thirds of those whose education has been affected needed extra help and support

Since school makes up such a large part of a child's daily life, being absent and/ or learning at a slower pace can also add to the difficulties they face in maintaining a place within the social fabric of their peer group. Embarrassment and a sense of exclusion may ensue if they are obliged to take regular breaks due to fatigue or if they require extra help and are unable to catch up or keep up with their friends' learning. Indeed, 39% of respondents whose education had been affected by their brain tumour said they felt worried or anxious about going to school, and those who reported such worry were more likely than those who did not to say that their brain tumour had had a negative impact on their relationship with friends.⁶

⁶ Those who said they felt worried or anxious about going to school/ college/ university were 1.4 times as likely as those who did not report such worry to say that their brain tumour had had a negative impact on their relationship with friends.



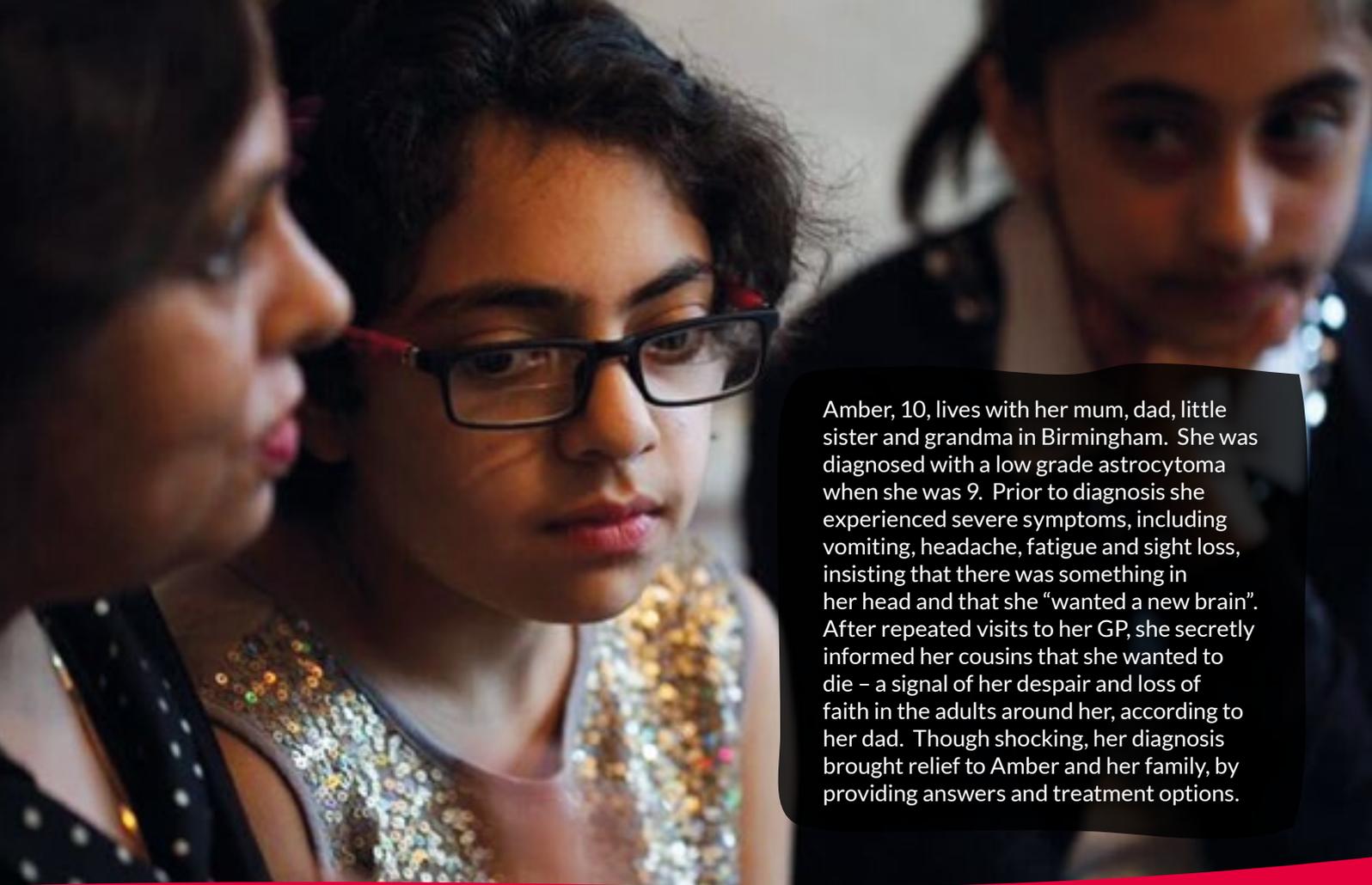
“I think sometimes she thinks she failed already which is really sad when she’s only 16, nearly 17, isn’t it? And you kind of have to keep on telling her how well she’s doing, considering that there’s a big hole in her head. It doesn’t help that Emily, her eldest sister, is a straight-A student, and is at university.” (Hannah’s mum, Jane.)

Hannah is 16 and lives in Chesterfield. She was diagnosed with a high grade glioma when she was 14, after a brain haemorrhage that happened whilst she was at a Christian festival with friends. She had surgery to remove the tumour, followed by radiotherapy and chemotherapy. Before she was diagnosed she was a top-grade student at school. She still hopes to go to university, but finds learning much harder.

“When I was diagnosed I didn’t really think I would have any future, because it was a Grade 4 tumour, you automatically assume... I didn’t feel like it was going to get better. But I feel like now, with the all-clear, I’ve got things to look forward to. The biggest change I’ve had to get used to is the fatigue. You don’t really understand how much it affects you, until you’ve got it. It stops you from doing the things you want to do. It makes me frustrated, when I can’t do things or when I’m just so tired that I can’t do any school work. I did a lot of Scouts and Explorers before – I still go to Explorers but I do a lot less of the physical activity that we used to do. And just going out – I always feel very tired if I go out and it’s a long day, whereas before I wouldn’t have

been as tired. I get frustrated with myself at school when I’m not as quick as other people, because I am aware that people are quicker than me with understanding things or writing stuff. Sometimes I struggle to express that frustration – I can’t get the words about how I feel. Because, with processing, my speech was disrupted, and I had to go to speech and language therapy. So sometimes I can’t get the word out that I want, or I get opposites mixed up. And the more frustrated I become, the more I can’t speak. If I’m getting frustrated, I have to stop what I’m doing and take a break for a bit, like 10/ 15 minutes, and then come back to it – just to clear my head before I go and try again.

I had a part-time job at one point and I’m glad I got the experience of a busy job, but I don’t think it was for me just because it was so busy, and the more flustered I get, the more I can’t process things. And because it was so busy, I thought I couldn’t carry on with it. I am a bit worried because I’m still not sure what I want to do when I grow up, but I think it’s good that I’ve got a course that I want to do, and I’ve got ideas for university.”



Amber, 10, lives with her mum, dad, little sister and grandma in Birmingham. She was diagnosed with a low grade astrocytoma when she was 9. Prior to diagnosis she experienced severe symptoms, including vomiting, headache, fatigue and sight loss, insisting that there was something in her head and that she “wanted a new brain”. After repeated visits to her GP, she secretly informed her cousins that she wanted to die – a signal of her despair and loss of faith in the adults around her, according to her dad. Though shocking, her diagnosis brought relief to Amber and her family, by providing answers and treatment options.

Lost inside a new self

Brain tumours may occur in any part of the brain and can therefore affect the full range of a child’s physical and mental functions. At a time when a person’s sense of self in the world is still developing, having a brain and body that don’t function like those of the people around you can be hard to accept, and even harder to talk about. The effects of treatment on a person’s physical appearance, such as weight changes, hair loss and scarring, may be particularly distressing, resulting in damaged self-esteem and reduced emotional wellbeing.



