brainstrust
the brain cancer people

# Who's who in your clinical team

Version 2.3: July 2018

## 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 55,500 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: *Improving outcomes for people with brain and other CNS tumours* (July 2018). This information can be sourced at **www.nice.org.uk/csgbraincns**

# Contents

## 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; otherwise 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**

## Who’s who

Even before a diagnosis is reached, several people may already have become involved with your situation. You would hope that everyone talks to everyone else, but it isn’t always the case. Most liaison is still done through letters. Whilst this may be archaic, it does actually work in the patient’s favour, because it means you can have copies of correspondence for your records. Ask for this 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 having all the information at your fingertips. For guidance on how to seek a second opinion visit **brainstrust.org.uk/second-opinions**

## Your GP

The most valuable of all of these people 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 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.

The 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**

## The consultant neurosurgeon

This is the person who deals with the cause. In an ideal world, the neurosurgeon will liaise with everyone else and vice versa, but remember that you are just another 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 a second or third opinion. 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**

# The consultant neurologist

This is the person who deals with the 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 done. It can be useful to take 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
- raised intercranial pressure (headaches, nausea, 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 weasily ways of manifesting itself. Remember though that not every headache or bout of nausea that you may have may be down to the tumour. You may just have a bug. But it is important to let your neurologist know. Not all tumour patients will have a consultant neurologist. The neurologist tends to be involved with patients with epilepsy and 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 ‘reads’ your MRI scans. Whilst this person may seem to be in the background, they are absolutely key, and it is good to get to know them as well, as they have got to know your brain tumour, although this isn’t always possible.

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, the same consultant radiologist reads your scans so that you have continuity, or make sure 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. Always take previous imaging with you, if you have it – easy if it is on a disc.

## 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**

## The neuropathologist

Now, this is an extremely important person, probably more important than you will ever know. Or rather, not know, as the chances of you meeting this person are pretty slim. The neuropathologist is the linchpin to your treatment. They determine what type of tumour it is you have (and it can be one of about 140) and 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 look 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. Increasingly, this may include an exploration of its genetic profile so that as accurate a diagnosis as 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 read scans and, what's more, write reports. We told you they are special.

## The neuro-oncologist

This person specialises in treating patients with brain tumours and/or the consequences of cancer upon the nervous system. They may be a trained neurologist, oncologist or neurosurgeon, but will have done additional training in neuro-oncology – *neuro* meaning ‘nerve’ or ‘of the nervous system’, and *oncology* meaning ‘cancer’. So 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 what 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 when a range of testing is done that measures 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. This 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 provide advice and counsel during the difficult times.

## The community neurological rehabilitation nurse

This is a fantastic person, and if you are lucky enough to be referred, either from 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 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 'know a man 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 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 nurse

These are specialist nurses who are trained to make a difference to families who are living with an incurable, life-limiting illness. Palliative care nurses 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.

## The specialist allied health professions (AHPs)

This is a group of health professionals, and you may well meet some or all of their representatives, 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 may well liaise with other AHPs. Allied health professions include:

**Occupational therapists:** Occupational therapists help you to overcome any 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 co-ordination, 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/or 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.

**Dieticians:** Good nutrition is essential when you are on this journey, and it will help you to regain your health afterwards. Clinical dieticians identify nutrition problems, assess the 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**

## The disability co-ordinator (if you are in higher education)

The disability co-ordinator deals with the additional support that you may need 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 responsibility for assessing and arranging support.

The disability co-ordinator 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 co-ordinator will also liaise with your tutor and lecturers, to save you the time.

For more information about the DSA see this site:
**www.gov.uk/disabled-students-allowances-dsas**

# My contacts

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**My consultant neurosurgeon is:**

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## The Brain Tumour Hub

Driven by patient demand, *brainstrust* has launched an easy-to-use, up-to-date and comprehensive database of brain tumour support services and UK brain tumour clinical trials (**www.braintumourhub.org.uk**). The tool has been developed with patients, neuro-oncology healthcare professionals and researchers from across the country, and answers an unmet need for an easy-to-use database of information.

The brain tumour hub was developed with the support and funding of Nominet Trust, an initiative that contributes to a safe and accessible internet used to improve lives and communities.

To see the database, and the brain tumour hub in action, visit **www.braintumourhub.org.uk**

## Patient guide

What care should you expect as a brain tumour patient? 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. 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.

To find out more or to request a printed copy of the Brain Tumour Patient Guide (limited numbers), email **hello@brainstrust.org.uk**, call us on **01983 292 405**, or download a copy from **www.brainstrust.org.uk**

## Contact details

If you would like any more information about *brainstrust* and how we can help, or 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**
**Cowes PO31 7QG**
Email: **hello@brainstrust.org.uk**
Telephone: **01983 292 405**
Web: **www.brainstrust.org.uk**

## My notes

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Production of *brainstrust*'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**

Health & care information you can trust
The Information Standard
Certified Member

Registered charitable trust – *brainstrust*
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Wales (1114634), and Scotland (SC044642)
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