

Introduction

Patient guide

1



What is the *brainstrust* 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 caregiver, 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, to offer useful signposting and to 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 *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 signposting may be helpful for children with a brain tumour and their families.

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 1 Aug 2021].

2 National Health Service 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 1 Aug 2021]. 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.

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 prompts, should you need them. 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 the sections will be relevant to you. Some never will be. Sections of the guide available are:

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

You can download these guides at brainstrust.org.uk/resources/downloads, 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 guide, see its web page: www.nice.org.uk/guidance/conditions-and-diseases/cancer/brain-cancers.



How can *brainstrust* help?

We believe in a world where people with a brain tumour and their loved ones are involved, resourced, confident and connected.

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

“ 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. ”

Get in touch:

email hello@brainstrust.org.uk

call **01983 292 405**

visit our website:

www.brainstrust.org.uk

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***braintrust* patient guide**

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

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