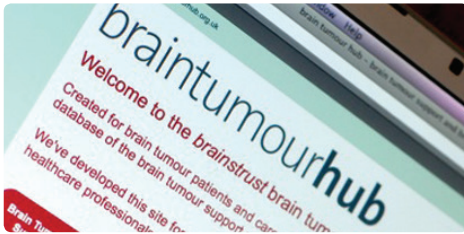
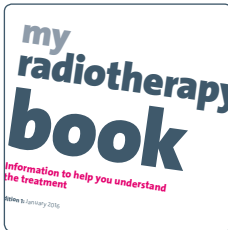


# What we do to help people living with a brain tumour

## brainstrust support catalogue



Resources to help you feel more in control



“I have got more information and support from talking with you in the last five minutes than I have ever had before.”

Neil



Resources to help you feel less alone



Practical resources you can pick up

“This was our first brainstrust Meetup and we were struck by the warmth and openness of this diverse group, and to know that we are not alone. Everyone was so willing to share information, which is brilliant.”

Diane

Resources to keep you informed

“Received the brain box yesterday – I cried with happiness. What a lovely box of surprises!”

Ella





**Hearing the words ‘you have a brain tumour’ leaves you in need of support from people who not only understand that fear but also know how best to overcome it. Everyone in the *brainstrust* community has experience of what it is like to be diagnosed and live with a brain tumour. At times it may feel like you are alone. You aren’t; we can help you feel less isolated.**

We’re always talking with the brain tumour community in order to understand the real challenges that you face when living with a brain tumour. We know, for instance, that not knowing what to expect after treatment is a real worry. We also know that you want better conversations with your clinical teams. And we know that living a good quality of life is of utmost importance. We thus tailor our support to meet these specific needs and help you face the many other challenges that follow a diagnosis.

**We’ve divided this catalogue into four areas:**

- **Resources to keep you informed** – these will help you fully understand your diagnosis so that you can confidently make your own choices.
- **Resources to help you feel more in control** – because more control can mean a better outcome. We know.
- **Practical resources you can pick up** – these include information that you can store and access at any time.
- **Resources to help you feel less alone** – *brainstrust* is very much a community. And we know how important it is to share experiences and be with people who truly understand what you’re going through.

Below are examples of these different forms of help available to you from *brainstrust*. Don’t hesitate to get in touch and talk to people who have been where you are now. We’ll help you get back on top of things.

# Resources to keep you informed

## 24/7 helpline

We know that the time you most need to talk to someone isn't always 9–5. We've been there. We know the fears that come at all hours, and that's why you can call us anytime. Open 24 hours a day, 7 days a week, the *braintrust* helpline offers people with a brain tumour and their carers support, information and pragmatic advice over the phone and

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

“I have got more information and support from talking with you in the last five minutes than I have ever had before”

Neil

## Information Standard certified information

Our website **www.braintrust.org.uk** and printed information features clear, accurate, balanced, evidence-based and up-to-date information, certified by the Information Standard.



## Helping you to understand the implications of the diagnosis

A brain tumour diagnosis can be very scary, and it is difficult to identify what you need and want to know. We can chat through the impact with you to help put you back in control.

## Interpretation of medical records

Medical jargon and terminology may be used in the records. If you choose to look at your records (and you are entitled to), you may need help understanding them, so interpretation can be provided. Visit our glossary [www.brainstrust.org.uk/glossary](http://www.brainstrust.org.uk/glossary), contact *brainstrust* on [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk) or call **01983 292 405**.

## Helping you seek a second opinion

Second opinions can help with decision-making, and it's your right to seek them. But we are mindful that everyone reacts to a serious diagnosis in different ways. We know that some people would prefer to know as little as possible about their diagnosis. Others like as much information as possible so that they can weigh up their options. We can only talk from our experience when we say that can be reassuring. We believe that you need to be informed to make decisions. And that might mean gathering information and then deciding not to make a decision. That's a decision too! For more information on second opinions, visit 'Just been told?' on [www.brainstrust.org.uk/symptoms](http://www.brainstrust.org.uk/symptoms).