92% of children/
young people said their
emotions were affected
by their brain tumour



Over 2 in 5 children/
young people aged over 11⁷
said they found it hard to
talk to close friends or family
about their brain tumour



71% of children/
young people reported
changes in their
physical appearance

⁷ At time of survey or, if deceased, at time of diagnosis.

“The brain tumour and treatment changed my child from an outgoing boy to someone who was unsure of himself — he became very quiet.”

Parent, son died aged 9 from a high grade tumour

Personality change and emotional turmoil

36% of respondents with symptoms reported that they experienced difficulties with cognition (thinking, concentrating, processing), whilst nearly a third said they had seen behaviour changes, and 3 in 10 reported changes to their personality. As well as the natural stress reactions a child may experience in the face of pain, weakness and loss of bodily functions, a brain tumour may cause direct changes to personality, cognition and behaviour that are not amenable to improvement with the child’s emotional adjustment to their condition.

However, the complexity of the brain, and the very real challenges the symptoms of a brain tumour present, can make it difficult to disentangle more enduring personality changes from reactive emotional distress. Mood swings, hypersensitivity and tantrums are behaviours any healthy child may display, as well as being an understandable response to the trauma of serious childhood illness and invasive clinical interventions. Indeed, when asked specifically about the effect of their brain tumour on their emotions, only 8% of respondents said they had experienced no effect whatsoever, and nearly two-thirds said it had affected them ‘quite a lot’ or ‘a lot.’

“Lucy has huge mood swings – very high or very low. She gets upset, angry and frustrated very easily. She has become even more sensitive to social situations and takes the slightest thing personally. Her very high days see her showing off and being ‘over excited’.”

Parent, daughter aged 5 with a low grade tumour

Worries about the future, loneliness, boredom, loss of self-esteem, and the distress and anger of dealing with symptoms and treatment, can all take a heavy toll on the mental wellbeing of children and young people with brain tumours. Young children may struggle to understand what is happening to them and become excessively fearful, sad and clingy, whilst older children may live in fear of dying and suffer acutely through social exclusion, lack of independence and loss of opportunity. Mental health problems such as mood swings, low mood, depression and anxiety are common.



“I hate my body! Every single thing about it. My body has totally changed since my surgery in 2008. I was paralysed down my right side and still can’t walk properly or exercise enough to lose weight. As well as being on steroids for life! I feel like I’m trapped inside a fat suit. My belly is huge, like I have a tyre wrapped around me, I have two different sized breasts because of my growth being stunted by the tumour, my feet are very small but very wide and I can never find shoes to fit. They are also a whole size different from each other. When I am with family or friends I feel like the elephant in the room as I feel like I can’t wear nice flattering clothes and shoes.”

Extract from Mel’s diary – a 22 year-old female, tumour grade unknown

Living in a body you don’t recognise

The psychological effects of living with a brain tumour may be greatly exacerbated by the effect of the tumour or its treatment on how a person looks, particularly during adolescence and early adulthood. 71% of respondents aged over 5 said either their tumour or treatment had led to changes in their physical appearance and 70% said these changes had affected their self-confidence.

Indeed, one of the cruel realities of treatment for brain tumours is that it is often invasive, with a heavy side-effect burden. Hair loss, weight gain or loss, stretch marks, scars from surgical interventions, malformation of the skull, arrested puberty, using a wheelchair or a hearing aid, are especially difficult to deal with during the teenage years, when social pressure to fit in and be body beautiful is at its height.

“He hated his hair loss, wearing an eye patch and loss of weight. He said that he looked like a freak and people stared at him in the street.”

Parent, son died aged 11, tumour grade unknown



71% of respondents aged over 5 said their tumour or treatment had led to changes to their physical appearance

Taken together with other effects of a tumour on cognition, speech and mobility, it is perhaps unsurprising that 85% of respondents in this study aged over 5 said their tumour had made them feel awkward during social situations, and nearly 6 in 10 said this affected them either ‘quite a lot’ or ‘a lot’. The parent of a young girl who gained weight due to steroid treatment described having to remove all the mirrors in the house because of the distress their daughter’s physical appearance caused her, whilst another recounted the difficulty their daughter faces in finding fashionable clothes to fit her larger yet still pre-pubescent body. Such changes made young people more self-conscious in public and caused them to worry about being stared at.



“Every day I put on a face so that my loved ones don’t see how shit I feel, emotionally and physically. Because there is nothing they can do to help me. I put on a face for friends and family, making sure my make-up hides how tired I look. I hate talking about my feelings especially with family. I am very much a closed book.”

Extract from Pippa’s diary — a 21 year-old female with a high grade tumour

Keeping your thoughts to yourself

Whilst the physical symptoms are there for all to see, it is much easier to keep private thoughts, doubts, questions and fears to yourself – particularly if you have involuntary difficulties with speech, if you feel that others will not understand, or might be distressed by what you say or the way in which you say it. In this study, over 2 in 5 respondents aged over 11⁸ said they find it hard to talk to close friends and family about their brain tumour. Understanding what motivates children and young people to keep their experiences from close friends and family is therefore important, especially given the negative impact brain tumours so often have on a child or young person’s emotional wellbeing. If they do not feel willing or able to share their more difficult feelings and experiences, they cannot get the care and support that might help to alleviate their psychological distress.

“I don’t talk to anyone about it as I don’t want to upset anyone or make them feel uncomfortable. It does make me feel down and means I have a lack of motivation on some days.”

Female, aged 21 with a low grade tumour

Some participants in this study described concern about upsetting other people or feeling embarrassed about sharing the extent of their difficulties, whilst others avoided talking about it as a form of denial or a way to keep themselves from getting upset. Fear of being treated differently, and of others not understanding or not knowing how to deal with it, were also mentioned. Indeed, family members may struggle with how to tackle the subject with their child, or with what to say if they do, particularly once treatment is over and more ‘normal’ daily life returns. For the parents of a young child the challenge of facilitating understanding without creating fear is considerable, whilst adolescence brings its own difficulties, in terms of how to raise and sustain conversations about intimate thoughts and feelings with a young person striving for independence from parental care.

“He refuses to talk to anyone about his experiences and prefers to ignore it. He seems quite angry at times, too. I strongly feel more mental health care should be offered as standard to help them deal with the experience of having cancer at such a young age.”

Parent, son aged 8 with a high grade tumour

⁸ At time of survey or, if deceased, at time of diagnosis.



