

# Who's who in your clinical team



## A small charity can make a big difference. We know.

We know how lost you can feel when you are told you have a brain tumour.

We know that there are going to be good days and bad days.

We know that it might actually get better.

But we know that maybe it won't.

Lost for words? We know.

Telling your child you have a brain tumour is hard. We know. And those 3 a.m. moments? We know about them too.

When you are diagnosed with a brain tumour, sometimes all you need is someone who understands. We know.

There are over 80,000 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 also know we don't have all the answers. But chances are we know someone who does. So get in touch today for 24/7 help on **01983 292 405**, email **hello@brainstrust.org.uk** or visit **www.brainstrust.org.uk**.

The information in this booklet is based on experience and also service guidance provided by NICE: *Brain tumours (primary) and brain metastases in over 16s* (July 2018). This information can be sourced at **www.nice.org.uk/guidance/ng99**

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## The following may help you get back on track

Please be aware that this information is based on experience, and things may vary from region to region.

The golden rule – keep records of everything. You will find that you (or someone who is prepared to take on this responsibility) will need to take on a ‘management role’. It is a bit like conducting an orchestra – everyone has a part to play, but not at the same time, or it becomes chaotic. This will just add to your anxiety and frustration. You may find the *brainstrust* website useful when navigating your journey: [brainstrust.org.uk](https://brainstrust.org.uk).

### Who’s who

Even before a diagnosis is reached, several people may already be involved in your situation. You would hope that everyone talks to everyone else, but that isn’t always the case. Most liaison is still done through letters. While this may seem archaic, it does actually work in the patient’s favour, because it means you can have copies of correspondence for your records. Ask for these at the outset. Some practitioners provide this information as a matter of course; for others, you may need to request it. Keep everything filed, in chronological order. This will enable you to keep your case history at your fingertips. You can also request a copy of your scans (about £30 a set). This is your data – it belongs to you.

And never, ever be afraid to ask for more opinions. You’ll need to make decisions, sometimes hard decisions. And you need to know that you made them with all the information at your fingertips. For guidance on how to seek a second opinion, visit [brainstrust.org.uk/second-opinions](https://brainstrust.org.uk/second-opinions).

## The GP

Your key contact will be your GP. This person is your port of call for those moments when everything seems to be stacked against you. This is the person who will fight your corner for you. They won't be an expert on brain tumours, but they will be an expert on patient care and will have your best interests at heart. So it is important to keep them updated with what is going on and for them to hear it from your point of view.

They will remain objective and make an excellent sounding board if you are trying to decide what to do.

Your GP is also the person who will refer you for a specialist opinion or a second opinion, if that is required. For guidance on how to seek a second opinion, visit [brainstrust.org.uk/second-opinions](https://brainstrust.org.uk/second-opinions).

## The consultant neurosurgeon

This is the person who deals with the cause and management of your brain tumour. In an ideal world, the neurosurgeon will liaise with everyone else and vice versa, but remember that you are just one patient in a day that is full of a huge and varied caseload. So be prepared to update them on what has been happening, how you feel and what medication you are taking.

Don't be afraid to ask for further opinions. A good neurosurgeon will willingly recommend another consultant if you ask. Sometimes they may come across as being quite dispassionate, but they are really listening to what is being said. Don't expect them to wave a magic wand – there isn't one.

To find out more about working effectively with your team, have a look at [brainstrust.org.uk/working-effectively-with-your-team](https://brainstrust.org.uk/working-effectively-with-your-team).

## The consultant neurologist

This is the person who deals with the diagnosis and medical management of neurological symptoms. Pretty much the same applies to this person as it does to the consultant neurosurgeon. They will liaise with each other, but if you can imagine this liaison happening for every patient, with letters flying to and fro, inevitably you will feel that perhaps your notes have not had the attention they should have. It can be useful to keep your own file. It can help to keep a diary of symptoms and to log the different ways your tumour is affecting you. Common symptoms are:

- seizures
- headaches
- memory problems
- personality changes
- fatigue
- blurred vision
- unsteadiness
- focal neurological deficit (weakness, speech problems, etc.).

You might try hard to find patterns in the symptoms, but there may be none. And just when you think you have it sorted, your tumour will find other weaselly ways of manifesting itself. Remember that not every headache you have may be down to the tumour, but it is important to let your neurologist know your symptoms. Not all tumour patients will have a consultant neurologist. The neurologist tends to be involved with patients with epilepsy and in the management of this, so don't think you are missing something if you haven't seen a consultant neurologist. Patients with low-grade gliomas are more likely to present with epilepsy.

## The consultant radiologist

This person interprets your MRI scans. While this person may seem to be in the background, they are absolutely key to your diagnosis and ongoing care.

Technology changes. You can have an MRI scan, and the next time you go, the scanner will have been updated. This is not significant. What is important is that, wherever possible, there is continuity in the interpretation of your scans, and that the radiologist has access to previous imaging when reporting on a current scenario. This will enable any changes to your tumour to be detected. All scans showing changes will be discussed at an MDT meeting with neuroradiologists present. Always take previous imaging with you, if you have it – this is easy if it is on a CD or USB drive.

