

1

Introduction

Patient Guide

What is the Brain Tumour Patient Guide?

The aim of this guide is to help you feel more in control of the journey you're on – whether you are the person living with the brain tumour or a carer, family member or person important to them. 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 to whom we should turn 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 is likely to happen next and at each point in the pathway, which can be different for each person (i.e. diagnosis, treatment)
- what the optimum standard of care is (according to the NHS and NICE Improving Outcomes Guidance^{1,2}) at each point of the pathway
- what else *braintrust* 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 *braintrust* can do to help.

This guide reflects the adult pathway, although the suggested questions and signposting may be helpful for children with a brain tumour and their families.

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1 National Institute for Health and Care Excellence. (2006). *Improving outcomes for people with brain and other CNS tumours*. [online] Available at: <https://www.nice.org.uk/guidance/CSG10> [Accessed 5 Jun 2018].

2 NHS and National Institute for Health and Care Excellence. (2018). *Brain tumours (primary) and brain metastases in adults*. Available at: <https://www.nice.org.uk/guidance/ng99> [Accessed 21 July 2018]. 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.

***brainstrust* patient guide**

This patient guide accurately reflects recommendations in the NICE guidance on brain tumours (primary) and brain metastases in adults.

National Institute for Health and Care Excellence

April 2019

How might I use the guide?

It is important to remember that this guide maps out the whole patient pathway, which might not be **your** pathway. There are over 140 different types of brain tumour, and people can live with a brain tumour for many years; they are not all life-limiting. So only refer to the guides that are relevant to your diagnosis. And remember that the pathway is not always linear.

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. For example, you may not know what choices you should have. This guide will help.

If you think something is missing in your care, share your concerns with your clinical team, i.e. your consultant or your GP, who is your primary NHS carer. Be mindful, though, that a GP may only see one person in their professional life who has been diagnosed with a brain tumour. This could be new territory for them too. The suggested lists of questions do not cover every topic but are intended as a prompt, should you need it. Before asking any questions, be aware of what you're willing to hear. Always remember that once you have been given knowledge, this can't be undone. Only ask the questions for which you want to know the answers.

How is it organised?

The guide is written in colour-coded sections. You may choose to refer to just one or many of them. Remember – not all of the sections will be relevant to you. Some never will be. Sections of the guide available are:

1 Introduction	5 Follow-up
2 Diagnosis	6 Survivorship
3 Receiving diagnosis after biopsy	7 Palliative care
4 Treatment	8 End of life care

You can download these guides at brainstrust.org.uk/advice-resources or email hello@brainstrust.org.uk or call 01983 292 405 for hard copies.

To find out what NICE has said on topics related to this guideline, see its web page: www.nice.org.uk/guidance/conditions-and-diseases/cancer/brain-cancers.

Support available

At times it may feel like you are alone, but you are not. 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, contact hello@brainstrust.org.uk or call 01983 292 405.

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.braintrust.org.uk/glossary, contact *braintrust* on hello@braintrust.org.uk or call 01983 292 405.

Helping you seek a second opinion

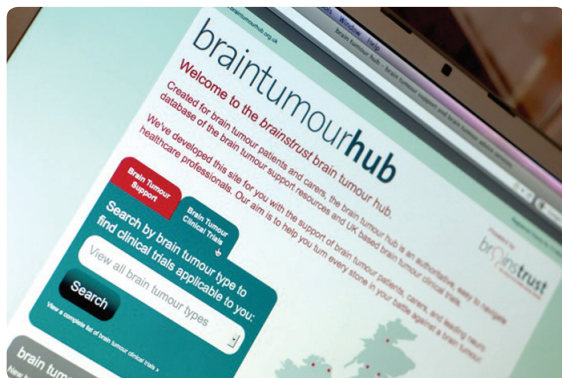
Second opinions can help with decision-making, and it's your right to seek them. But we are mindful that everyone reacts to a serious diagnosis in different ways. We know that some people would prefer to know as little as possible about their diagnosis. Others like as much information as possible so 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.

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 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 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.

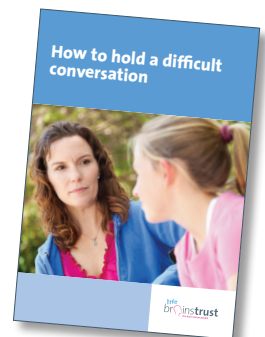
Hypnotherapy

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.

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 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.

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.



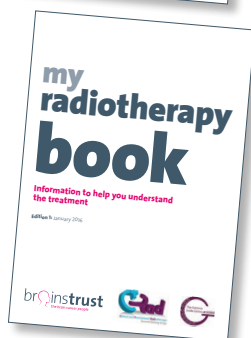
Little White Book

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.



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.

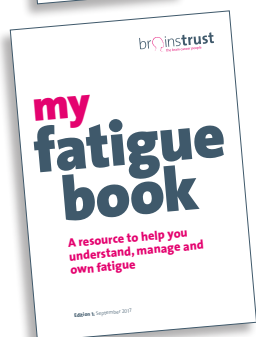


Who's Who in your Clinical Team

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.

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.

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.

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 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 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 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.



Production of *braintrust*'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

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