brainstrust
the brain cancer people

# Our impact
2024

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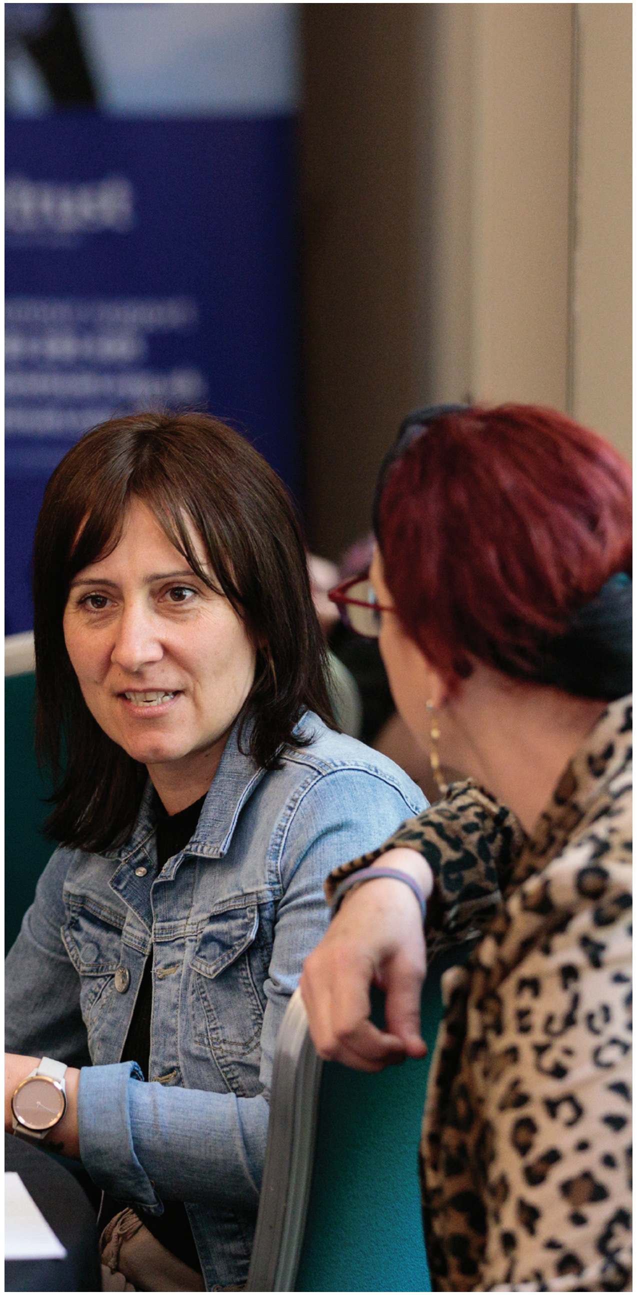
> *It was so helpful! I am really grateful for all of your guidance and advice. It makes such a difference to feel we have people to reach out to when things feel tough!*
>
> **Patient**



# Introduction

**This report illustrates the impact *brainstrust* has had for people living with a brain tumour and their caregivers in 2024.**

Someone is diagnosed with a brain tumour every 30 minutes in the UK. They face not only a cancer diagnosis but also a debilitating, progressive disease that impacts on cognitive, emotional and physical needs. Work stops, relationships change, and for many, they are living with a limiting deadline. Over the last 19 years, people have told us that the challenges they need help with aren't always the clinical ones. They're not the problems that doctors can fix in clinic. People tell us they need help living life to its full potential, which means tackling the problems that people face, not the problems that challenge us as patients.

As you read this, day or night, a member of the *brainstrust* team is ready to help. And in 2024 we've helped more people with a brain tumour and delivered more impact than ever before. Read on to discover the impact we've made as we've continued to serve those who need us most.

# Our challenge

**More than 102,000 people in the UK are living with a brain tumour diagnosis, with over 28,000 new primary and secondary (brain metastasis) diagnoses each year. But within the clinical process, there is little provision or care for the patient's emotional, psychological or practical needs, or support for caregivers. Founded in 2006 by a family whose daughter was diagnosed with a brain tumour, *brainstrust* has grown to support thousands of people across the UK who have been diagnosed with a brain tumour, their caregivers and their families.**

The burden of a brain tumour diagnosis is multifaceted. From experiencing symptoms such as fatigue, memory loss and personality change to feeling lost in an unreliable system, people feel disempowered, dejected and dismissed. Patients and their loved ones must become experts in their care and navigate the complicated and emotional world of living with a brain tumour.