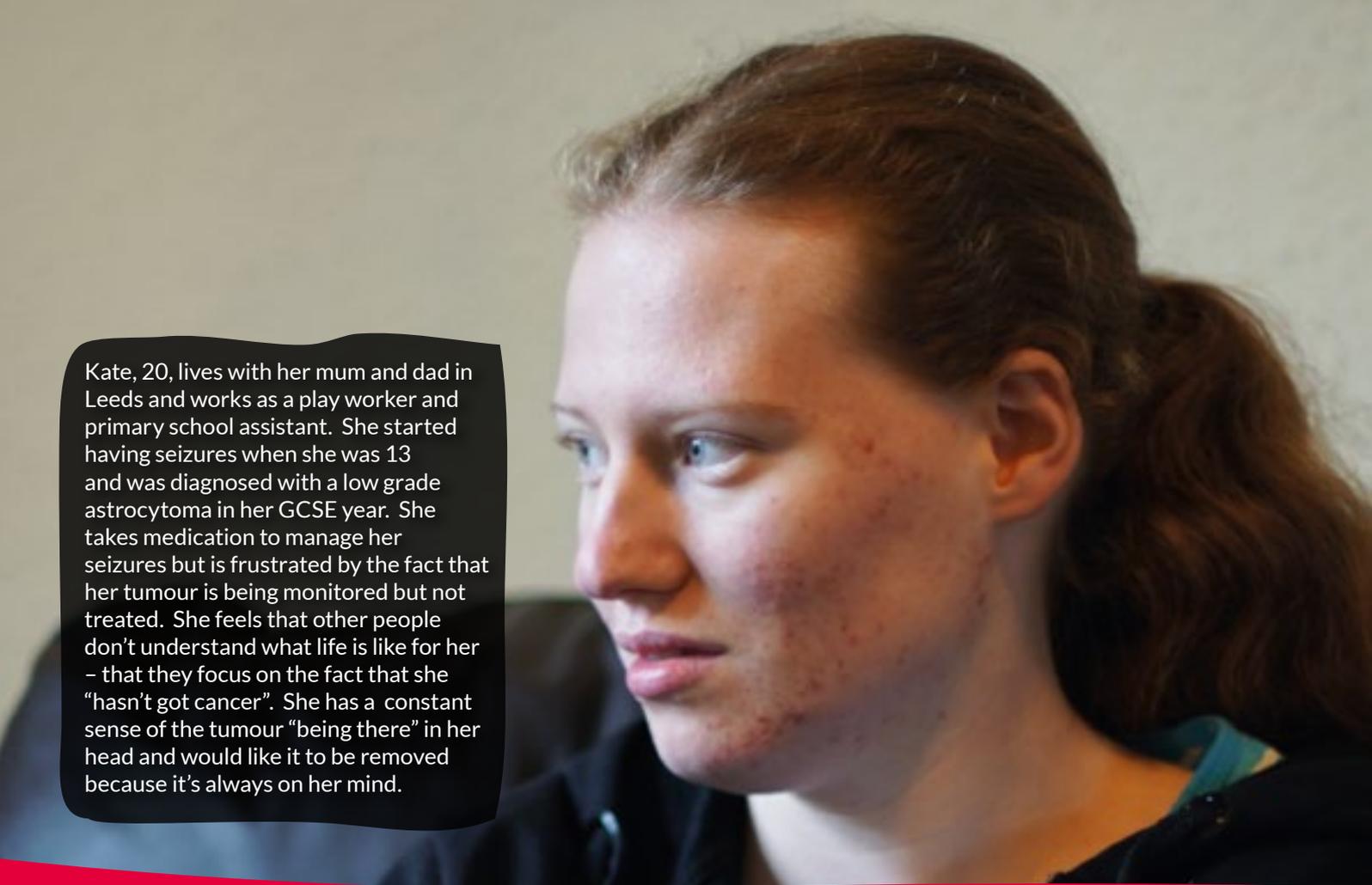
“I’ve always worried that he’s going to internalise all his worries and his anxieties, because you hear about... worst-case scenario, in his 20s he’s going to do something stupid because he’s so fed up with it all – because he’s not talked about how he feels.” (Taylor’s mum, Rochelle.)

Taylor is 14 and lives in Manchester with his mum, his dad, and little brother. He was diagnosed with a craniopharyngioma when he was 5 years old, following an eye test at school. He underwent surgery, which partially removed his tumour, and his vision in his right eye was lost. Though his tumour is low grade, there is a risk of regrowth and it remains potentially life-threatening because of its location on his pituitary gland. Having lived with this condition for as long as he can remember, Taylor appears to take it in his stride, but his mum is concerned that he doesn’t talk to anyone about it.

“I feel like he hides a lot. I don’t know what is going on in his head, emotionally. It worries me. As a young boy, a teenager – they’re not the best at talking about how they feel; at being emotional. I don’t want to push him: ‘How do you feel? How do you feel?’ So, I’m really trying to encourage him to talk about how he feels, but he says ‘I’m fine. I’m fine.’ It’s all one word: fine. He wants to be treated as normal – but it’s very difficult for a parent. I try and let him lead a normal life, but I don’t know if I do. I worry about him going out with his friends and being able to look after himself.

I don’t know if he realises how serious his illness is. His tumour caused damage to his pituitary gland, so that’s led to him having a life-threatening illness because he doesn’t produce the hormones – cortisol, thyroxine and so on – so he has to take a lot of pills. He takes 13 a day, throughout the day, and he has to inject himself at night with growth hormone, and he doesn’t always remember. And I’m having to say all the time ‘Have you had your pills? Have you had your pills?’

I think between the ages of 5 and 13 it didn’t really hit him. For him it’s just normal – he just takes pills. He got upset for the first time recently when the doctors found two new small areas on his brain – they still aren’t sure what the changes are. And when he had this outburst of worry and upset, that was quite scary for us to see, because he obviously does worry – he was worried at that point, because he thought ‘Is something wrong? But we just had a blip for a few months: ‘Is it changing?’ But it can, in 7, 10, 20 years’ time – it could still change. So he has to have his regular scans. He’ll never get the all clear and be free. And that’s just the tumour. The damage the tumour’s done with all the hormones he doesn’t produce – that’s his day-to-day illness.”



Kate, 20, lives with her mum and dad in Leeds and works as a play worker and primary school assistant. She started having seizures when she was 13 and was diagnosed with a low grade astrocytoma in her GCSE year. She takes medication to manage her seizures but is frustrated by the fact that her tumour is being monitored but not treated. She feels that other people don't understand what life is like for her – that they focus on the fact that she “hasn't got cancer”. She has a constant sense of the tumour “being there” in her head and would like it to be removed because it's always on her mind.

Other people don't understand

The impact of a brain tumour, in terms of symptoms, side-effects of treatment and prognoses, are many and varied, making the implications of a diagnosis difficult for other people to understand. Some children and young people encounter a lack of sympathy or comprehension because they 'only' have a low grade tumour, whilst others experience exclusion and bullying due to physical changes to their body that are beyond their control. Relating to someone who is neither dying nor able to live a completely normal life is particularly challenging for individuals who have no prior experience of serious illness at such an early stage in their lives.



84% of children/ young people said their brain tumour had made them feel lonely



Nearly 3 in 5 children/ young people said their brain tumour had had a negative impact on their relationship with friends



15% of those whose education had been affected by their tumour said they had been bullied

“Her friends deserted her. As she put it: ‘People don’t get long term illness — they expect you to get better, or die!’”

Parent, daughter died aged 19 from a high grade tumour

Friends don’t want to know

Loneliness is a common feature of living with a brain tumour in childhood, with 84% of respondents in this study saying their brain tumour had made them feel lonely, and 55% of this group saying they felt this ‘quite a lot’ or ‘a lot’. More than a third of those in education⁹ said they felt lonely at school, college or university. Only 1 in 5 respondents said their brain tumour had had no impact on their relationships with friends, whilst 59% said its impact had been negative. Indeed those who said they felt lonely at school were nearly twice as likely to report that their brain tumour had had a negative impact on their relationship with friends as those who did not report such loneliness.

People described friends drawing away from them or simply refusing to talk to them after they found out they had a brain tumour, and reports of friends and acquaintances feeling awkward and not knowing what to say or how to act were numerous. Children were more likely to be excluded from social activities, by both peers and parents of peers, because of knowledge of their illness and fear of what might happen.

One bereaved parent explained that if her son were to go out with friends they had to be able to take him to the toilet, which few were willing to do. Such accounts highlight the increased demands that a brain tumour can place on friendships, which can be difficult for some children to cope with. Unfortunately, such a loss of care and peer contact can create a vicious cycle with respect to self-confidence and emotional wellbeing. Rejection or non-inclusion can cause further damage to a person already struggling with their self-esteem. This in turn can make it even harder to be proactive in sustaining friendships or making new ones, which entrenches isolation and feelings of personal inadequacy.

