

**When I am
a patient, I am
dependent.**



**When I am
a person, I am
resourceful.**

Help on your brain tumour journey

Find out how *brainstrust's* proven support can help you and the people you care for.



Let us show you how it feels to thrive.

We believe in a world where people with a brain tumour and their loved ones are involved, resourced, confident and connected. They are living the lives they want, to the best of their potential, because they are people first, and patients and caregivers second.

We provide personalised support and build resources that help people with a brain tumour and their loved ones live the lives they want after diagnosis.

We have divided this catalogue into four areas. Each section will include details of our support and resources that will help you feel:

- **on top of things, not overwhelmed**
- **prepared, not panicked**
- **confident, not confused**
- **included, not isolated.**

Get in touch:

email hello@brainstrust.org.uk or call 01983 292 405

'I can't tell you how much better it has made me feel just reinforcing that I'm not alone and there's a whole community out there.'



Feel on top of things, not overwhelmed

In this section, you will find information and support services to help you feel better supported and on top of things.

‘Without the counselling, I would not have been able to face my neuro appointment with such positivity and hope.’

24/7 helpline

At times of distress and fear, it can be difficult to know where to turn to and who to talk to.

The *brainstrust* helpline offers people with a brain tumour and their caregivers, support, information and pragmatic advice over the phone and by email 24 hours a day, 7 days a week.



Call 01983 292 405 or email hello@brainstrust.org.uk for 24/7 support

‘I honestly can’t tell you what a weight this has lifted. I’ve been really alone since my last consultation, as I feel like I’m burdening friends and family by discussing it over and over, but at the same time, it’s such a huge decision that I don’t want to make on my own. This consultation will honestly be amazing and will help me so much.’

Coaching to help you cope

We know that when life feels all-consuming by a brain tumour diagnosis, coaching helps you to take control and focus on the things that matter the most. You will come away from your coaching sessions with strategies and tools to help you achieve clarity and improve your quality of life.

As trained coaches, our support specialists will help you to identify how to make change happen. They will work with you to identify what you need to do to help you feel in control. This can mean helping you to identify what questions you need answered, what you value most, and who's on your team to give support when you most need it.

'Today I am taking your very good advice – I have written down my priorities, and I am going to sort them out one by one. That might sound very black and white, but my goodness, it's a good feeling that it just might get me somewhere. What you have said to me is brilliant! I know what I am doing.'

Find out more: brainstrust.org.uk/coaching
or email hello@brainstrust.org.uk

Sign up to coaching with Thrive

Thrive enables you to build up structure and direction with the support you receive. The platform allows you to choose when the sessions take place and what they focus on.

This means you can define a clear pathway to help you achieve your goals. As a video platform, you also see your support specialist during the sessions, so you feel as connected as possible with your coaching journey.



Find out more and sign up now: brainstrust.org.uk/thrive



Rapid-access counselling

When you find yourself in a time of distress and are struggling to cope, our rapid-access counselling service can help you to make sense of your situation and focus on specific, immediate goals. We can quickly connect you to a network of counsellors and give you the space to talk through your feelings in a safe and confidential place.

Find out more: brainstrust.org.uk/counselling

Hypnotherapy

Hypnotherapy can be used as a complementary therapy alongside conventional medical treatments for a number of purposes. It can help to manage anxiety and stress, build resilience and confidence, and reduce the side effects of treatments.

Find out more: brainstrust.org.uk/counsellinghypnotherapy

*‘Facing your own mortality is a big thing
when you’ve got young family.’*

Feel prepared, not panicked

In this section, you will find details of resources that will help you to feel better resourced.

brainstrust
Introduction

'From the moment my son was diagnosed with a tumour, and we contacted brainstrust, in what was the darkest hour of our lives, the charity gave us hope.'

The brain box

The *brainstrust* brain box is the must-have toolkit for people living with a brain tumour diagnosis. It contains a number of essential things to support you and help you feel better resourced and more in control.



Order a brain box: brainstrust.org.uk/the-brain-box

'brainstrust was my first port of call after my diagnosis – the brain box turned out to be a lifeline I could never forget.'

Brain tumour Know Hows

Our brain tumour Know Hows allow you to access concise, clear and impartial information about topics related to life with a brain tumour diagnosis, including dealing with the overwhelm, cannabinoids, how to prepare for medical appointments and living with uncertainty. They provide an excellent starting point so you can fully engage with issues faced by our community.