This has been spelled out by our community:

*As a carer, I'm trying to work and then trying to do the calls and find people – you feel you're letting your partner down.*

**Caregiver**

*With brain tumours it's a multi-faceted issue. You have to fight every step of the way. When you're exhausted, it's really hard and there's not really a point identifying needs when they can't be met. You're told you have needs, but have nowhere to go.*

**Caregiver**

*It's a lot of information, and it is hard to take in. You need someone to talk to. It was really confusing and it still is. I don't even know what I have, and it changes based on who I speak to.*

**Patient**

*After surgery, I needed to give myself rest. As much as I wanted to get back into a 'normal routine'. I had to listen to my body, so when I needed sleep, I had a snooze. I needed to feel connections with my family and close friends. Most importantly, I needed the guidance of my doctor to tell me how things went – and the reassurance that came with it.*

**Shan**

# Our strategy

**In April 2019, we launched 'First, we are people', a strategy that called for a fundamental shift: from seeing people purely as patients to recognising the rich, complex lives they lead beyond a diagnosis. This approach places greater emphasis on the emotional, practical and cultural realities of living with a brain tumour – not just the clinical ones.**

Our aim has remained clear: to help people to be less isolated, more in control, actively engaged in their care, emotionally resilient and better equipped to live the life they want.

## Why this approach?

Everything about this strategy comes from what the brain tumour communities tell us matters most:

- You are a person for far more time than you are a patient.
- As a person, you face challenges with more confidence.
- Your choices are driven by what you value, not just what your symptoms are.
- What matters to you shapes your path more than what is the matter with you.
- Where patients see problems, people see possibilities.

This feedback shaped our direction. Together we built a strategy that doesn't just treat a condition; it respects a whole person.

Years on, 'First, we are people' continues to guide our work. It's a strategy we're delivering with the community, and it's helping people with a brain tumour feel informed, supported, connected, involved and hopeful. Because before anything else, we are people.

## What we do

We help people to be less alone, part of a community, on top of things, resourced, supported and better able to navigate their clinical care.

We do this for the people who need us, with the following services:

### 24/7 helpline

Offering people with a brain tumour and their caregivers support, information and advice whenever they need it.

### 1:1 coaching

Helping people to manage anxiety and overwhelm, and to be more actively involved in crucial decisions about their care and treatment.

### Counselling

Helping people make sense of their situation and providing a safe space to talk when someone is struggling to cope.

### Resources

Toolkits and patient guides that equip patients and caregivers with the information they need to feel confident and in control.

### Events

From meet-ups to expert-led webinars, to connect brain tumour patients and caregivers with valuable support and knowledge.

### Peer support

Connecting patients with a volunteer who has been through similar experiences, to help reduce isolation and reduce fear of the unknown.

# Our impact last year

**Here you can see the powerful overview of the progress and difference we've made in the last year, driven by our community and our commitment to putting people first.**

> *More people than ever before have called upon* brainstrust *for help, and in all measures, we have been able to deliver our greatest-ever impact for people living with a brain tumour. We have grown without compromise for our communities and can't thank enough our supporters and our teams for all their commitment and hard work to help us make this happen.*

**Dr Helen Bulbeck**, *brainstrust* Co-founder and Director of Services and Policy

## In 2024

**136,529 people** engaged with **our service**

**We provided** direct support to **4,577 people**

Of those, **1,211 individuals** were **completely new** to us

**New people supported 2024**

Our support team continues to provide top-level, wraparound support to those who need us – when they need us most. In this year, we had our largest year in terms of support, with our total number of individuals supported at 4,577, our biggest year yet, up 157 from the previous year's 4,420.

These interventions and services provide a positive impact on people we support, focused on various priorities, explored further on page 7.