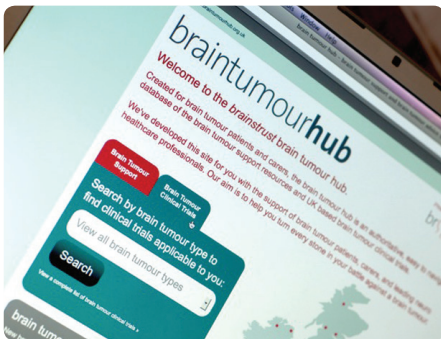
## Clear signposting

What do you want to know? *brainstrust* can point you towards valuable and trusted resources to help navigate your journey.

## [www.braintumourhub.org.uk](http://www.braintumourhub.org.uk)

Created for people with a brain tumour and their carers, the brain tumour hub is an authoritative, easy-to-navigate database of brain tumour support resources and UK-based brain tumour clinical trials. It is intuitive, easy

to use, developed with clinicians, patients and carers, and constantly evolving with regular updates.



# Resources to help you feel more in control

## The brain tumour patient guide – know what care to expect on your journey

What care should you expect as a brain tumour patient? Good question. For some answers, check out the brain tumour patient guide. *brainstrust* has published the first comprehensive, easy-to-understand guide to the adult brain tumour care pathway, to help you know what to expect and to feel more in control on your journey. It's written in eight easy-to-understand sections, to be used individually or as a complete set. It will be particularly useful to patients and carers before they embark on each stage of their journey.

Written alongside esteemed clinicians and expert patients and carers, and in accordance with NHS England's Information Standard, this guide is invaluable to people on the bewildering journey that comes with having a brain tumour. It is based on the NHS and National Institute for Health and Clinical Excellence (NICE) 2018 Improving Outcomes Guidance (or IOG) to help patients and carers understand:

- what happens at each point in the brain tumour pathway (i.e. diagnosis, treatment, follow up care)
- what the optimum standard of care is (according to the NHS and the IOG) at each point of the pathway
- what else *brainstrust* thinks you can expect – to help you make the most of the resources around you
- suggested questions you can ask clinicians (but only if you want to)
- what *brainstrust* can do to help.



Visit [www.brainstrust.org.uk/patient-guide](http://www.brainstrust.org.uk/patient-guide) to read the patient guide.

## Coaching

The support team at *brainstrust* uses a coaching approach. We listen, listen some more and then ask questions. We focus on helping you achieve specific immediate goals that relate to specific areas.

For example, weighing up the pros and cons of having a particular treatment, or overcoming a problem with caring. We also know that through coaching, clients can experience a sense of healing as they make courageous decisions about their lives. Coaching is about developing strategies and clarity to achieve a better quality of life.

## Counselling

When there is too much distress and a psychological intervention is needed, counselling can be useful. It is suitable for someone who is struggling to cope or feeling very anxious and therefore finding it hard to focus on specific immediate goals. *brainstrust* has a network of counsellors who can help you make sense of your situation so that you can make better decisions about the future.

## Hypnotherapy

There is plenty of evidence that hypnotherapy helps people with cancer and those who care for them. Hypnotherapy can be used as a complementary therapy alongside conventional medical treatments for a number of different purposes. It can help to manage anxiety, reduce stress, build confidence and optimism, prepare for surgery and promote post-operative healing, reduce the side effects of treatments, optimise a healthy lifestyle and build resilience.

For more information about each of these services, just visit [www.brainstrust.org.uk/counsellinghypnotherapy](http://www.brainstrust.org.uk/counsellinghypnotherapy).

## How to hold a difficult conversation

We know how hard it is, explaining brain cancer and having to hold those difficult conversations. This guide helps families with approaching these moments. It features tips that will help you get your thoughts together and clarify how you feel about what it is you're facing so that you can hold better conversations and feel more in control. Visit [www.brainstrust.org.uk/advice-resources](http://www.brainstrust.org.uk/advice-resources) to read the difficult conversations guide.