“A few people refused to talk to me after they found out because they found it very hard to deal with the idea, probably. Some people refuse to acknowledge that I have it and treat me like I was before my diagnosis.”

Female, aged 16 with a low grade tumour

⁹ Refers to respondents who are currently in education, or have been in the past, and were diagnosed with their brain tumour during that time.

Bullying and being different

Whilst the incidence of loneliness and friendship breakdown reported by participants in this study is high, only 15% of respondents whose education had been affected by their brain tumour said they had been bullied. Bullying can be a frustratingly difficult phenomenon to measure with any accuracy, since the behaviours people associate with the term may vary considerably between individuals – and some may be unwilling to disclose such experiences. Indeed, given the difficulty that some young people have in talking about their experiences with friends and family, some of the parents in this study who responded on behalf of their child may simply not have been aware of any bullying going on. Indeed, participants in this study who said their brain tumour had had a negative impact on their relationship with friends were more likely than those who said it had no impact or a positive impact to also say that they found it difficult to talk to close friends and family about their brain tumour.

Casual teasing by children and adolescents can quickly escalate to what amounts to a bullying experience for the individual, through social contagion, when the dynamics of the group take hold and hurtful treatment becomes a routine or in-joke. Indeed, verbal labels have a tendency to stick, and even in the absence of more systematic abuse, they can be incredibly damaging to a young mind. ‘Tumour’ can sound like a dirty word to a child, and at a time of life when serious illness is rare, ignorance or misunderstanding about disease in general, and brain tumours in particular, can make fertile ground for rumour and prejudice.

“She has been bullied at school and can’t make children her own age understand.”

Parent, daughter aged 12 with a low grade tumour

Participants spoke of a struggle to make other children understand their condition – a challenge sometimes even greater when a child’s symptoms are principally cognitive, such as difficulty understanding social cues, or problems with recall and processing during conversation. Some people felt they experienced prejudice precisely because their symptoms did not appear to be severe or their tumour was low grade, and they were therefore judged as not having ‘proper cancer.’

“He has had some bullying from his peers at school. The scar has been described as ‘yuck’ or ‘disgusting’. Others have laughed at him in P.E., as he isn’t as good as them due to his balance and co-ordination being affected. He has also been teased that he’s ‘useless’ at everything or ‘has no brain in there’.”

Parent, son aged 10 with a low grade tumour

“I did suffer from ‘unsupportive’ teachers, as they couldn’t seem to understand how I was disabled and that I needed things to be explained a number of times, as I forgot what I was meant to be doing. I have a really short attention and concentration span which infuriated my teacher, thinking I was just being rude. I needed them to slow things down, as I can’t process information at a ‘normal’ rate.”

Female, aged 21 with a high grade tumour

Teachers need to understand

Responses in this study indicate that many young people with brain tumours find that their teachers respond to them with a care and compassion. 71% of those who were currently in education or who had been in education during and/or after diagnosis said teachers had been supportive and understanding, and only 12% reported dissatisfaction in this area. Given how vulnerable and misunderstood children and young people may be in their peer relationships, being able to count on a consistently kind and sensitive response from teachers and other responsible adults around them is vitally important.

“Her primary school in particular seemed unable to assess and provide for her additional requirements because apparently she looked so normal... her secondary school have been great.”

Parent, daughter aged 13 with a high grade tumour

However, being emotionally supportive is not the same as having the knowledge and understanding of brain tumours that is necessary to provide the appropriate learning experience and practical assistance for a child with the condition, in the classroom and the playground. In this study there were a number of comments describing inadequate responses from within the school environment, including an inability to assess and provide for a child’s needs, a lack of expertise around brain tumours, both amongst teaching staff and Special Educational Needs Coordinators (SENCOs), and a lack of coordination and communication between hospital and school.

One parent characterised the experience as a failure to recognise that a ‘medical need was an educational need too’. Others described teachers interpreting cognitive difficulties as rudeness or defiance on the part of the child, or failing to provide support because their child looked ‘normal’, suggesting a gap in understanding surrounding the symptoms of brain tumours.

Losing out in love

As with friendships, romantic relationships are also more likely to be negatively, than positively, affected by the onset of a brain tumour. 45% of participants who were in a relationship, or who had been in one at some point during or after diagnosis, said their brain tumour had had a negative impact on their relationship with their partner. Nearly 80% of young people who were willing to answer the question said it had caused them at least some difficulty in starting a new relationship or dating and nearly 3 in 5 of those aged 16 and above said their brain tumour meant they missed out on sex. Just as in friendship, disease and fear of dying have no natural home in the romantic relationships of youth, and living with a boyfriend's or girlfriend's brain tumour demands a degree of commitment that is too much for some to cope with at such a young age.

Participants in this study described partners leaving after diagnosis, or trying to go on but being unable to cope. One parent explained that her son had been handsome and sporty before he became ill, but when treatment caused him significant weight gain, his girlfriend ended their relationship.



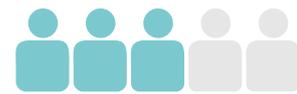
45% of young people in a relationship said their brain tumour had had a negative impact on it

Meanwhile, difficulty in meeting potential partners or dating may be an unfortunate side effect of loss of friendships – the narrowing of a person's social life reduces opportunities for new encounters that might lead to romance. Even when socialising is possible, attracting a potential partner may be a formidable task when living with, and presenting oneself with, the symptoms of a brain tumour, and/ or the physical effects of treatment.

However, over a third of respondents to whom the question was relevant said their brain tumour had had a positive impact on their relationship with their partner, illustrating the power serious illness has not only to break, but also to make, relationships. Indeed, if an individual is able to overcome the significant psychological barriers to beginning dating again after diagnosis and/ or treatment, then it is possible to find new love, even after another relationship has ended, as the account of one female participant in this study demonstrated.

“When I was diagnosed my partner left me. I was single for almost 12 months through treatment. I have since rebuilt confidence and met someone new.”