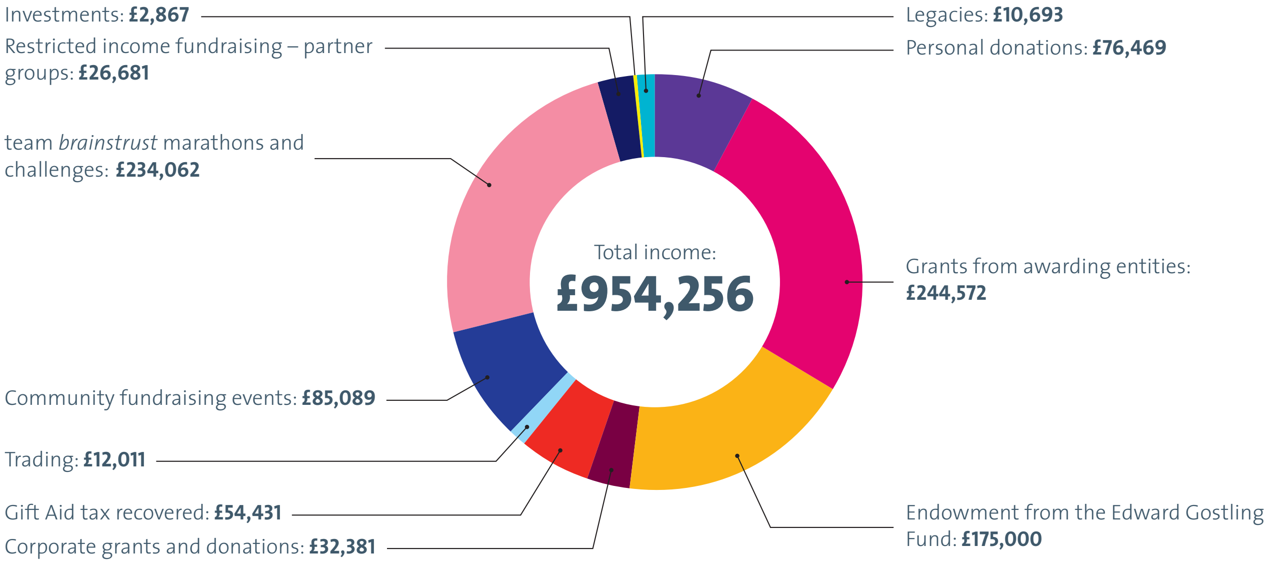
## Funding this work

This year our supporters contributed £958,450 to fund *brainstrust*'s mission . This income comes from a diversified mix of traditional charity fundraising activity.

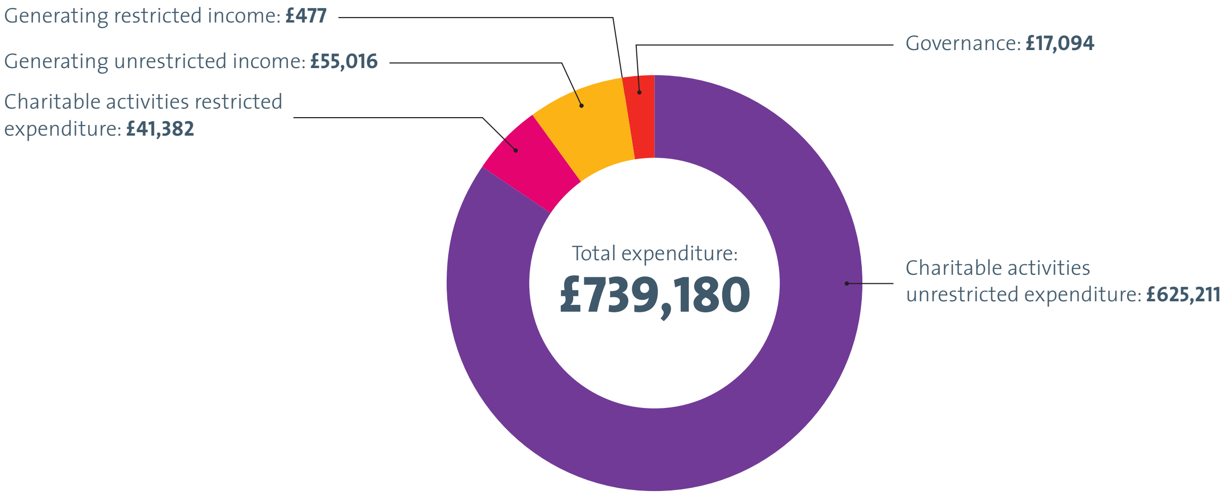
Our funding comes from:

- trusts and foundations
- direct and regular giving
- companies who support our work
- sponsored events and challenges
- community fundraising
- Gift Aid recovery
- in-memory giving
- trading
- special-purpose fundraising to enable people to access novel treatments and therapies.

# Our income 2024

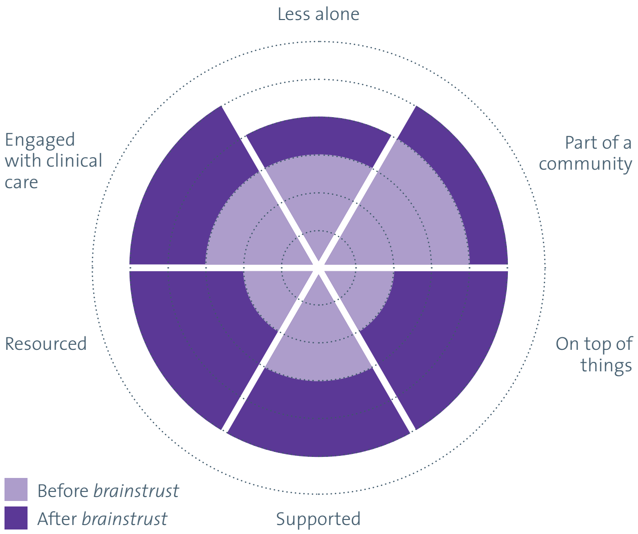


# Our expenditure 2024



## Meet Heather

Heather was diagnosed with a meningioma in late 2023, which she describes as having impacted all aspects of her life, including her independence. When she reached out to us initially in 2024, we arranged to send her a brain box – specifically tailored to providing her with physical resources that would enable her to start taking back control of her life. She then went on to access more of our services, including our coaching service, where she would have a series of sessions outlining how she could feel more on top of things and work towards desired outcomes while facing this diagnosis and journey.