# Proton beam therapy guide

Written alongside esteemed clinicians, scientists and expert patients and carers, and in accordance with NHS England's Information Standard, the proton beam therapy guide is invaluable if you want to understand more about this treatment. These booklets have been written to tackle the popular questions, dispel many of the myths that have developed in recent years and, first and foremost, to help you make informed decisions about proton beam therapy with the most balanced and up-to-date information to hand.

This information has been created to help people:

- feel more confident about PBT
- be more informed and engaged in their situation
- either be assured they are on the best care pathway or feel comfortable and confident in exploring further options
- understand how *brainstrust* can help
- know where further help and information may be available to them.

To order printed copies of this information, simply call us on **01983 292 405** or email **hello@brainstrust.org.uk**, stating which guides you'd like to receive and where you need them sending.





# Practical resources you can pick up

## Brain box

The *brainstrust* brain box is the ‘must have’ support and information toolkit for people with a brain tumour diagnosis and their carers.

“Received the brain box yesterday – I cried with happiness. What a lovely box of surprises!”

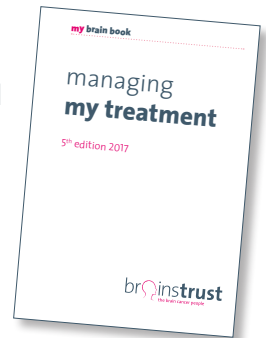
Ella



We appreciate how difficult things can be once you or a loved one are diagnosed with a brain tumour. So to assist brain tumour patients, we provide this unique, invaluable aid. Request a brain box at [www.brainstrust.org.uk/the-brain-box](http://www.brainstrust.org.uk/the-brain-box).

## My Brain Book

As the patient journey unfolds, you will need to record lots of things. This is a place for you to do just that. In this patient folder, you can record information about yourself, about the team that are looking after you, you can record appointments and outcomes, and there's also plenty of space for you to jot down those questions that pop into your head in the early hours. Patients can also keep a disc of their brain scans in here, and there's also a pocket in the back of your brain book where you can file letters, or receipts for travel expense claims. Give us a call on **01983 292 405** to get your hands on a copy of the *brainstrust* Brain Book.



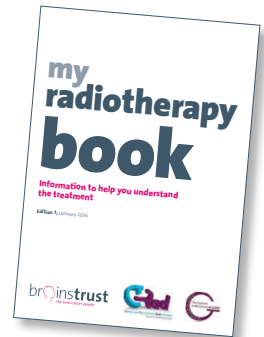
## Little White Book

A comprehensive, easy-to-navigate compendium of UK brain tumour support resources. These are produced regionally. Read more about the Little White Books at [www.brainstrust.org.uk/advice-resources](http://www.brainstrust.org.uk/advice-resources).



## My Radiotherapy Book

This outlines and explains the range of radiotherapy treatments that are currently available so that you know what might be the best treatment for the type of brain tumour you are living with, whether you are a carer or a patient. Download a copy of the book at [www.brainstrust.org.uk/radiotherapybook](http://www.brainstrust.org.uk/radiotherapybook).



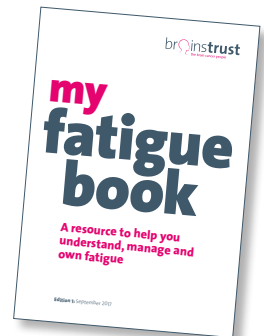
## Who's Who in Your Clinical Team

Many patients find that they are left to manage their care pathway for themselves. *brainstrust* has developed this handy resource to outline the healthcare professionals who may be involved in your care, and it tells you what it is they can do for you. The resource is available to download at [www.brainstrust.org.uk/who-is-who](http://www.brainstrust.org.uk/who-is-who).



## My Fatigue Book

We know that fatigue is the number one concern of patients and caregivers who are living with a brain tumour. This is a super resource that helps you to understand fatigue that comes from living with a brain tumour – what we mean by fatigue, why patients get fatigue, how fatigue that comes with a brain tumour is different from other fatigue and the challenges of living with fatigue. This book will enable you to explore strategies so that fatigue,



can be managed and quality of life is improved; you will own the fatigue rather than it owning you. [www.brainstrust.org.uk/fatiguebook](http://www.brainstrust.org.uk/fatiguebook).