Female, aged 23 with a low grade tumour



Three fifths of those aged 16 and over said they missed out on sex



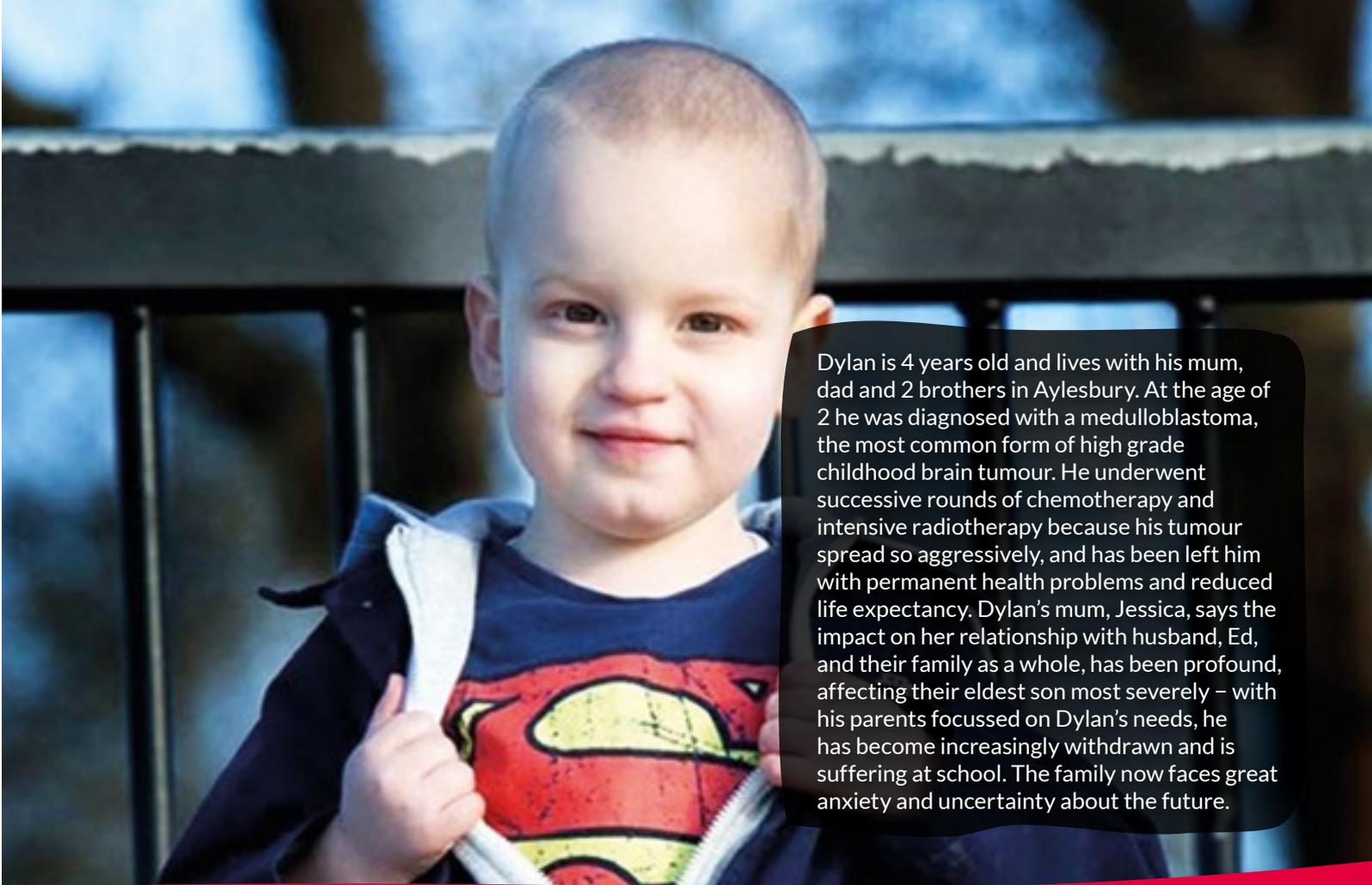
“Her friends were really nice with her and supported her up to the operation, but once she’d had it I think they kind of expected her to snap out of it. Their view was that because it wasn’t cancerous, it wasn’t anything special. I think this is quite common, and people didn’t realise what an enormous thing it is to have a brain tumour.” (Phoebe’s mum, Sheena.)

Phoebe is 19 and is at Oxford Brookes University studying Communication, Media and Culture. She was diagnosed with a low grade glioma when she was 18, whilst she was in sixth form and living at home with her mum and dad in Surrey. She had surgery to remove the tumour, but now has epilepsy and experiences ongoing fatigue and cognitive impairment. When she was first diagnosed her school friends were sympathetic but became less tolerant of her needs after surgery. She has since found a more supportive environment at university, with friends who cope better with her seizures and day-to-day difficulties.

“Her school friends would write things on her Facebook page, like ‘Thinking of you, babe’ and all that rubbish. There were lots of offline comments like ‘I’m going to do the eulogy at your funeral’, where they get a bit carried away, thinking about the glamorous side of it. On the whole they stayed friends with her but I don’t think she got fantastic support – but they’re 18, and they probably weren’t the most mature people in the world”
(Phoebe’s mum, Sheena.)

“When my friends found out about my tumour they were like ‘Oh my god!’, because they thought it was cancer. They were all really cool in the beginning and then they were like ‘You’ve used it enough now, it’s not an excuse, you need to get on with stuff.’ So they were all quite shitty on that front. I felt a lot of teachers were quite patronising as well. One would give me stickers and stuff for turning up and it was really embarrassing.

The effect on my love life has been really weird – if anything people have got slightly more interested. I think some people have got this really weird thing where they want to go out with people who are dying. It didn’t affect sex much, but I hated my scars because they’re a bit disgusting. It has changed how people treat me in bed, though. They’re like: ‘Oh my god, be careful. Don’t hit your head on the wall!’ And I’m like: ‘I’m not going to haemorrhage and die!’ It’s ridiculous, they’re like: ‘Should we call your parents if something happens?’ Would you really want to?!”



Dylan is 4 years old and lives with his mum, dad and 2 brothers in Aylesbury. At the age of 2 he was diagnosed with a medulloblastoma, the most common form of high grade childhood brain tumour. He underwent successive rounds of chemotherapy and intensive radiotherapy because his tumour spread so aggressively, and has been left with permanent health problems and reduced life expectancy. Dylan's mum, Jessica, says the impact on her relationship with husband, Ed, and their family as a whole, has been profound, affecting their eldest son most severely – with his parents focussed on Dylan's needs, he has become increasingly withdrawn and is suffering at school. The family now faces great anxiety and uncertainty about the future.

Family life is not the same

No family is left unchanged by the diagnosis of a childhood brain tumour, though the effect of such an event on home life is seldom entirely negative. News of serious illness can bring previously estranged family members closer together and deepen emotional bonds – it can also stretch those ties to breaking point, through fear, anger and exhaustion. As parents become consumed with hospital appointments, medication, and caring for their sick child, siblings may be forced to bear greater responsibility within the household, and experience feelings of abandonment, resentment and loneliness.



56% of children/ young people said that their brain tumour had had a positive impact on their relationship with their parents or guardians



Nearly three-quarters of parents said their child's brain tumour had had a moderate or severe impact on their own mental health



95% of parents with more than one child said the lives of their other children had been affected by their child's brain tumour

“My daughter was jealous of the attention Ben was getting and the fuss everyone made of him. She felt pushed out during the hospital stays with my son. She starved herself for attention and ended up in hospital herself. I believe she isn’t the girl she should have been emotionally because of what happened.”

Parent, son aged 13 with a low grade tumour

Closer bonds bearing greater loads

When a child becomes seriously ill, the role a parent plays in their life changes forever in ways that impact on every member of the family unit. Yet for many families the strain and sorrow of this experience is matched by a deepening of love – this study found that for the majority of respondents, parent-child relations improved after diagnosis. No less than 56% of participants reported that their brain tumour had had a positive impact on their relationship with their parents or guardians, and only 18% said the impact that was negative.

Many children and young people become more dependent on their parents and family members, both to manage the basics of daily life and to provide the time, attention and social contact no longer available from friends and partners. Thus, whilst many modern families struggle to enjoy quality family time, the unavoidable increase of family contact and interaction that a brain tumour causes can be the unexpected benefit of a terrible disease. Indeed, after a diagnosis, families may re-evaluate their priorities and actively choose to do more together, putting greater emphasis on experiences and making memories.

Nevertheless, the new demands placed on family routines and roles can also be a source of considerable friction, misunderstanding and withdrawal, and parent-child relationships may endure considerable shocks on the way to becoming stronger.

“It’s made my relationship with my parents stronger in some ways, but also more strained. I can’t go out very much as I get fatigued.”

Female, aged 23 with a low grade tumour

Brothers and sisters feel pushed out

Parental time and attention are finite commodities, and there are inevitable losers as well as winners when the care needs of one child greatly exceed those of other family members. In this study 95% of parents with other dependents said their child’s brain tumour had affected the lives of their other children to at least some degree, and 73% said the effect was moderate or severe.

Nearly a third of respondents with siblings said their brain tumour had had a negative impact on their relationship with their brothers and sisters, though 38% said the impact had been positive, and a further 30% reported no change.