Access them here: brainstrust.org.uk/knowhows

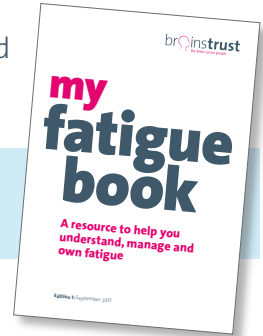


Managing fatigue

'My fatigue book' is a resource that will help you understand fatigue that comes from a brain tumour diagnosis – what we mean by fatigue, why people living with a brain tumour get fatigue, and the challenges of living with fatigue. This resource will enable you to explore strategies so that you can manage fatigue and your quality of life will improve.

Get your copy:

brainstrust.org.uk/my-fatigue-book



Coping with behaviour and personality change

Behaviour and personality change as part of a brain tumour diagnosis can make people feel disempowered, helpless and daunted. The 'Behaviour and personality change' resource will help you understand behaviour and personality change, the causes, and how it manifests. It will also enable you to explore strategies to help you cope with these changes.

Get your copy:

brainstrust.org.uk/bpc-resource



How to hold a difficult conversation

The 'How to hold a difficult conversation' guide helps families approaching the moments of explaining a brain tumour diagnosis and holding those difficult conversations. It features tips that will help you get your thoughts together and clarify how you feel about what it is you are facing, so that you can hold better conversations and feel more in control.

Access it here:
brainstrust.org.uk/difficult-conversations



The brain tumour hub

The brain tumour hub is an easy-to-navigate database of brain tumour support resources and UK-based brain tumour clinical trials. It enables you to find support services in your area based on the type of support you want to access.



Access it here: braintumourhub.org.uk



'I suddenly feel I'm not on my own.'

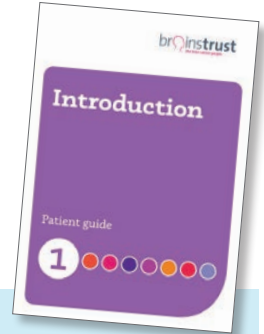
Feel confident, not confused

In this section, you will find details of resources and services that will help you feel more engaged with your clinical care.

'When you hear the words 'you have a brain tumour', your life changes in a split second. Having brainstrust there has helped me to deal with it, and I will be forever grateful.'

The brain tumour patient guide

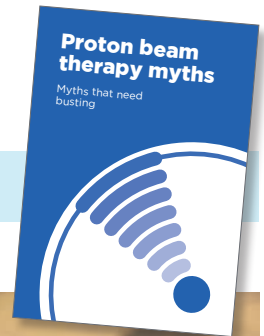
The brain tumour patient guide is a comprehensive, easy-to-understand guide to the adult brain tumour care pathway. It is designed to help you know what to expect and to help you feel more in control of your journey. It is written in eight sections, to be used individually or as a complete set.



Get your copy: brainstrust.org.uk/patient-guide

Proton beam therapy

The proton beam therapy guide is written in 10 easy-to-understand sections that can be used individually or as a complete set. These booklets will dispel many of the myths that have developed over recent years, and they will help you to understand more about proton beam therapy and make informed decisions about proton beam therapy as a treatment.



Get your copy: brainstrust.org.uk/pbt



Who's who in your clinical team

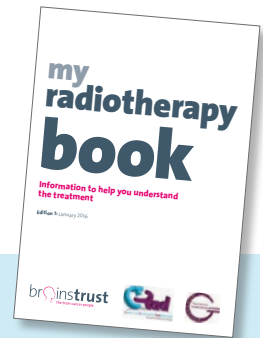
'Who's who in your clinical team' is our guide to medical professionals that you may meet along your journey. This useful guide can help you to navigate your pathway and keep track of essential contacts within your clinical team.



Get your copy: brainstrust.org.uk/who-is-who

Understanding radiotherapy

'My radiotherapy book' outlines and explains the range of radiotherapy treatments that are currently available, to help you feel more informed about this type of treatment and what may be the best option for the type of brain tumour you are living with.



Get your copy:
brainstrust.org.uk/radiotherapybook

Helping you seek a second opinion

Second opinions can help with decision-making, and it is your right to seek them. What is right for one person may not be right for the next, but the key is knowing what your options are. There are different routes that you can take to get a second opinion, and this is where we can help.

