

Who's who Children and teenagers' clinical team

A resource for parents or caregivers
of children with a brain tumour



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A resource for parents or caregivers
of children with a brain tumour

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

We know how lost you can feel when you are told your child has 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 they have a brain tumour is hard.

And those 3 a.m. moments? We know about them too.

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

Around 500 children are diagnosed with a brain tumour each year, and thousands of families are 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.

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**. This guide has been developed in consultation with caregivers and healthcare professionals.

Contents



Anaesthetist	3
Endocrinologist	3
Neurologist	4
Neuro-ophthalmologist	4
Neurosurgeon	5
Neuro-oncologist	5
Radiologist	6
GP	6
Epilepsy nurse	7
Neuro-oncology clinical nurse specialist (CNS)	7
Palliative care nurse	8
Ward nurse	8
Clinical psychologist	9
Dietician	10
Family social worker	10
Occupational therapist	11
Physiotherapist	11
Play specialist	11
Speech and language therapist	12
Therapeutic radiographer	12
Disability coordinator (if your child is in higher education)	13
Neuropathologist	14
Ward teacher	14
Your child's contacts	15
Brain tumour hub and patient guide	19
Contact details	20

The doctors – you'll meet many of them, and they wear many hats. Here are some you are likely to meet.

Anaesthetist

These are specialist doctors who give anaesthetic to your child for certain treatments that require your child to be asleep.



Endocrinologist

These doctors specialise in managing hormone changes. Not all children or teenagers may encounter hormone changes. It all depends on the location of the tumour and the treatment they may have.



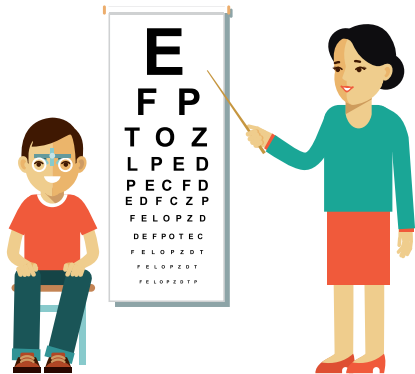
Neurologist

A neurologist treats problems with the brain and central nervous system. They will manage your child's brain-tumour-related symptoms, such as seizures.



Neuro-ophthalmologist

This is a doctor who specialises in treating and diagnosing eye problems. Sometimes the brain tumour may impact your child's eyesight. Keep a note of any visual changes your child mentions to you, and discuss it with your neuro-ophthalmologist.



Neurosurgeon

If your child requires surgery, this will be done by a specialist doctor called a neurosurgeon.



Neuro-oncologist

A neuro-oncologist is a doctor who specialises in diagnosing and treating brain tumours. So if you need any adjuvant therapies (radiotherapy and/or chemotherapy, for example), there are two neuro-oncologists who you may meet:

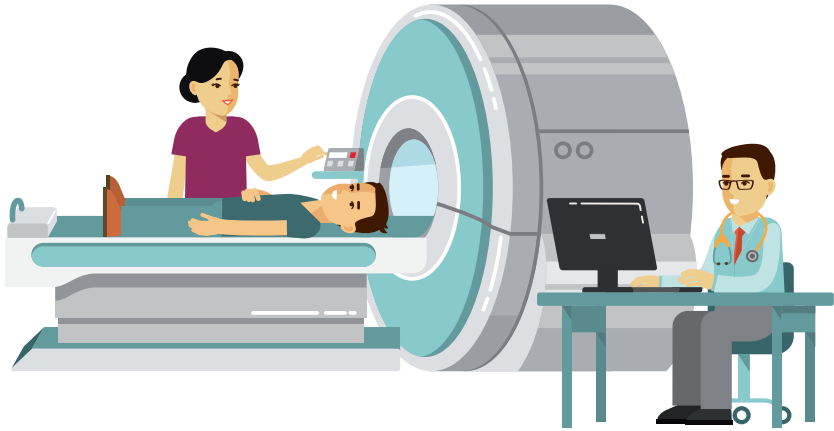
- A medical neuro-oncologist diagnoses, assesses and treats brain tumour patients. They support families in the decision process and discuss treatment options. They can prescribe chemotherapy and discuss radiotherapy.
- A clinical neuro-oncologist uses radiotherapy and chemotherapy to treat and manage brain tumours. Only clinical neuro-oncologists can prescribe radiotherapy. They also use a wide range of other treatments to treat brain tumours, other than surgery.