Many children and young people with a brain tumour require a much greater degree of care than other children of their age, and this may mean siblings are left to fend for themselves and feel pushed out at home. In this study 47% of young people with a brain tumour aged 15 and above¹⁰ reported having at least some difficulty getting ready in the morning, including getting dressed and bathing.

Meanwhile, greater parental absence from the home due to medical appointments and hospital stays, or the shipping off of brothers and sisters to stay with extended family, can create a serious rupture in the structure of the family unit. This experience can also impact on the education of siblings, through their own absence from school, emotional distress, and lack of parental help and input.

“Our daughter felt neglected when our son was ill. It severely affected her academic performance when she did AS levels.”

Parent, son aged 22 with a low grade tumour

Participants in this study described many different manifestations of trauma experienced by brothers and sisters of a child with a brain tumour – increased clinginess amongst young siblings due to parental absences and reduced opportunity for interaction; fear and anxiety for the wellbeing of their sibling in older children, as well as jealousy and anger about what appears to be attention focused on a single family member to the exclusion of others.

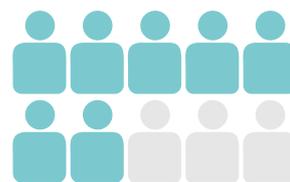


Nearly a third of respondents with siblings said their brain tumour had had a negative impact on their relationship with their brothers and sisters

Some incidences of more severe mental illness were also reported, including depression and self-harm. Living with the impending loss of a brother or sister, and dealing with life after they've gone, is an especially traumatic experience for a child, who has to live with the consequences of their parents' grief, as well as their own.

“Have three other children. One is very angry – has been hospitalised for self-harm and reviewed by CAMHS¹¹. One was a baby when his brother was diagnosed, plays up because he doesn't get the attention he deserves.”

Parent, son aged 10 with a low grade tumour



More than 7 in 10 parents with other dependents said the impact of their child's brain tumour on siblings was moderate or severe

The way in which families choose to spend leisure time together may be fundamentally altered when a child is diagnosed with a brain tumour. When one member of the family is no longer able to participate in certain types of activity, this has a knock-on effect on everyone else. Brothers and sisters may feel frustrated, saddened or resentful that the range of options for days out and trips away is smaller than that of their peers in other families. Meanwhile parents must contend with the anxiety and regret inherent in trying to balance each of their children's needs and desires, knowing that the care of their least able child cannot be compromised.

¹⁰ At the time of survey completion or at the time of their death, as reported by bereaved parents.
¹¹ CAMHS is the Child and Adolescent Mental Health Services.



“I have found that dealing with my child’s illness has only served to enhance pre-existing areas of conflict and dissonance in my relationship with my partner. The time and energy required to work through these is taken up with dealing with the immediate evolving situation with my child. My partner living at home with the other kids, and me living in hospital with my child, are two very different worlds which are difficult to appreciate. When we are all living at home together again re-entry is difficult and the ‘old way’ of how things used to work is no longer appropriate, yet finding a new way forward isn’t easy.”

Extract from Louisa’s diary – parent, daughter aged 14 with a high grade tumour

Adult relationships suffer

No parent can remain emotionally untouched by the serious illness of their child, and 99% of parents who participated in this study said their child’s brain tumour had affected them emotionally, with nearly 6 in 10 saying the impact was severe.

Parents caring for a child with a brain tumour face enormous pressure and competing demands, from both within and beyond the home – 83% of working parents involved in this study said their working life has been moderately or severely affected by their child’s illness, and two-thirds of all parent respondents reported a moderate or severe impact on their finances. Meanwhile, as many as 9 in 10 parents who participated in this study said their child’s brain tumour had made them feel at least somewhat lonely or isolated – 62% said ‘quite a lot’ or ‘a lot’.

“My friends, while happy to help and be supportive to begin with, are now very bored of the situation. I rarely see anyone.”

Parent, daughter aged 4 with a high grade tumour

This is also reflected in the fact that just over three-quarters of parents said their child’s brain tumour had had at least some negative impact on their relationships with their own friends, and 36% said it had impacted these friendships ‘quite a lot’ or ‘a lot’. With so much time and energy invested in their child, parents may find they have little left to devote to sustaining adult relationships – and, like their children, some find that friends drift away in the face of the chronic illness and uncertain prognosis that a child with a brain tumour represents.



90% of parents said they felt lonely or isolated as a result of their child’s brain tumour



“Even for the little one she had a lot to cope with, because suddenly Mum and Dad weren’t around – they are in hospital all the time and her sister’s not coming home.” (Amber’s aunt, Shabnam, talking about Amber’s little sister.)

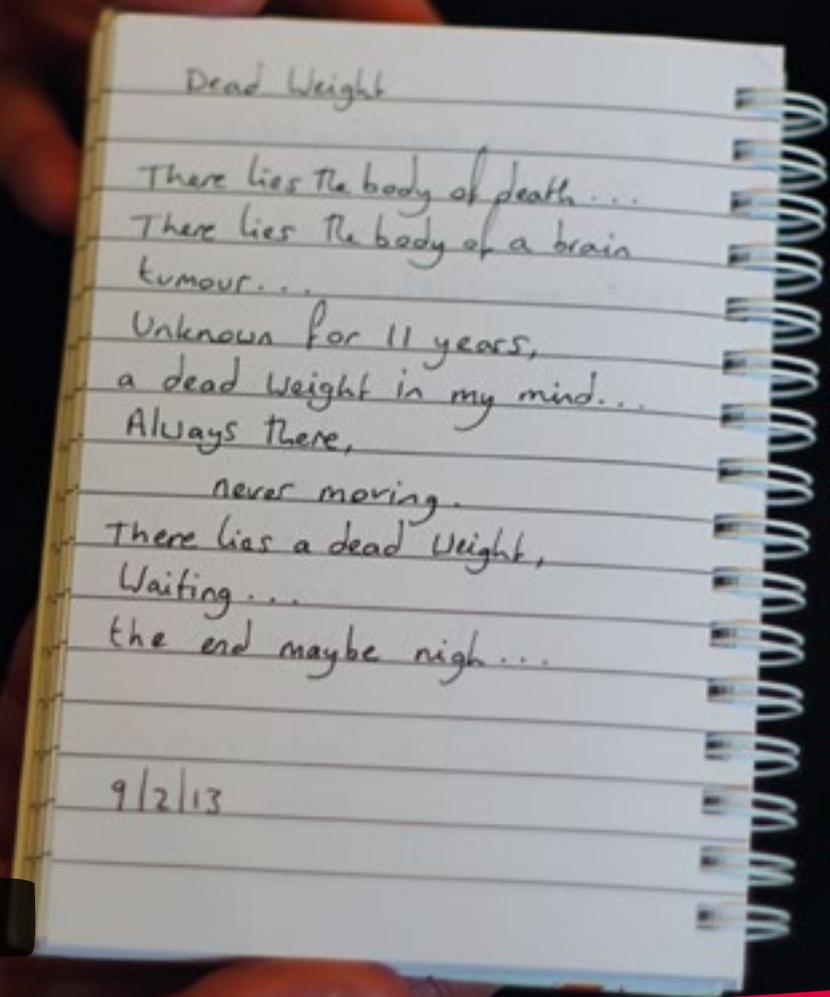
Shabnam’s niece, Amber, was diagnosed with a low grade astrocytoma when she was 9, as well as a rare genetic disorder, CTX. Amber’s family are very close and everyone was deeply affected by this. The pressure on Amber’s parents, Nadeem and Zainab, was considerable and, like many other parents in their situation, they found this put a strain on their relationship. Since Amber underwent surgery to remove her tumour and her CTX has been stabilised with medication, family life has begun to settle down. They now place greater value on spending time together, and Amber and her sister have a better relationship than before her diagnosis.

