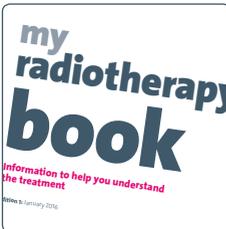


What we do to help people living with a brain tumour

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”

Patient



Resources to help you feel less alone



Practical resources you can pick up

“This was our first brainstrust Meet Up 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”

Patient



“Received the Brain Box yesterday – I cried with happiness what a lovely box of surprises!”

Carer



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 surgery 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 anytime.
- **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 help line

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 *brainstrust* help line 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@brainstrust.org.uk** for 24/7 support.

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Patient

Information Standard certified information

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



Help 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/advice-glossary.php, contact *brainstrust* on hello@brainstrust.org.uk or call 01983 292 405.

Help 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/advice-symptoms.php

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

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 new 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) 2006 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/advice-resources.php#patient-guide to read the patient guide.

Coaching

The team at *brainstrust* comprises trained coaches. We listen, listen some more and then ask questions. We focus on helping you achieve specific immediate goals, which 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

brainstrust has a network of counsellors to help you. 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 depressed and therefore finding it hard to focus on specific immediate goals. Counselling aims to help the individual make sense of the situation in which they find themselves, in order to make better decisions about what they want and need for 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. *brainstrust* works with hypnotherapists who want to help patients and carers.

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 can 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.php to read the Difficult Conversations guide.

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.

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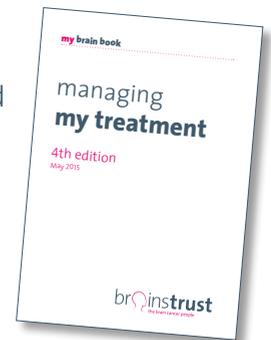
Carer



We appreciate how difficult things can be once you 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/advice-resources.php

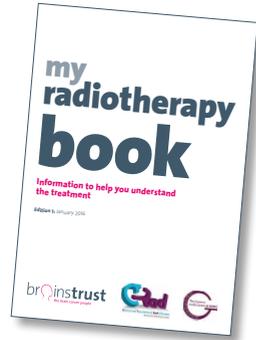
My Brain Book

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 292405** 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.php#5



My Radiotherapy Book

This outlines and explains the range of radiotherapy treatments that are currently available, so that you know what would 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/advice-resources.php#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/advice-resources.php#6



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 292405** to request a copy of the book.



More information about each of these resources can be found at www.brainstrust.org.uk/advice-resources.php

Resources to help you feel less alone

Meet Ups

At a *brainstrust* Meet Up, 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 Meet Ups have involved pizza and wine, bowling, and cream teas. Visit www.meetup.com/brainstrust to see a list of upcoming Meet Ups across the UK.



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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 to request an invitation to the group.

Facebook UK brain tumour carers group

This is a group page for carers of people with brain tumours 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 they look after. Type in www.facebook.com/groups/ukbraintumourcarers/ to join the online carer community.

For more information about any of these resources, visit www.brainstrust.org.uk contact hello@brainstrust.org.uk or call 01983 292 405

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

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