



Newly diagnosed – knowing what to ask

brainstrust information sheet

Know Hows are published by *brainstrust* to help people living with a brain tumour to understand current topics. They are produced with input from relevant scientific and clinical experts and are written in a way that should help you to understand often complicated topics.

If you have an idea for a Know How, then please let us know.

If you have any queries, don't forget you can talk to one of our support specialists on **01983 292 405**, or email **hello@brainstrust.org.uk**.

Why do we need this Know How?

Nothing can really prepare you for the news that you or someone you love has been diagnosed with a brain tumour. Whether you knew that something hadn't been quite right for a while, or whether it was a sudden discovery, it tears at the warp and weft of your life; it changes everything.

The route to receiving this diagnosis may look different for each person. You may have been experiencing some symptoms for a while, or it may have come out of the blue – referred to as an incidental finding. However you come to receive your diagnosis, you will find yourself in the shock of the new, wondering what this means and what is next.

In this Know How, we will explore some resources and information that can help you to find out what you need to know following a new diagnosis of a brain tumour, as well as the support that is available to you. We know it is better to look the tiger in the eye and have as much information as possible – it doesn't take the fear away, but it does help you to have more control over the situation.

What does this mean?

There is no right or wrong way to respond to the news that you or someone you love has a brain tumour – there's no rule book for this. The one certainty is that there is a team of people around you to support you, and we don't just mean your clinical team. When you receive life-altering news like this, it opens the door to new people entering your life and taking on roles to support you, and key people already in your life taking on new roles.

The concept of asking people for things is something that may not come naturally to some of us. When we make an ask of somebody else, we tend to worry about the implications for them rather than ourselves. In certain situations, you may need to look past this fear and think of the question 'What is the harm in asking?' Another thing you can do is put yourself in the shoes of the person you are asking – you'd want to help just as much as they do.

What to ask when you are diagnosed with a brain tumour

Before we go through what to ask, let's start with who to ask.

Clinical team

These will be the people who have delivered the news that you have a brain tumour. They are also the people who will be able to answer the more medically specific questions that you have.

First things first, you need to know what you are dealing with. There are many different types of brain tumours, and determining what type you have will guide what comes next, so if you haven't been told what type you have, ask this question. You can find more information about the diagnosis stage of the pathway [here](#).

Our 'Diagnosis' patient guide is a great resource, with suggestions for questions to ask. You can find this [here](#).

When you are first diagnosed, you may not know immediately what the next steps will be in terms of treating or monitoring the brain tumour. It is helpful to have access to information early on that can aid any decisions you may have to make in the coming weeks or months. Our 'Treatment' patient guide is a great resource to refer to at this stage of the pathway. You can find this [here](#).

If surgery is an option for you, then our Know How on tissue collection will provide you with information about this process, and it suggests questions to ask your clinical team. Asking these questions will make sure that any tumour tissue is preserved in the way that gives you the best options going forward. You can find this [here](#).

You may also find it useful to get yourself a separate notebook as a space to jot down any questions that may spring to mind and notes about upcoming appointments or treatment. Our 'brain book' is a great tool for keeping everything in one place. You can get one of these as part of our brain box, which you can register to receive [here](#).

One key question that you may find very helpful to ask your clinical team early on is 'Who can I go to with questions or concerns?' The answer to this will vary depending on your tumour type and hospital services. Make a note of this person's contact details so you have them to hand. 'Who's who in your clinical team' is our guide to medical professionals who you may meet along your journey. This useful guide can help you to navigate your pathway and keep track of essential contacts within your clinical team. Download your copy [here](#).

A good clinical team will want to explore options with you about next steps. It helps if you know what is important to you and what matters to you; this will help guide discussions so that any decisions made are shared between you. This is called shared decision-making. It is important that you own the decision about what happens next and that it isn't imposed upon you.

Family and friends

A good support network can be key to helping you deal with your brain tumour diagnosis. Support from family and friends can come in many different forms. Often people want to help but may not know what that help looks like.

Take your notebook and make a list. What do you need to do? What do you need help with? Who can you ask? In the early stages of diagnosis, it is usual to feel overwhelmed and not know where to start – this is where making a list and delegating tasks can prove helpful.

Our '[How to deal with the overwhelm](#)' Know How has some strategies that can also help with this.

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At *brainstrust*, we aim to support everybody living with a brain tumour diagnosis at any stage of the pathway. The sooner you know where to go for support, the more prepared and in control you can feel in relation to your diagnosis.

We are the people you can ask questions of, and if we don't know the answers, we usually know someone who does, and we can signpost you to reliable sources.

Our website also has a wealth of information designed to help you when you are living with a brain tumour diagnosis, and we have a variety of resources that you can access online, or we can send you copies in the post.

Take a look at our available resources [here](#).

Ask yourself

- What am I struggling with the most?
- Who is in my team?
- What does feeling supported look like to me?
- What do I need?
- What is missing?
- What do I want to know?
- What do I need to know?
- Who can help?

Contact

Talk to *brainstrust*. We can help. You can call, write, type, text. Email for help and support:

hello@brainstrust.org.uk.

Telephone: **01983 292 405.**

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