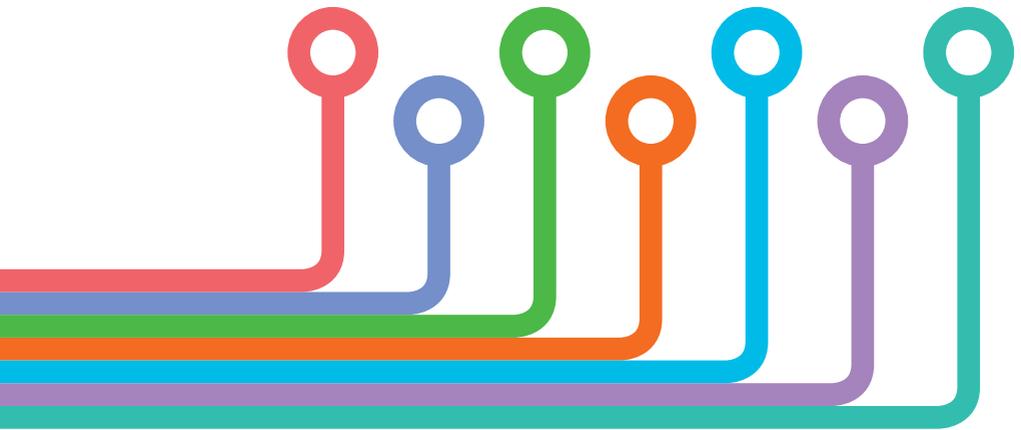


**Patient Guide**

# **Introduction**



# What is the Brain Tumour Patient Guide?

The aim of this guide is to make you – whether you are a brain tumour patient or their carer – feel more in control of the journey you're on. This can be a very scary time for everyone involved. In times like this, we are not always sure what we want and need to know, what we should ask and who we should turn to for additional help and information. To help you with this, this guide is intended to help you understand what to expect, offers useful signposting, and will make you aware of:

- what happens at each point in the pathway (i.e. diagnosis, treatment).
- what the optimum standard of care is (according to the NHS and NICE Improving Outcomes Guidance<sup>1</sup>) at each point of the pathway.
- what else *brainstrust* thinks you can expect – to help you make the most of the resources around you. This is over and above the optimum standard.
- suggested questions you can ask clinicians (but only if you want to).
- what *brainstrust* can do to help.

This guide reflects the adult pathway, although the suggested questions and sign posting maybe helpful for children with a brain tumour and their families.

## How might I use it?

You can refer to this guide at any point. It may be particularly useful before you embark on each stage of your journey, so that you know what to expect. You can compare the care offered with the ideal optimum standard. If you think something is missing in your care, share your concerns with your clinician. The suggested lists of questions are not comprehensive, but intended as a prompt should you need it. Before asking any questions, be aware of

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<sup>1</sup> NHS and National Institute for Health and Clinical Excellence, *Guidance on Cancer Services: Improving outcomes for people with brain and other central nervous system (CNS) Tumours*, 2006. This is a document published by the NHS and NICE. It gives advice on the service arrangements for people diagnosed with a brain or CNS tumour. It is referred to as the IOG.

what you're willing to hear. Always remember that once you have been given knowledge, this can't be undone. Only ask the questions that YOU want to know the answers to.

## How is it organised?

The guide is written in colour coded sections. You may choose to refer to just one, or many of them. Sections of the guide available are:

### 1 Diagnosis

### 2 Receiving diagnosis after biopsy

### 3 Treatment

- of low-grade glioma (grades 1 and 2 in the World Health Organization (WHO) classification).
- of high-grade glioma (WHO grades 3 and 4).
- of meningioma.

### 4 Follow-up

### 5 Survivorship

### 6 Palliative care

### 7 End of life care

You can download these guides at [www.brainstrust.org.uk](http://www.brainstrust.org.uk) or email [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk) or call **01983 292 405** for hard copies.

## Support available

At times it may feel like it, but you are not alone. Everyone in the *brainstrust* community has experience of what it is like to be diagnosed and to live with a brain tumour. We can help you to feel less isolated – we understand. Below are examples of the 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.

## What can *brainstrust* do to help?

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

### Resources to keep you informed

- **Information Standard certified information**

on our website [www.brainstrust.org.uk](http://www.brainstrust.org.uk). Clear, accurate, balanced, evidence-based and up-to-date information, certified by the Information Standard.

- **24/7 help line**

We know that you don't just need to talk to someone 9-5. We've been there. We know the fears and the need to talk to someone who understands at all hours. That's why you can call us anytime. Open 24 hours a day, 7 days a week, the *brainstrust* help line offers brain tumour patients and carers support, information and pragmatic advice over the phone and by email. Call **01983 292405** or email [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk)

- **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. Contact *brainstrust* on [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk) or call **01983 292405**.