Find out more: brainstrust.org.uk/second-opinions



'The guidance they gave meant my son underwent an awake craniotomy after we were told his tumour was inoperable. Through brainstrust we have felt supported and much more empowered. We can never thank you enough and will always feel indebted to you. Thank you brainstrust!'

Feel included, not isolated

In this section, you will find details of services that will help you to feel less alone and more part of a community.

'Hearing other people's experiences and realising that I'm not alone in many of the thoughts that go through my head has really helped me. Although I can't control what is happening to me, I feel I now have a better understanding of a way to approach things, and a framework of things to try.'



Thrive with *brainstrust* webinars and workshops

‘Thrive with *brainstrust*’ webinars and workshops are meticulously curated by *brainstrust* and hosted by leading experts to help you tackle the challenges that make life with a brain tumour so hard.

‘Thank you so much! You’ve opened up a new avenue for me that just wasn’t coming from the GP or hospital. This was so helpful for me, as I’m trying to learn about the future.’

Find out more: brainstrust.org.uk/events

‘The webinar helped me understand and find a solution to an ongoing problem that no one has been able to help me with.’

Connect with others at a Meetup

Meetups are an opportunity for you to connect with others who understand, in a more informal setting. No matter where you are on your journey, you can share experiences and seek information from people who know what you’re going through.



Find out more: brainstrust.org.uk/events

Peer support

Through our informal peer support service, we can connect you with someone else in the same situation, or someone who has been there, so that you can share experiences and support one another.

Find out more: email hello@brainstrust.org.uk or call 01983 292 405

Facebook support group

Come and join our welcoming and supportive online community in our closed and carefully moderated Facebook group. With over 2,500 members, it is a safe space for you to share experiences and support others.

Join the group:

facebook.com/groups/braintumoursupportbrainstrust

Support for caregivers

We know that caregivers play a key role in seeking support and information related to a brain tumour diagnosis. We also know that caregivers need support themselves. Our website has dedicated information that will help caregivers feel better resourced, less alone and more part of a community, more engaged with the clinical care of their loved one, and more supported and on top of things. You don't need to feel alone as a caregiver.

Visit: brainstrust.org.uk/caring

'You truly are a ray of light and the support we need at this time, as my father and I feel very much alone in caring for my mother.'

brainstrust's Patient Research Involvement Movement (PRIME) brings people closer to brain-tumour-focused research, and the research closer to people.

PRIME actively supports the research community with its work to secure funding and therefore more investment for research, and it ensures clinical research projects are aligned with patient needs. *brainstrust's* PRIME has also helped to attract £17m of investment into brain tumour research.

**Find out more: brainstrust.org.uk/prime
or email hello@brainstrust.org.uk**

Clinical engagement

Working with healthcare partners is an important part of our strategy, so that you have the support and resources from us that will allow you to best support your patients.

Our current strategy, 'first, we are people', which was launched in 2019, sees us work to eliminate isolation, grow involvement with care and the condition, reduce fear, and improve knowledge and understanding.

We do this through events, coaching, training, information and advocacy, collaborating wherever possible.

By connecting with *brainstrust*, you can provide your patients with trustworthy information and personalised support, and there are opportunities to share your expertise and enhance your portfolio by helping to review our resources or speak at our events.

**Find out more: brainstrust.org.uk/healthcare-partners/
or email hello@brainstrust.org.uk**

little brainstrust is here to support families where a young person or parent has a brain tumour.

Coaching

We provide a unique coaching-led support service by phone or email, helping families overcome challenges and find the best possible outcomes for their child and family.

Community

We can help families feel less alone by creating communities of peer support through local events and our closed Facebook support group. Visit www.facebook.com/groups/littlebrainstrust to request an invitation to the group. This allows families to connect and share experiences with others who really understand.

Resources and information

We have a range of useful, practical resources that are endorsed by the clinical community, to help bring clarity, relief and hope when families are feeling overwhelmed. For more information visit www.littlebrainstrust.org.uk



For more information on *little brainstrust*, contact hello@brainstrust.org.uk or call 01983 292 405

'I can't tell you how reassuring it is to have you on the other end of the phone; there are a handful of good organisations, but brainstrust offers personal, realistic support. And you instinctively understand the challenges we feel.'

There are over 80,000 people living with a brain tumour in the UK. *brainstrust* is the charity and the community that's here to help these people and those who look after them, whoever they are and no matter where they are on their journey.

Get in touch today for 24/7 help on **01983 292 405**
or email **hello@brainstrust.org.uk**.

www.brainstrust.org.uk

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