

Have you
lost your way
and **don't know**
which way
to turn?



Meg was just 19 when she was diagnosed with a brain tumour, just as she was about to begin a new life at university. Her symptoms include epilepsy, memory loss, hallucinations, visual disturbances, extreme fatigue, disorientation, nausea and headaches. Meg is fortunate – her tumour has been successfully resected in Children's Hospital, Boston, USA by Professor Black, one of the world's leading neurosurgeons and one of *brainstrust's* eminent patrons.

After a year of searching for support, Meg's family realised that there just isn't much 'out there' in terms of co-ordinated support, even though brain tumours account for one death in every hundred. So the seed for *brainstrust* was sown. If *brainstrust* helps one family to avoid the struggle that they have had then it will have been worth it.

***brainstrust* has one mission...** to build solutions for people who, like Meg, have brain cancer. Whether that is through improving care, updating treatment or saving lives – *brainstrust* is there.

It is working in partnership with the National Hospital Foundation at the National Hospital for Neurology and Neurosurgery, London, to sustain clinical work and with the University of Portsmouth, to support laboratory-based research and translational medicine. The charitable trust is dedicated to improving proactive care for brain tumour sufferers and providing co-ordinated support in their search for treatment, through addressing the lack of co-ordinated support and lack of UK wide strategy for the treatment of, and research in, brain cancer. We explore the availability of treatment worldwide, raise awareness and are proactive, not reactive.

***brainstrust* – good for brains,
bad for brain tumours.**

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The following may **help you** get back on track...

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

There are recommendations, and expectations, that in a few years time, the care of all patients with brain tumours will be co-ordinated through a model of multidisciplinary assessment and care. However, you need help today, here and now, and you may find that you are left to manage the 'care pathway' yourself. This booklet will help you to do this.

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, other wise it becomes chaotic. This will just add to your anxiety and frustration. We have found that it has been pretty much left to us to orchestrate things – make appointments, ask to see people, ask questions, find out who is out there who can help. We weren't even told, for example, that Meg is entitled to free prescriptions.

Here are the people who are very much involved in Meg's care and who have helped us.

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 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; 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. We take this file with us to all appointments, because invariably the consultants haven't got the notes (they are somewhere else) or they haven't always read them prior to the appointment.

We also have copy scans (about £30 a set – with your doctor's permission). These are now on disc, not film. This makes it much easier to carry around, or to send for second opinion.

And never, ever be afraid to ask for second, third, or even fourth opinions. It's worth it – 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.

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 are 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. Our GP frequently plays devil's advocate with Meg to make sure that she is certain about the choices she has made. We try to see Meg's GP at least three times a year for twenty minutes, with no agenda other than to touch base and chat about how things are. This is over and above any other appointments that may arise.

The GP is also the person who will refer you for a specialist opinion or a second opinion, if that is required.

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 case load. 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.

In the early stages we left these appointments feeling very frustrated and no further forward – that is OK. It took us 18 months to understand and, more importantly, accept, that they don't have all of the answers.

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 not feel that perhaps your notes have had the attention they should have done. In fact, we have been to consultations where there are no notes, so always take your own file. It is very important to keep a diary of symptoms and to log the different ways your tumour is affecting you.

Common symptoms are:

- Seizures.
- Raised intracranial pressure (headaches, nausea, blurred vision, unsteadiness).
- Focal neurological deficit (weakness, speech problems etc).

We have tried hard to find patterns in the symptoms but there are 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 in 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 – easy if it is on a disc.

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. This came about because of the problems Meg has with short term memory loss and disorientation and it came from the community rehabilitation nurse (see entry on page 10). 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 which 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. In Meg's case, the neuro-ophthalmologist measures her field of vision so that any improvement or deterioration in her eyesight can be identified and acted on accordingly. This is another good way of establishing a baseline to measure the effect and impact of her brain tumour.

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 neuro-oncology clinical nurse specialist

An alternative to the neurological rehabilitation nurse is the neuro-oncology clinical nurse specialist. These people provide 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 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 (AEDs) 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 with 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, which 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.

The specialist allied health professions (AHPs)

Speech and language therapists:

These people (also known as SLTs) will assess if there are speech and/or language difficulties, communication 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 to 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)

OK, so it took Meg a year before she decided to meet the disability co-ordinator at her university. And guess what? She really wished she had gone to see her sooner. But you need to come to this decision in your own time and Meg just wasn't ready for it in her first year. The disability co-ordinator deals with the additional support that you may need and every HE 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.

Meg's disability is hidden. Things like short term memory loss and disorientation are not obvious. But the disability co-ordinator unlocked the Disabled Students' Allowance (you don't have to pay this one back!) for her. 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. And as a parent, this person has been great to have at the end of phone or on email.

For more information about the DSA see this site:

http://www.dfes.gov.uk/studentssupport/students/stu_students_with_d_1.shtml

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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My **consultant radiologist** is:

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My **neuro-oncologist** is:

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My **clinical psychologist** is:

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My **neuro-ophthalmologist** is:

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Telephone:

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My **community neurological rehabilitation nurse** is:

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Telephone:

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

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Telephone:

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My **epilepsy nurse** is:

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My **occupational therapist** is:

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My **physiotherapist** is:

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My **speech and language therapist** is:

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My **dietician** is:

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My **disability co-ordinator** is:

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Email:

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.

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brainstrust is proud to be an active member of the Brain Tumour Research Group, which creates one voice for the purposes of lobbying, sharing information, support and representation, so that we can create a better world for brain cancer sufferers.

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