## The therapeutic radiographer

Therapeutic radiographers are highly trained in radiotherapy and patient care. They work closely with the doctors and other staff to accurately plan and give radiotherapy treatment. They are the only healthcare professionals qualified to deliver radiotherapy. They are always happy to help with any worries or concerns you may have during your treatment; they are trained to provide most of the care, information and support required during this time.

If you are having radiotherapy, don't forget to order our resource 'my radiotherapy book' or visit [brainstrust.org.uk/radiotherapybook](https://brainstrust.org.uk/radiotherapybook).

## The neuropathologist

Now, this is an extremely important person, probably more important than you will ever know. However, the chances of you meeting this person are pretty slim. The neuropathologist is the linchpin of your treatment. They determine what type of tumour you have (and it can be one of about 150), and they will play a key role in the MDT meeting about what the options are for your treatment.

So what exactly does the neuropathologist do – apart from looking at cells through a microscope? Once a biopsy is done, your brain tumour will be the focus of an intensive investigation using all sorts of complex tests. It is increasingly likely that this will include an exploration of its genetic profile so that the most accurate diagnosis possible can be formed and the right therapies can be matched to your need. The tests guide your treatment so that it is optimised for you. In addition, the neuropathologist has to be able to interpret scans and, what's more, write reports. We told you they are important.



## The oncologist/neuro-oncologist

This person specialises in treating patients with brain tumours and the consequences of cancer upon the nervous system. If you need any adjuvant therapies (radio or chemo, for example), then the neuro-oncologist will be involved.

They are a key member of your team and will:

- work with your other doctors
- assess the need for and be responsible for administering adjuvant therapies
- give advice about a range of issues, including recovery from problems caused by therapy
- monitor and evaluate your progress and any changing needs.

But you need to do your bit too. Ask questions about side effects and expected benefits. Ask how many patients they see a year. Ask about clinical trials, about other team members, about who is responsible for each aspect of your care, and also ask about communication – who will be keeping your GP informed? Finally, as with all consultations, ask for copies of your consultation reports for your file.

## **The clinical psychologist**

You may not get a referral automatically to the clinical psychologist, but this is a good person to have on your side. In an initial meeting, lasting about two hours, the clinical psychologist will talk to you and listen to how your daily life is being affected. At this point, they will make a decision as to whether yours is a case that is worth following up. Three two-hour sessions will then follow, during which a range of testing is done to measure IQ, memory and other cognitive brain functions, although this may vary according to a patient's needs. The psychologist will be able to suggest strategies that will help you to cope with day-to-day living. More importantly, however, the tests form a baseline against which any deterioration or improvement in brain function can be measured.

## **The neuro-ophthalmologist**

This person specialises in the treatment and diagnosis of eye problems connected to a neurological condition. Eye health is a good way of establishing a baseline to measure the effect and impact of your brain tumour.

## **The neuro-oncology clinical nurse specialist**

The neuro-oncology clinical nurse specialist provides an excellent link between your medical, nursing and practical needs. They can facilitate referrals and investigations, and they provide advice and counsel during difficult times. They will generally know you best during your treatment and follow-up, can advise on many issues or get help from the appropriate clinician for your symptoms.

## The community neurological rehabilitation nurse

This is a fantastic person, and if you are lucky enough to be referred to one, either by your GP or one of your consultants, this person can unlock many things for you. Their role is to provide support for people who have had some sort of head trauma. The community neurological rehabilitation nurse will visit you in your home to talk to you about what is going on and what support is available. They will provide support and advice to help you manage your condition. And if they can't help, then they will refer you to someone who can.

## The epilepsy nurse

This person is your point of contact for information and support to do with epilepsy. They can provide treatment advice, information and support specific to your needs, presentation, medication and management plan. This includes:

- anti-epilepsy drug (AED) side effects or seizures and their management
- interactions between AEDs or a newly prescribed medication and an AED
- advice when medication is missed
- different seizure types, their presentation and documentation
- exacerbating factors
- imaging, EEG procedures, their findings and their significance
- first aid for seizures.

## The palliative care team

These are specialists who are trained to make a difference to families who are living with an incurable, life-limiting illness. Palliative care nurses, who will be part of the team, are experts in pain and symptom management, promoting comfort and the highest quality of life possible for their patients. In this role, they reduce the symptoms and suffering for patients and their families as they live with life-limiting progressive illnesses. They also provide emotional support and counsel regarding end-of-life decisions and care of survivors. They will have access to doctors in palliative care.

## The specialist allied health professions (AHPs)

This is a group of health professionals, and you may well meet representatives from some or all of their professions, depending on the nature of support that you need. You may not meet any of them if you don't need any support. It is just useful to know that they are there. These people have knowledge and experience, and they may well liaise with other AHPs. Allied health professions include:

**Occupational therapists:** Occupational therapists help you to overcome any practical difficulties that may be the result of your illness. They will work with you to help you lead a full and independent life and, where possible, prevent disability.

**Physiotherapists:** Physiotherapists aim to aid the management of problems such as loss of movement, sensation, balance or coordination, through advice, education, exercises and management programmes and strategies. By working together with you, they aid the return to activities and interests.