After receiving our support, which also included attending meet-ups, accessing patient guides around clinical care and receiving support on behaviour and personality change, Heather felt more resourced, more on top of things and all round better equipped to handle her diagnosis.

> *My partner has really benefited from speaking to others going through it, and I am so grateful for this. Without* brainstrust *we would be a lot less positive and probably a lot more fearful than we are! I can't thank them enough for the work they do and the difference they make. They are truly lifesavers.*
>
> **Caregiver**

# Helping more people to make more progress

**We work to help people have their best possible day, every day, after they've been told they have a brain tumour. We help people to be more in control of what matters most to them. We track the progress people make on a personal basis across six priorities. These priorities have been highlighted to us by the brain tumour community as the most important aspects with regard to quality of life.**

## Methodology

We measure progress using six key indicators, identified by our community of patients and caregivers as essential to quality of life. These are:

- feeling less alone
- feeling part of a community
- feeling on top of things
- feeling resourced
- feeling supported
- feeling able to navigate clinical care.

To understand how people are doing in these areas, we use our progress tracker tool. This tool offers a simple, flexible and human way to capture the difference we're making. Progress trackers are completed in collaboration with our beneficiaries, helping us to identify where support should be focused to help them move forward.

For each indicator, patients and caregivers rate how they're feeling on a scale from 1 to 5, with 5 meaning things are as good as they can be under the circumstances. By completing multiple trackers throughout their journeys with us, we're able to build a meaningful picture of their progress over time, which we refer to as 'distance travelled'.

## Our community in 2024

We use this data to drive our personal coaching conversations with people, and we can aggregate the data to monitor the impact we are having for our communities.

The year 2024 saw our highest average distance travelled yet, based on where people were when they first came to us and where they are after receiving our support. On average against our six indicators, we helped people to improve by 35%, or 1.38, from their initial score on a scale of 1 to 5. This data is aggregated from 51 responses over the year.

The graph on page 8 shows our team and volunteers have delivered our strongest year in terms of patient support, in all measures. Our biggest impact was in helping people to feel part of a community, with a 42% increase on average from the initial score.

Our smallest difference was seen in helping people to feel able to navigate their clinical care, which still had a strong increase of 29% on average from the initial score.

We also sent out 358 brain boxes. Individuals are able to choose the resources they feel are most relevant to them, and each person receives their tailored box of physical resources free and delivered directly.

## The impact of our brain box

A brain tumour diagnosis brings with it uncertainty, confusion and overwhelming emotional and practical challenges. Our brain box is a support toolkit that helps people with a new diagnosis, and their caregivers, feel better resourced, less alone and more in control at a time when everything can feel out of their hands.

This toolkit is tailored to the needs of each individual and includes guides, co-produced with the brain tumour community, on navigating treatment, understanding fatigue and personality changes, approaching end-of-life care and holding difficult conversations. It also contains age-appropriate and role-specific resources, from materials for teenagers and young adults to versions designed especially for parents and caregivers.

It connects people with reliable information when it is most appropriate for them, helping them make informed decisions with clarity and confidence.

> *My brain box arrived yesterday! These are excellent resources, and the brain book is going to be invaluable for me keeping everything together. What an excellent idea.*
>
> **Patient**

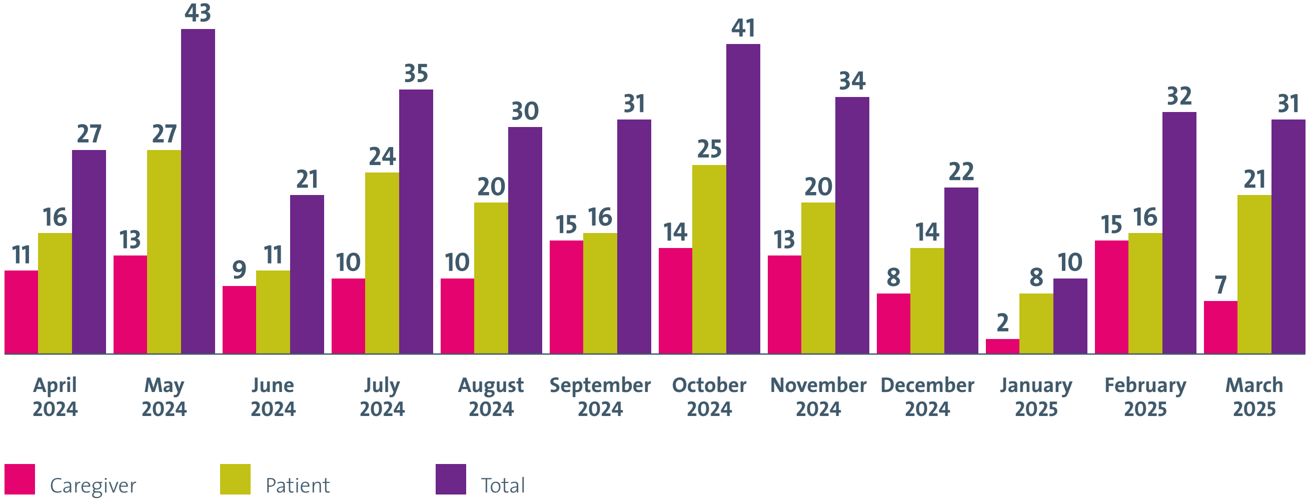
## Brain box reach

Over the past year, 357 brain boxes were delivered to people affected by brain tumours, including:

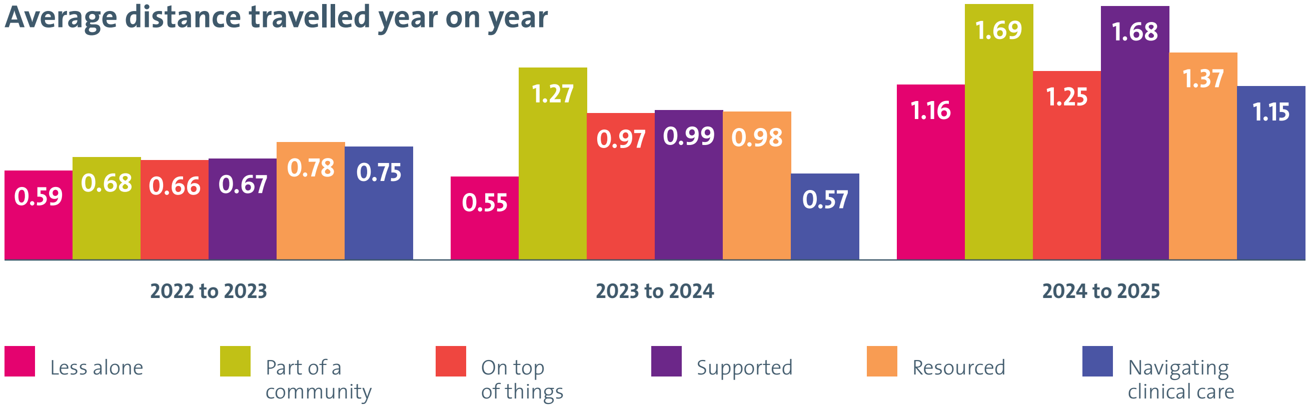
- 217 patients receiving a box tailored to their tumour type and stage
- 127 caregivers supported with tools to better understand and navigate the journey alongside their loved ones
- healthcare professionals (included in the total), helping them support their patients with trusted, tailored resources.

This growing reach we have seen reflects the trust people place in this resource, as well as the deep need for accessible and personal support when it's needed most.

### Brain boxes supplied



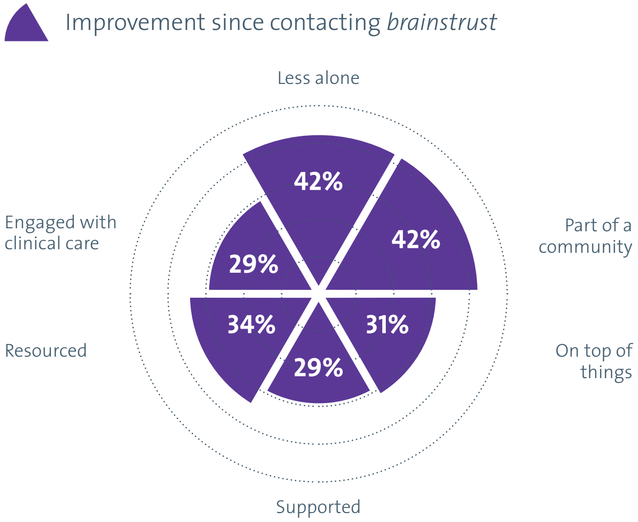
## Average distance travelled year on year



# The impact of coaching with *brainstrust*

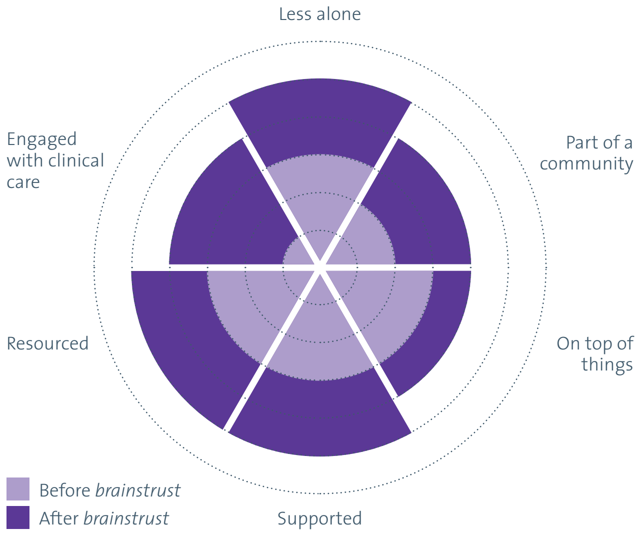
We know that coaching plays a powerful role in driving positive change for patients, for those around them and for our healthcare systems. It empowers people to manage their own health and well-being, which in turn, people tell us, improves confidence, purpose, resourcefulness and proactivity. For our health systems, activated or coached patients make for reduced healthcare