They are fundamental members of your team and will work with other doctors.



Radiologist

A radiologist is a specialist doctor trained to analyse diagnostic imaging like X-rays, MRI and CT scans.



GP

The GP may provide support outside of a hospital environment and closer to home. They may not be experts in brain tumours, but they want the best for you and your child.



Nurses have hidden capes because they are superheroes in disguise – you will meet many, but here are some key ones to look out for.

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 child's needs, presentation, medication and management plan.



Neuro-oncology clinical nurse specialist (CNS)

The neuro-oncology CNS provides an excellent link between your child's medical, nursing and practical needs. They can facilitate referrals and investigations, and provide advice and counsel during the difficult times. Share your worries with your CNS, and keep them close, as they have a wealth of contacts for different services.



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 manage the symptoms 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 for the whole family.



Ward nurse

A ward nurse provides care and treatment when your child needs to stay in hospital wards. They will help you understand treatments and talk to other healthcare professionals.



Allied health professionals (AHPs) – you will see and meet variations of AHPs in the hospital. Have a peep at their ID badges, because they all do very different things. Here are some you may meet.

Clinical psychologist

You may not get a referral automatically to a clinical psychologist. But this is a good person to have on your side. A clinical psychologist may follow you and your child from diagnosis to long after treatment finishes. They work with everyone in the family, including siblings, to help you manage your emotions. You can ask to go in as a family or have separate sessions.



Clinical psychologists offer a good ear, so talk to them and be open. Talk about how life has changed for you, for your child and the rest of your family and relationships.

A range of testing may be done to measure your child's 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 and your family 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.

Dietician

Good nutrition is essential when your child is on this journey, and will help them regain their strength afterwards. Clinical dietitians identify nutrition problems, assess nutritional status, develop care plans and monitor the effectiveness of dietary changes.

If you're worried about your child not eating, or losing or gaining a lot of weight, give these folks a shout. They can explain the causes and give practical advice on any dietary problems your child is facing, and will ensure they get the nutrients and calories they need.



Family social worker

Family social workers support the whole family from the moment a child is diagnosed with cancer. They help families to adjust to a new way of life by assessing any adaptations you as a family may need to smooth out your experience. They help with every part of your journey, from giving emotional support and financial or welfare guidance, to helping your child transition back into school or college.



Occupational therapist

Their role is to help your child recover and overcome any difficulties that may be the result of their illness. They assess your child's functions and work on developing their skills. An occupational therapist will work closely with you and your child to help them lead a safe and independent life where possible and prevent disabilities.



Physiotherapist

Sometimes, following brain tumour treatment, your child may find it hard to walk or move some parts of their body. But don't worry, because a physiotherapist will help your child become strong by using exercise and massage therapy to increase their mobility and improve balance. They do assessments on many areas and provide information to you about how to manage and maintain movement. Physiotherapists and occupational therapists work very closely together.



Play specialist

Play specialists support children going through treatment by creating a relaxed environment, usually through games and play therapy. If your child is ever feeling stressed or struggles to have their medication, ask your nurse to track down a play specialist. They also help prepare children for procedures, manage stress and teach coping strategies.



Speech and language therapist

Speech and language therapists will assess whether there are difficulties in communication, eating, drinking or swallowing. The therapist will consider the impact these will have on your child's life. If appropriate, the therapist will decide how you can help your child to reach their full communication potential.



Therapeutic radiographer

If your child needs radiotherapy as part of their treatment, then you will meet some radiographers, who work closely with clinical oncologists and physicists to plan and deliver accurate radiotherapy treatment. You may see them five days a week for many weeks, so keep them updated with any side effects your child may have. They are always happy to help with any worries or concerns you have during your child's treatment. They are trained to provide most of the care, information and support required during this time. They work closely with play specialists to help prepare your child for their treatment.