- **Help you seek a second opinion**

We are mindful that everyone reacts to a serious diagnosis in different ways. It is your right to seek further opinions, and this will empower some people. Some people would prefer not to exercise this right. Some people prefer to know as little as possible about their diagnosis; some people like to relinquish control of their situation to others. All of these are perfectly normal and acceptable ways of coping. And seeking second, even third

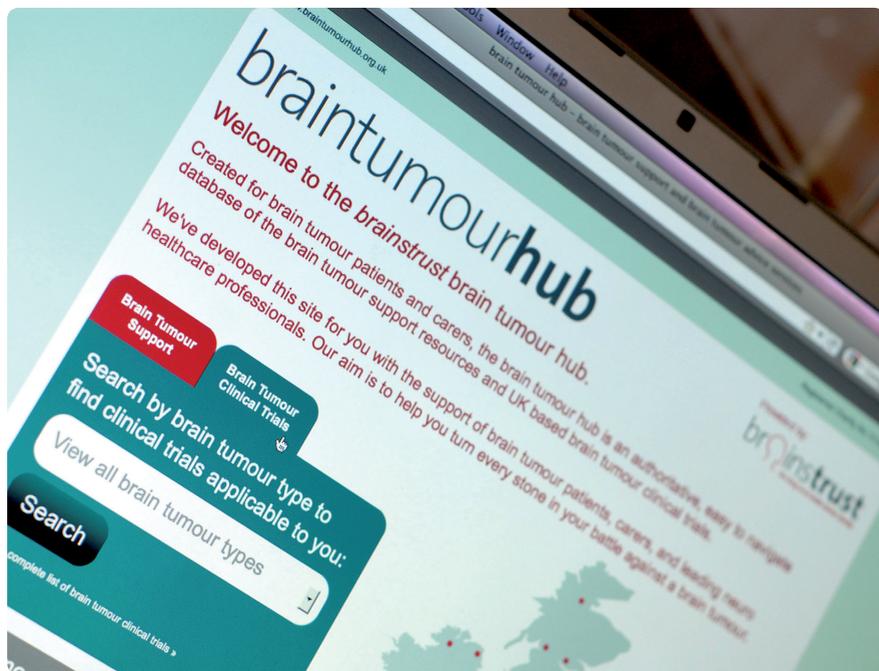
opinions can cause confusion and stress. But they can inform, and help with decision-making. They can also be reassuring. We can only talk from our experience. We believe that you need to be informed to make decisions. And that might mean gathering information and then deciding not to make a decision. That's a decision too! For more information on second opinions, visit 'Just been told?' on [www.brainstrust.org.uk/advice-symptoms.php](http://www.brainstrust.org.uk/advice-symptoms.php)

- **Clear signposting**

*brainstrust* can point you towards valuable resources to help navigate your journey.

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

Created for brain tumour patients and 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

- **Coaching**

At *braintrust* we listen, listen some more and then ask questions. We focus on achieving 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 and work. Coaching focuses on the future and the development of a workable solution. It's 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 depressed and therefore finding it hard to focus on specific immediate goals. Counselling has a broader focus and greater depth than coaching and so is usually a slower-paced intervention. It is concerned with the individual and their relationship to self, as well as with their family and communities. It is less solution focused than coaching (sometimes there is no solution to the problem) and instead 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. In some situations formal counselling may not be appropriate and instead a supportive listening relationship might be more useful.

- **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 and for a number of different purposes. Hypnotherapy can help brain tumour patients and carers to: manage anxiety, reduce stress, create a different experience of pain, build confidence and optimism, prepare for surgery and promote post-operative healing, reduce of side effects of treatments, e.g. nausea and fatigue, optimise a healthy lifestyle to build resilience.

## Practical resources you can pick up

- **Brain box**

[www.brainstrust.org.uk/advice-resources.php#2](http://www.brainstrust.org.uk/advice-resources.php#2)

The *brainstrust* brain box – the ‘must have’ support toolkit for people with a brain tumour diagnosis and their carers. We appreciate how difficult things can be once you are diagnosed with a brain tumour; the ‘4.00am moments’, the travelling to and from appointments, the stream of questions that pop into your head, trying to remember the jobs of all the people that you’ll meet on your journey, and knowing who to turn to and when. A juggling act that you don’t need when you just want to focus your energy on feeling better. So to assist brain tumour patients, we provide this unique invaluable aid.



- **Little White Book**

[www.brainstrust.org.uk/advice-resources.php#5](http://www.brainstrust.org.uk/advice-resources.php#5)

A comprehensive, easy to navigate compendium of UK brain tumour support resources.



- **Snaggle Tooth Splat**

[www.brainstrust.org.uk/advice-resources.php#7](http://www.brainstrust.org.uk/advice-resources.php#7)

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 forward 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.



- **Have you lost your way**

[www.brainstrust.org.uk/advice-resources.php#6](http://www.brainstrust.org.uk/advice-resources.php#6)

Many patients find that they are left to manage their care pathway for themselves. *brainstrust* has developed this handy resource to help you navigate your journey. It outlines all the healthcare professionals who may be involved in your journey and tells you what it is they do.



## Resources to help you feel less lonely

- **Meet Up**

[www.meetup.com/brainstrust](http://www.meetup.com/brainstrust)



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, pub grub, and cream teas.

- **facebook brainstrust brain tumour support group**

[www.facebook.com/groups/braintumoursupportbrainstrust/](http://www.facebook.com/groups/braintumoursupportbrainstrust/)

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.

- **facebook UK brain tumour carers group**

[www.facebook.com/groups/ukbraintumourcarers/](http://www.facebook.com/groups/ukbraintumourcarers/)

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 about care, offer advice, have a general chat, a good laugh or rant/sound off when you need to without offending or upsetting those they look after.

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

With sections for patients and carers, the forum is a great place to get talking, seek support and answers to all sorts of questions.



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