## Our year, April 2024 – March 2025



## Meet Angela

Angela has been supported by *brainstrust* since 2021, having found community and clarity by engaging continually with our service. Living long-term with an acoustic neuroma, Angela has found support, resources and the ability to engage more confidently with her clinical care. She did this by accessing and taking part in services such as PRIME (our Patient Research Involvement Movement), attending our regular fatigue webinars and also accessing our welfare and benefits support service.



costs through appropriate presentation, healthier lifestyles and better personal management of conditions. We see improved patient experience and a shift in focus, where the patient becomes an equal and active partner, or co-pilot, in their care.

> *I now feel better equipped to deal with things and I remember to park the things, that I have no control over and only deal with the things I can control.*
>
> **Patient**

Our whole service is built on coaching principles, and people can also book one-to-one coaching sessions with our trained support specialists.

Evaluation of 100 coaching sessions that were conducted between patients or caregivers and their *brainstrust* coach on the Thrive platform reveals impressive impact.

When asked to score out of 10 whether the coachee would recommend coaching to another person in their position, the average score was 9.59.

When asked to score their satisfaction with their coach out of 5, the average was 4.93, and session satisfaction was rated at 4.74.

The popular topics that people tell us they want to address with coaching are 'finding what is right, not what is wrong' (25/100), 'learning to be resilient' (22/100) and 'learning how to live with uncertainty' (14/100).

> *I find speaking to Mariel helps me organise what is important to me. Before this session, I felt anxious and gloomy, but I feel I am now more aware of my behaviour, what I can do and how I can look after myself better.*
>
> **Patient**

> *Ellie was fantastic as always and has really started to help me recognise my default of 'what have I done wrong', which is a big step to recognising my needs are still important.*
>
> **Patient**

## A closer look at our support services

Progress trackers are completed before and after access to any form of support offered by *brainstrust*. This support ranges from easy-to-access online information to more intensive interventions, such as coaching or peer support.

We acknowledge that the size of a dataset can limit the depth of our insights. We are committed to expanding our data collection efforts to ensure we have a deep and robust understanding of the needs of those we support. Maintaining and improving the quality and scope of our data remains a key priority as we continue to strengthen the impact of our work.

## Volunteers

In the last year, we've put great focus on engaging, growing and diversifying our volunteer community. These volunteers have received support and training in delivering their respective aspects of our service to the community effectively.

We ended the year with:

- five volunteer counsellors
- five volunteer coaches
- 53 volunteer peer supporters
- 153 PRIME advocates (representing the patient community in research projects).

# The role of information

**Here we take a closer look at the more nuanced, lasting impact of our work. These are areas that help people not just cope but adapt and thrive. They support the long-term difference we aim to make in helping people to feel seen, heard and supported.**

## Helping our community online

In the last year, we've seen high levels of traffic across our various online resources and information pages on our website. **136,529** people sought information on **brainstrust.org.uk**, contributing to a total of **180,564** sessions.

The total time people spent looking at information on our website was **2,307** hours.

**8,035** people accessed and downloaded our online resources, which include:

- My Fatigue Book
- Behaviour and Personality Change
- Patient Guide 4: Follow-up
- How to hold a difficult conversation
- My Radiotherapy Book.

These people downloaded **12,540** resources.

People were most interested in content about brain tumour symptoms and diagnosis, end-of-life care, brain tumour types and anatomy, and the stories of others. Our 'Get help now' page was also popular, providing a gateway to all facets of our service. We saw significant growth in interest in diagnosis-specific advice, including information about glioblastoma and novel treatments and therapies. This content has been co-created with the glioblastoma community and is a vital hub that saves patients and their caregivers many hours of research.

The 'Helpful score' is a metric users can engage with on our web pages to let us know if they've found our information valuable.

### 1. Brain tumour symptoms and diagnosis

| Users | Helpful score | Indicators |
|---|---|---|
| **24,082** | **92.86%** | **Resourced, on top of things** |

The brain tumour symptoms and diagnosis page helps individuals recognise early signs of a brain tumour and understand the diagnostic process, empowering them to seek timely care and feel more informed at a critical stage.

### 2. End-of-life care

| Users | Helpful score | Indicators |
|---|---|---|
| **17,225** | **91.45%** | **Engaged with clinical care, supported** |

The end-of-life care page provides compassionate guidance for patients and caregivers navigating the final stages of life, helping them plan, communicate and find dignity and support during this deeply difficult time.