Some additional folk – you could call them hidden heroes.

Disability coordinator (if your child is in higher education)

The disability coordinator deals with the additional support that your child 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 coordinator can also unlock the Disabled Students' Allowances (DSAs). This funds IT equipment and non-medical help, including photocopying. The coordinator will also liaise with your child's tutor and lecturers to save them the time.

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



Neuropathologist

The neuropathologist works behind closed doors. You may never meet them. They determine what type of tumour your child has and play a key role in the multi-disciplinary team meeting about what the options are for your child's treatment.

So, what exactly does the neuropathologist do? Once a biopsy is done, your child's brain tumour will be the focus of an intensive investigation using all sorts of complex tests. They look at genetic profiles so that they can form the most accurate diagnosis and suggest the optimum therapies.



Ward teacher

Sometimes your child may have to stay in hospital over a long period of time. Many hospitals now have teachers that come to you and help your child keep up with schoolwork. It is very flexible and works around you and your child's needs.

They often liaise with your child's school and assist in the transition period once treatment has been completed.



Your child's contacts



Your child's anaesthetist is:

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Telephone:

Email:

Your child's endocrinologist is:

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Telephone:

Email:

Your child's neurologist is:

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Telephone:

Email:

Your child's neuro-ophthalmologist is:

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Telephone:

Email:

Your child's neurosurgeon is:

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Telephone:

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Your child's neuro-oncologist is:

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Telephone:

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Your child's radiologist is:

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Telephone:

Email:

Your child's GP is:

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Telephone:

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Your child's epilepsy nurse is:

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Telephone:

Email:

Your child's neuro-oncology clinical nurse specialist (CNS) is:

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Telephone:

Email:

Your child's palliative care nurse is:

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Telephone:

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Your child's ward nurse is:

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Your child's clinical psychologist is:

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Your child's dietician is:

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Telephone:

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Your child's family social worker is:

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Your child's occupational therapist is:

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Your child's physiotherapist is:

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Your child's play specialist is:

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Telephone:

Email:

Your child's speech and language therapist is:

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Telephone:

Email:

Your child's therapeutic radiographer is:

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Telephone:

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Your child's disability coordinator is:

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Telephone:

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Your child's neuropathologist is:

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Telephone:

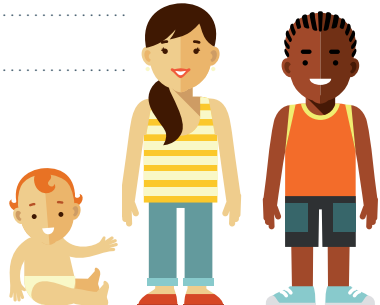
Email:

Your child's ward teacher is:

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Telephone:

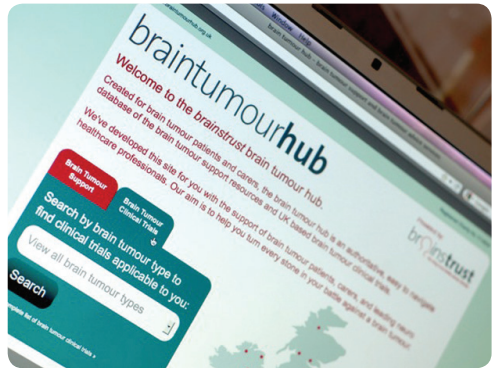
Email:



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: the brain tumour hub. 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.

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



Patient guide

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 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 will prove 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.



Contact details

If you would like any more information about *braintrust* 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: ***braintrust*, 4 Yvery Court, Castle Road,
Cowes PO31 7QG**

Email: **hello@braintrust.org.uk**

Telephone: **01983 292 405**

Web: **www.braintrust.org.uk**

Facebook support group for parents and caregivers:
www.facebook.com/groups/littlebraintrust



My notes

Production of *little brainstrust's* information is supported by the Anna Horrell Fund and Children with Cancer UK.



Registered charitable trust – *brainstrust* is a registered charity in England and Wales (1114634), and Scotland (SC044642). First published December 2019, due for review December 2022.

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