“Things deteriorated between myself and my wife. It was just a lot of stress and it was difficult and so we obviously took it out on each other. When you look back on it, it was silly of us, but it’s just a natural thing, isn’t it? There was pressure, we were worried, not sleeping well, not eating too well...and not knowing what the future was.

I think there was a stage when I thought: I need to be the one who says everything is alright; I need to be that person. I was just trying to keep myself together, keep everything together and just work our way through day-by-day. It was just because we had so many issues and they were hitting us: bam, bam, bam!

Amber’s little sister has been very good. But she’s been side-lined, if I’m being totally honest, because we had to concentrate on Amber. You try not to be – you try to balance it out, but it’s not possible at times. Her relationship with her sister has grown, though – they were much more fractious before, but now she just follows her around. They still have days...you know, they’re children, but they’re much better friends now, which is quite nice, isn’t it?”

(Amber’s dad, Nadeem.)



“Dead Weight” by Kate – see page 15

An ending too soon

A brain tumour is a serious diagnosis, regardless of tumour grade, and inevitably confronts a child and their family with questions of mortality. The complexity of the brain means that, in the best of circumstances, outcomes may be difficult to predict, and many children and young people endure an underlying fear of dying, even when treatment is successful. Meanwhile those with a terminal prognosis and their family face the reversal of the map of their lives, with the reality of being, or loving, a child who will never grow old.



50%¹² of children/ young people said they were afraid of dying because of their tumour



Nearly 3 in 5 children/ young people said they were not comfortable talking about dying



79% of bereaved parents said their child died in the place they wanted to

¹² The percentages reported in this section are based only on those who said they felt comfortable answering questions about dying. 39 people declined to answer questions in this section.

“My son is highly anxious and he worries about death. At 7 he asked if he died and was born again would he be a normal kid? Children shouldn’t ever think things like that.”

Parent, son aged 15 with a low grade tumour

Facing death at an early age

Fear of dying is a phenomenon which transcends grade and tumour type, in both adults and children with the disease. Nearly half of participants in this study who were prepared to answer the question agreed that they were afraid of dying because of their brain tumour, including significant minorities of young children. Indeed, there was very little difference between the proportions of younger and older children who reported fear of dying in this study – only 31% of children under 10 years of age were reported to not to be afraid of dying, compared to 29% of those aged 10 and above. The many and varied forms, progressions and prognoses associated with brain tumours make comprehending the implications of one’s diagnosis a difficult task for adults with the disease – for a child the line between living with and dying from a tumour may even more difficult to discern.

What it means to be a child with a tumour in your head is not the stuff of fairy tales, cartoons or pantomime. Making sense of your illness within the context of everyday play and fantasy can therefore be extremely challenging. Indeed, once a child is old enough to have a sense of their own place in the world, the fact that they are unusual amongst their peers in having a serious illness will become quickly apparent. With no point of comparison for their experience within their friendship group, nor in the games they play or the stories they read, they cannot obtain reliable information from their social environment about what to expect and what to fear.

Whilst adults may provide reassurance, other children may conjure up horror stories that may be difficult for a young mind to distinguish from reality. Living with anxiety about your own mortality is something many children and young people with brain tumours endure – this year’s clear scan offers no guarantees for the coming year or the year after. When the possibility remains that a tumour may grow or change, the fear of ‘What if?’ becomes a fixture in the background of day-to-day life.

Talking about dying

Difficulty with talking about dying is an unfortunate counterpoint to such widespread anxiety experienced by children and young people with brain tumours – nearly 3 in 5 of those who answered the question said that they felt uncomfortable talking about dying, and only just over a quarter said they felt comfortable doing so.

There is no easy or right way to talk about death, least of all when a child has a definitive terminal prognosis, and some parents choose never to tell their child that they are dying, or wait as long as possible before breaking the news to them. Talking to a child about their own mortality is a horrifically incongruent task in early parenthood, and yet it is clear that, whether they share their fears with others or not, many children and young people continue to live with them – and it is a heavy burden to bear alone.

“The time spent in the hospice was a very special time for us all and my son fell asleep very peacefully and in no pain.”

Parent, son died aged 21 from a high grade tumour

Finding your peace

Each and every one of us hopes for peace and comfort at the end of our life, and none more so than the parent who has to say goodbye to a child they brought into the world. It is therefore encouraging that nearly 8 in 10 of the bereaved parents willing to respond to the question agreed that their child had died in the place of their choosing. The unpredictability of terminal illness may prevent the best laid plans for end-of-life care from being realised. However, adequate preparation and support can make a significant positive difference to the degree of trauma experienced by all involved.

In this study, 67% of bereaved parents and parents or children with a terminal prognosis agreed that they had received the right information about care at end of life, whilst just over a quarter disagreed with this statement and the same proportion disagreed that they had been given a choice of end-of-life care options. These figures suggest there is more to do in this area.

“My child wanted us to care for her. The palliative care nurses were amazing, and let us do as much as we could. They were of tremendous support to us and also my dying child’s sister. They guided us through the whole process.”

Parent, daughter died aged 4 from a high grade tumour

Nevertheless, reports of good end-of-life experiences were numerous. These exemplify the enormous value of investing time and expertise into supporting children and young people with terminal brain tumours, who deserve, as a minimum, the comfort and consolation of dying well.

Conclusion

Every child, young person and family member who participated in this study has faced their own individual journey to find their place in a world forever changed by a brain tumour diagnosis. Each story is different, but what is universal is the reality that when this potentially life-threatening disease occurs in childhood, it interrupts the natural process of growing capacity and independence from parental care in ways no-one involved can anticipate or prepare for.

A brain tumour is not merely a medical diagnosis, it is the starting point for reorientation in every aspect of a child's life, with implications for their psychological, social and educational needs, well beyond the crucial clinical considerations. The mental wellbeing of a child with a brain tumour may be dangerously compromised if their complaints are not taken seriously in the critical period prior to diagnosis, or if their private fears and frustrations during and after treatment have no outlet. Meanwhile, siblings whose parents are necessarily consumed with caring for a sick brother or sister may also suffer significant emotional injury if their needs go unmet for extended periods of time.

The findings from this study indicate that few families affected by a childhood brain tumour are strangers to loneliness, and that every family member may be touched by it in their own ways, at different times. A brain tumour brings its own inevitable burden of fear and pain – and parents and children alike may feel obliged to conceal or minimise their own feelings in order to avoid adding to this. However, this study has shown that the cost of adopting such coping strategies may be very high for individual mental health, for family life, and for parents' relationships.

To properly address this, the negative emotional and social impact of childhood brain tumours must be taken for granted as part of the wider symptomology of a brain tumour diagnosis, deserving as much care and attention as the clinical dimension. A brain tumour affects the way a child or young person is able to interact with the world, and responding appropriately requires effort to understand the combination of practical and psycho-social needs this creates in play, rest, education and work, so that kindness and empathy also translate into proactive, person-centred intervention. Every child and young person wants to be 'normal' and fit in with their peers. It is therefore crucial that adaptation to the different and distinct needs of a child with a brain tumour does not cause them to be defined by need and difference.

This study found abundant evidence of existing good practice in the care and support provided to respond to these needs. However, room for improvement and innovation remains – no small ambition under the current conditions of resource scarcity in the public sector. Nevertheless, The Brain Tumour Charity's own work has shown how much can be achieved by harnessing the expertise of those who live with brain tumours every day, and it is vital that the unique insight and quiet wisdom of children and young people with the condition is recognised and fully utilised in this endeavour. With a clear and comprehensive understanding of the challenges they face, and the hopes they hold, we can help them to navigate the difficult practical realities of living with a brain tumour in childhood, whilst respecting their desire and right to be young.