## The Snaggle Tooth Splat

Written for *brainstrust* to help parent carers or patients broach a brain tumour diagnosis with their children. It is a beautifully illustrated book and has featured in the BMA newsletter and Oncology News. The foreword has been written by the lovely actress and *brainstrust* supporter, Julie Walters. If you are a parent who has been diagnosed with a brain tumour, or are looking after a poorly little patient, then you can have a copy of this book, for free. Call us on **01983 292 405** to request a copy of the book.



More information about each of these resources can be found at [www.brainstrust.org.uk/advice-resources](http://www.brainstrust.org.uk/advice-resources).

# Resources to help you feel less alone

## Meetups

At a *brainstrust* Meetup, members of the brain tumour community get together to have fun. No matter where you are on your journey or what role you have (such as carer, patient, health care professional), you can share experiences, and seek information from people who know what you're going through. But only if you want to. Feel free to just come along and enjoy. Past Meetups have involved pizza and wine, bowling, and cream teas. Visit [www.meetup.com/brainstrust](http://www.meetup.com/brainstrust) to see a list of upcoming Meetups across the UK.

“This was our first *brainstrust* Meetup and we were struck by the warmth and openness of this diverse group, and to know that we are not alone. Everyone was so willing to share information, which is brilliant.”

Diane

*meetup*

## **brainstrust events**

We run a whole range of events to help you feel less alone and better resourced. These range from being small and cosy to grand conferences. There's something for everyone, and we build in lots of time for people to meet and chat. Cake is usually on the agenda too. These include:

- support groups
- health and wellbeing days
- information events around hot topics such as cannabinoids and immunotherapy
- national symposiums
- coaching workshops around key topics such as fatigue, dealing with the overwhelm, and behaviour and personality change.
- families and children's events
- research trial proposal focus groups
- caregiver events
- peer supporter training
- events for specific groups, e.g. counsellors or nurses.

For more information about any of these events, contact **hello@brainstrust.org.uk** or your regional support specialist. And keep an eye on the Meetup site: **www.meetup.com/brainstrust**.

## **Peer-to-peer support**

We know how important it is to be with others who truly understand. Our informal peer-to-peer service connects you with someone else in the same situation, or who has been there, so that you can share experiences and support one another. Contact **hello@brainstrust.org.uk** to become a peer or find out more about the service.

## Facebook *brainstrust* brain tumour support group

If you are on Facebook, you can join this closed support group where a lot of very friendly patients and carers hang out. It is a really warm and welcoming group who will comfort you, answer questions, make you smile and, importantly, are in the same boat as you.

Visit [www.facebook.com/groups/braintumoursupportbrainstrust](https://www.facebook.com/groups/braintumoursupportbrainstrust) to request an invitation to the group.

## Facebook UK brain tumour carers group

This is a group page for carers of people with a brain tumour in the UK. It can be very hard and lonely being a carer, so this group is for any carers to ask others questions, offer advice, have a general chat and good laugh or rant/sound off when you need to without offending or upsetting those you look after. Type in [www.facebook.com/groups/ukbraintumourcarers](https://www.facebook.com/groups/ukbraintumourcarers) to join the online carer community.

**For more information about any of these resources, visit [www.brainstrust.org.uk](https://www.brainstrust.org.uk), contact [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk) or call 01983 292 405.**





Production of *brainstrust's* information is supported by the Anna Horrell fund. Anna, wife and mum, tragically passed away in August 2017 after a valiant fight against a glioblastoma. Throughout her life and her illness, she was an inspiration to us all, fighting bravely and cheerfully in the face of adversity. She was the beating heart of our family, and her loss left a hole in our lives that can never be replaced. In her incredible memory, we are passionate about helping others diagnosed with a brain tumour to navigate this most difficult of journeys.

**Mike, Tom, Rebecca, Charlie & Sophie**

There are over 55,500 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.

We know we don't have all the answers, but chances are we know someone who does. Get in touch today for 24/7 help on **01983 292 405** or email **hello@brainstrust.org.uk**.

**[www.brainstrust.org.uk](http://www.brainstrust.org.uk)**

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