### 3. Types of brain tumour and brain anatomy

| Users | Helpful score | Indicators |
|---|---|---|
| **5,829** | **79.90%** | **Engaged with clinical care, on top of things** |

This page offers clear explanations of brain anatomy and tumour types to help people make sense of complex medical information and feel more confident when discussing treatment options.

### 4. Your stories

| Users | Helpful score | Indicators |
|---|---|---|
| **4,976** | **N/A** | **Part of a community, less alone** |

Our stories page shares real-life experiences from others affected by brain tumours, offering comfort, hope and a sense of community to those feeling isolated or overwhelmed.

### 5. Brain tumour support

| Users | Helpful score | Indicators |
|---|---|---|
| **3,896** | **94.12%** | **Less alone, supported** |

The brain tumour support page connects people with practical and emotional support tailored to their needs, including coaching, resources and peer support, to help them feel less alone and more in control.

### 6. Glioblastoma treatments, trials and information

| Users | Helpful score | Indicators |
|---|---|---|
| **3,623** | **70.83%** | **Resourced, engaged with clinical care** |

These glioblastoma pages give up-to-date, trustworthy information on glioblastoma care, research and clinical trials, helping people make informed decisions and access the latest options.

Together these web pages offer clear, compassionate and practical support for anyone affected by a brain tumour. From understanding symptoms, diagnosis and tumour types to navigating complex treatment options, like those for glioblastoma, the pages provide reliable information tailored to real experiences.

Here is an overview of our most popular resources for both patients and caregivers, and for healthcare professionals. This data provides us with the insight to better empower the brain tumour community with the support and information it needs around fatigue, behaviour and personality change and navigating clinical care.

### Top five resources: patients/caregivers (April 2024 – March 2025)

| Rating | Resource name | Units dispatched |
|---|---|---|
| 1 | My Fatigue Book | 400 |
| 2 | Behaviour and Personality Change | 352 |
| 3 | Patient Guide 5: Follow-up | 320 |
| 4 | Patient Guide 4: Treatment | 316 |
| 5 | How to hold a difficult conversation | 293 |

The most accessed resources by brain tumour patients and caregivers reveal the wide-ranging needs faced by those affected. The high demand for My Fatigue Book highlights how common and disruptive fatigue is, offering reassurance and practical strategies that help patients feel less alone and more in control. Similarly, the popularity of the Behaviour and Personality Change guide reflects the emotional impact of cognitive and behavioural changes on both patients and caregivers, helping families understand and adapt to what can be distressing changes in identity and communication.

The strong uptake of both Patient Guide 4: Treatment and Patient Guide 5: Follow-up points to a consistent need for clear, accessible information throughout the care journey, from diagnosis through to long-term monitoring. These resources help reduce anxiety and empower patients to engage with their treatment and recovery. Additionally, the demand for the How to hold a difficult conversation book shows the importance of supporting open, compassionate communication during some of the hardest moments families may face. These resources demonstrate the value of practical, empathetic information in helping people navigate not just the clinical aspects of a brain tumour diagnosis but also the emotional and everyday challenges the community faces.

**Top five resources: healthcare professionals (April 2024–March 2025)**

| Rating | Resource name | Units dispatched |
|---|---|---|
| 1 | My Fatigue Book | 656 |
| 2 | Behaviour and Personality Change | 343 |
| 3 | My Radiotherapy Book | 244 |
| 4 | Who's Who in Your Clinical Team | 216 |
| 5 | What to Expect If You Are Diagnosed leaflet | 202 |

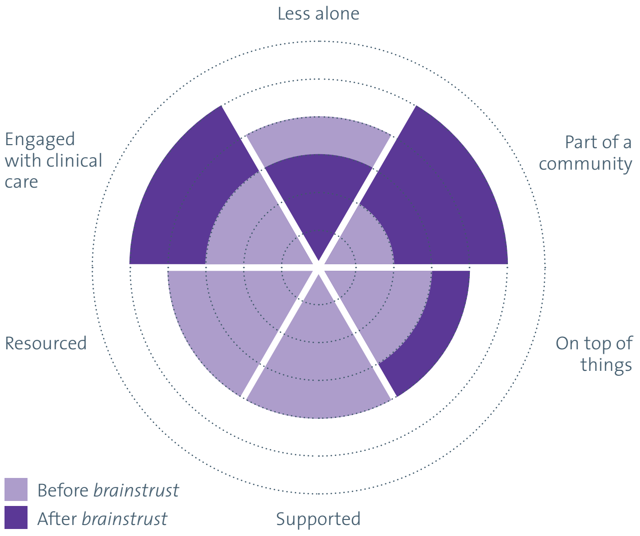
The resources most frequently ordered by healthcare professionals reflect a commitment to providing patient-centred support beyond the clinical. My Fatigue Book, the most widely accessed, highlights how commonly fatigue is raised in consultations and how vital it is for professionals to offer patients something tangible to help them manage this invisible yet debilitating symptom. Similarly, the use of the Behaviour and Personality Change guide suggests that healthcare professionals are actively supporting families through some of the more emotionally challenging effects of brain tumours, equipping them with information and reassurance that these changes are medically understood and manageable.