**Speech and language therapists:** These people (also known as SLTs) will assess if there are speech and language difficulties, communication difficulties, or eating and drinking difficulties. The therapist will consider the impact these will have on your life. If appropriate, the therapist will decide how you can be helped to reach your full communication potential. Treatment plans often also involve those with whom you have a close relationship, including family.

**Dietitians:** Good nutrition is essential when you are on this journey, and it will help you to regain your health afterwards. Clinical dietitians identify nutrition problems, assess nutritional status, develop care plans and monitor the effectiveness of dietary changes. They give practical advice for dietary problems. They can explain the causes of any problems you may have with your diet and will ensure that you have the nutrients and calories you need.

For more information about nutrition, visit [www.brainstrust.org.uk](http://www.brainstrust.org.uk).

## **The disability coordinator (in higher education)**

The disability co-ordinator organises any additional support that you may need in higher education, and every higher education institution will have one.

This support is for any student who needs help to learn, whether or not they are disabled. It may relate to physical or mental health, to a recognised disability or to a particular learning difficulty.

They have the responsibility assessing and arranging support.

The disability coordinator can also unlock the Disabled Students' Allowance (you don't have to pay this one back!). This funds IT equipment and non-medical help, including photocopying. The coordinator will also liaise with your tutor and lecturers, to save you the time.

For more information about the DSA, visit

**[www.gov.uk/disabled-students-allowances-dsas](http://www.gov.uk/disabled-students-allowances-dsas)**.

## My contacts

### My GP is:

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Telephone: .....

Email: .....

### My consultant neurosurgeon is:

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Telephone: .....

Email: .....

### My consultant neurologist is:

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Telephone: .....

Email: .....

### My consultant radiologist is:

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Telephone: .....

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### My therapeutic radiographer is:

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Telephone: .....

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### My neuropathologist is:

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Telephone: .....

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**My oncologist/neuro-oncologist is:**

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**My clinical psychologist is:**

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**My neuro-ophthalmologist is:**

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**My neuro-oncology clinical nurse specialist is:**

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**My community neurological rehabilitation nurse is:**

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**My epilepsy nurse is:**

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Email: .....



**My palliative care team contact is:**

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Telephone: .....

Email: .....

**My occupational therapist is:**

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Telephone: .....

Email: .....

**My physiotherapist is:**

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Email: .....

**My speech and language therapist is:**

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Email: .....

**My dietitian is:**

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Telephone: .....

Email: .....

**My disability coordinator is:**

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Telephone: .....

Email: .....

## **brainstrust support**

- **Coaching** – When life feels all-consuming by your brain tumour, coaching helps you to take control and focus on the things that matter the most. You will come away from your coaching sessions with strategies and tools to help you achieve clarity and improve your quality of life. To get in touch with a coach, email [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk).
- **Counselling** – When you find yourself in a time of distress and are struggling to cope, our rapid-access counselling service can help you to make sense of your situation and focus on specific, immediate goals. We can quickly connect you to a network of counsellors and give you the space to talk through your feelings in a safe and confidential place. Find out more: [brainstrust.org.uk/counselling](https://brainstrust.org.uk/counselling).
- **Thrive with *brainstrust* webinars and workshops** – ‘Thrive with *brainstrust*’ webinars and workshops are meticulously curated by *brainstrust* and hosted by leading experts to help you tackle the challenges that make life with a brain tumour so difficult. Find out more: [brainstrust.org.uk/events](https://brainstrust.org.uk/events).
- **Connect with others at a Meetup** – Meetups are an opportunity for you to connect with others who understand, in a more informal setting. No matter where you are on your journey, you can share experiences and seek information from people who know what you’re going through. Find out more: [brainstrust.org.uk/events](https://brainstrust.org.uk/events).
- **Helpline** – In times of distress and fear, it can be difficult to know where to turn and who to talk to. The *brainstrust* helpline offers people with a brain tumour and their caregivers support, information and pragmatic advice over the phone and by email 24 hours a day, 7 days a week. Call **01983 292 405** or email [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk) for 24/7 support.

- **Brain tumour hub** – The brain tumour hub is an easy-to-navigate database of brain tumour support resources and UK-based brain tumour clinical trials. It enables you to find support services in your area based on the type of support you want. Go to **[brainstrust.org.uk/brain-tumour-hub](https://brainstrust.org.uk/brain-tumour-hub)**.
- **Downloads and resources** – *brainstrust* resources are designed to help you feel more informed, more in control and more engaged with your care, no matter where you are on your brain tumour journey. Go to **[brainstrust.org.uk/resources/downloads](https://brainstrust.org.uk/resources/downloads)** to download our resources and request a brain box. If you'd like hard copies rather than downloadable versions, please email **[hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk)**.

## Contact details

If you would like any more information about *brainstrust* and how we can help, or if you would like to organise an event or have suggestions for the trustees, please contact HQ. You can donate online or send donations by post to our address. Don't forget to make a Gift Aid declaration – download a form online.

Address: ***brainstrust*, 4 Yvery Court, Castle Road,  
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