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 most 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 more¹³. This means that more than 5,000 people lose their lives every year¹⁴. In addition, brain tumours reduce life expectancy by an average of 20 years, the highest reduction of any cancer¹⁵. Despite these stark statistics, less than 2% of the £500 million invested in cancer research in the UK every year is spent on brain tumours¹⁶. 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 disability¹⁷. 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

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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



SMART

A HIGH
PERFORMING TEAM



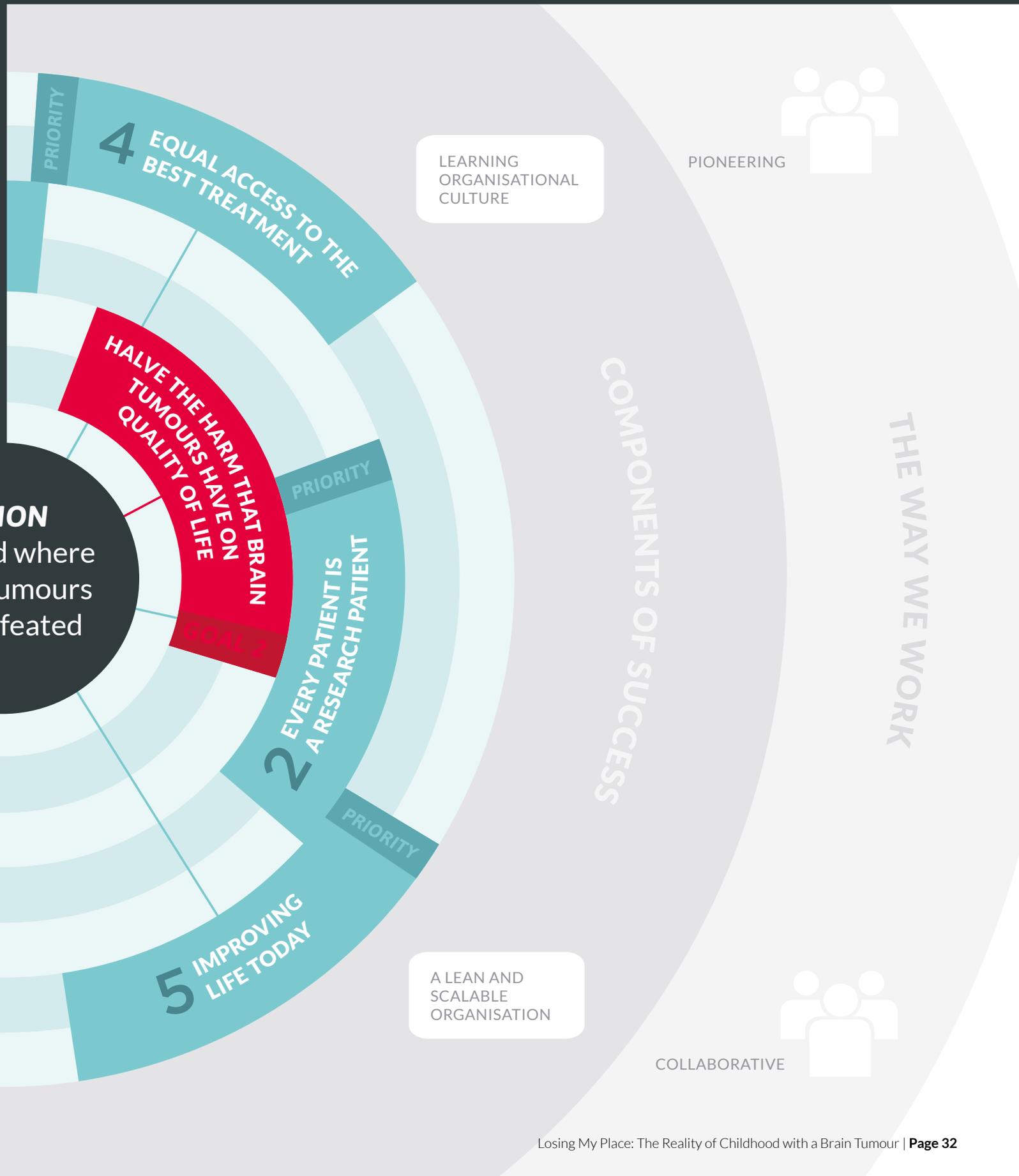
%

with a brain tumour
affects their
mental health

LESS THAN 2%

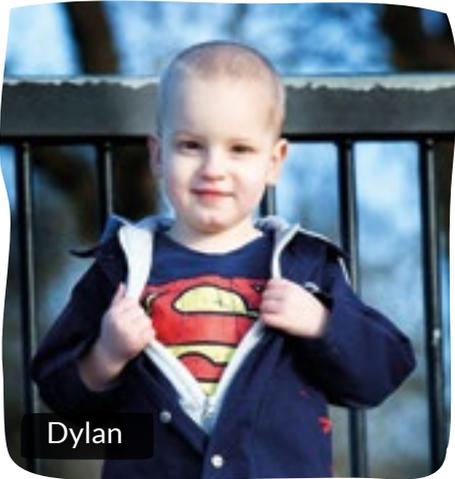
of the cancer research
funding in the UK is
spent on brain tumours

Brain tumours reduce
life expectancy
by on average
20 YEARS



ION
d where
umours
feated

With thanks to...



Dylan



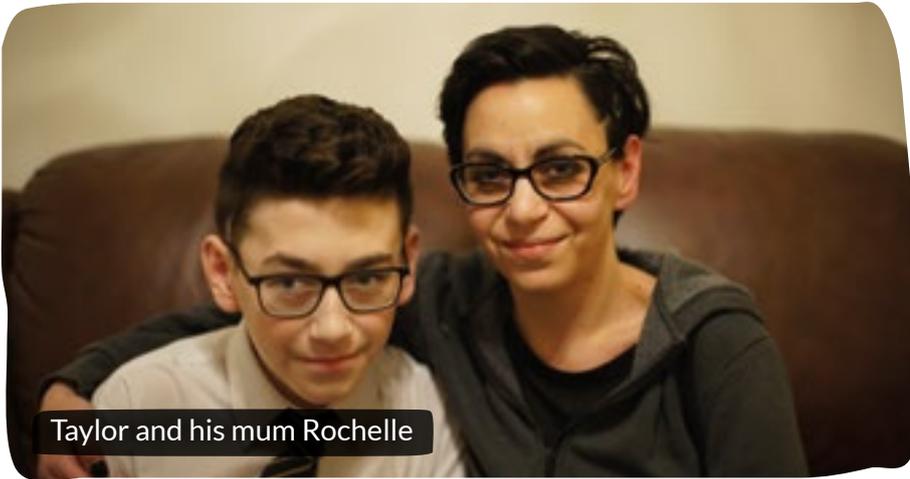
Phoebe and her mum Sheena



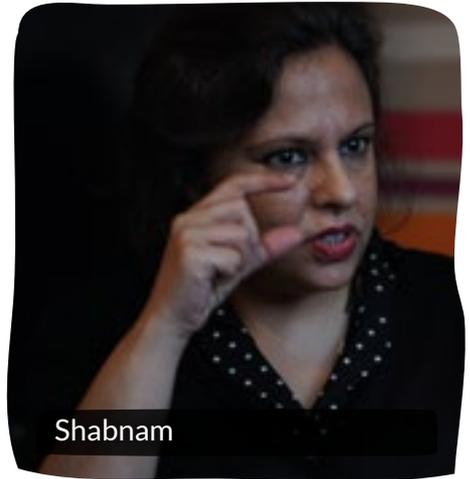
Amber and Marissa



Josh and his mum Wendy



Taylor and his mum Rochelle



Shabnam



Hannah



Kate



Nadeem



Jane

In partnership with:

alterline

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