The popularity of My Radiotherapy Book indicates a focus on preparing patients for treatment with clear, accessible explanations and helping to demystify radiotherapy and reduce fear. The Who's Who in Your Clinical Team book plays a crucial role in bridging communication gaps, helping patients and families understand the roles of various specialists involved in their care. Lastly, the What to Expect If You Are Diagnosed leaflet demonstrates the importance of meeting patients at the very start of their journeys with calm, compassionate guidance. These top resources show how healthcare professionals are not only treating the disease but also working to ensure that patients and caregivers feel resourced, supported and on top throughout the process.

## Meet David

David came to us in late 2024, having received news he would be going into a biopsy to remove a high-grade brain tumour. David received immediate email support from one of our support specialists and was set up quickly with a peer supporter who could offer relevant information and reassurance for his situation.

After a few months, David felt a huge improvement in terms of feeling part of a community, as well as feeling more engaged with his clinical care and on top of things. Over time, we identified that this journey had made him feel more lonely, which is an area his assigned support specialist aims to tackle together with David moving forward.



*Together, our web pages and resources work to create a more seamless and effective journey for beneficiaries looking to feel more on top and in control. From offering support at diagnosis to promoting awareness through our various pages, we ensure that our support service works efficiently, with every person who needs us having access to exactly what they need, when they need it.*

**Adam Thomson**
Impact Officer

# PRIME: Patient Research Involvement Movement

**PRiME** Patient Research Involvement Movement

**In 2021, we launched the Patient Research Involvement Movement (PRIME) to close the gap between the clinical research community and people affected by brain tumours. PRIME helps ensure clinical research is shaped by the real experiences of patients and caregivers – making trials more relevant and fundable, and ultimately improving treatment options for the brain tumour community.**

The PRIME community continues to grow steadily. Starting with 53 advocates and partners, we grew the community to 115 in 2022, to 151 in 2023, and now 168 in 2024. These people have experienced life with a brain tumour. They are engaged and research-primed. They bring invaluable insight to the research process and are delivering top-level support across brain tumour studies.

We're raising the standard of patient and public involvement and engagement (PPIE) in clinical research, while growing and evolving the service. Our efforts include:

- collaborating with other charities, such as Brain Tumour Research
- exploring new ways to connect clinicians with our services
- engaging in more discussions with researchers and funders to secure investment in this vital work
- expanding our training and webinar programme for volunteers
- continuously adapting how we deliver the most impactful involvement.

Brain Tumour Research

Since its inception, PRIME has successfully supported research applications to the value of over £30m, with partners who include:

Cochrane

NIHR | National Institute for Health Research

UNIVERSITY OF LEEDS

University of BRISTOL

UNIVERSITY OF CAMBRIDGE

UNIVERSITY OF LIVERPOOL

THE UNIVERSITY of EDINBURGH

CRAF Cancer Research Advocates Forum UK

Coventry University

# Moving forward

**As we look ahead, our focus is on sustaining and deepening the impact we've already made, while ensuring no one affected by a brain tumour is left behind. We're working to create and support prompter, fairer access to both emotional and clinical support, recognising that timely intervention can make all the difference in a person's ability to regain control. Too often people describe the experience of being left to navigate the aftermath of treatment with little guidance or clarity. We're determined to bridge that gap by offering continuity, clarity and compassion when it's needed most.**

Our new strategy is built around scale and opportunity: reaching more people, at the right time in their journeys, and providing meaningful support that grows with their needs. To do this well, we're also evolving how we understand and demonstrate our impact. By making our data more robust and responsive, we'll not only refine our own services but strengthen the case for systemic change across the wider landscape. Progress, for us, means helping people move forward with confidence, and building a future where no one is left to face a brain tumour diagnosis and journey alone.

> *I love [the* brainstrust *meet-ups], because we are all so forgiving and supportive. It is one place in our lives where we can be honest. No keeping up appearances, no societal expectations, and a wealth of knowledge and understanding. Thank you.*
>
> **Patient**

*I reached out to* brainstrust *during a period of intense depression that followed a string of complications after my meningioma was removed. I was supposed to be one of the lucky ones, but I didn't feel like it. Mariel has been completely amazing: our coaching sessions got me through that difficult time, and she also set me up with a peer supporter, who has been equally wonderful. I don't really know what I would have done without this support, which was offered when I really needed it.*

**Patient**

brainstrust
the brain cancer people

Trusted Information Creator
Patient Information Forum

Registered with FUNDRAISING REGULATOR