

Your child's health team (children with brain tumours)

To ensure that your child receives the best possible care, a team of healthcare professionals from different specialities will come together to treat and look after your child.

You may hear this team referred to as the MDT, which stands for 'Multi-Disciplinary Team'.

The MDT works together to create an individual treatment plan for your child. It also meets regularly to ensure all aspects of this care plan are carried out, reviewed (and changed, if necessary) as treatment continues.

This fact sheet outlines the roles of some of the professionals who may be part of your child's MDT and who you may meet.

In this fact sheet:

- The health professionals who would typically care for your child
- An outline of some additional health professionals who may be involved in the care of your child following their diagnosis

Neurologist

A neurologist specialises in problems relating to the brain, spinal cord and nerves in the body. Your child may be referred to a neurologist for their initial diagnosis.

Neurologists may also be involved at other stages of treatment and follow-up after treatment is complete.

Neurosurgeon

Your child will be referred to a neurosurgeon if their tumour can be operated on.

The neurosurgeon might carry out a biopsy (removal of a small piece of the tumour) so that the tumour can be analysed and diagnosed.

Or the neurosurgeon may be able to fully or partially remove the tumour. This operation is known as a craniotomy. The tumour tissue removed will be analysed and diagnosed.

Your child will see their neurosurgeon before and after surgery and for follow-ups in outpatient clinics.

For further information, see our *Neurosurgery in children* webpage, animation and fact sheet.

Neuropathologist

A neuropathologist diagnoses diseases of the central nervous system (brain and spinal cord) by looking at a sample of the tumour tissue removed by the neurosurgeon

The neuropathologist will look at the tumour cells under a microscope and also analyse the tumour's genes. From these examinations, the neuropathologist will be able to give a diagnosis of the type and **grade** of your child's brain tumour. This is important as it will help plan your child's treatment.

Oncologist

Oncologists are doctors who treat tumours. There are different types of oncologists who may be involved in your child's treatment and care. Sometimes, although they may have a different job title, their role is the same.

Below are some of the job titles your child's doctor may have:

Clinical oncologist

Clinical oncologists are doctors who use non-surgical ways of treating tumours. This includes radiotherapy and/or chemotherapy.

They work out which treatment to use by looking at the type and grade of your child's tumour, where it is in the brain, as well as your child's age and general health.

They will plan your child's treatment and monitor your child's progress throughout the treatment.

Clinical oncologists train in all types of tumour, but specialise in one or two types as a consultant - for example, brain tumours.

If they specialise in brain tumours, they may use the job title of neuro-oncologist.

Neuro-oncologist

Neuro-oncologists are clinical oncologists who specialise in the non-surgical management of patients with tumours of the brain and spinal cord. This includes treatment using radiotherapy and/or chemotherapy.

Medical oncologist

Medical oncologists diagnose and treat people with malignant (high grade) tumours, mainly using chemotherapy. They can advise on all aspects of treatment, including radiotherapy, but only clinical oncologists can prescribe radiotherapy.

Paediatric oncologist

Paediatric oncologists are doctors who specialise in the diagnosis, treatment and follow-up care of children and young adults with tumours and leukaemia.

Most tumours affecting children are different to those affecting adults and often respond differently to treatment, so treating children is a separate speciality.

The oncologist treating your child will be a paediatric oncologist. The term 'paediatric' means the branch of medicine dealing with children.

Clinical nurse specialist (CNS)

A clinical nurse specialist (sometimes called a neuro-oncology nurse) acts as the point of contact between you, your child and family, and the rest of the MDT.

Your child's clinical nurse specialist (CNS) will be able to help with any questions or concerns you may have about treatment, either directly or by liaising with other members of the MDT.

They can be your voice on the MDT, expressing your concerns and asking your questions.

They also work to ensure good communication between the health professionals within the MDT.

This is important as it helps to make sure that all aspects of your child's condition are considered when planning and carrying out treatment and during their follow-up care.

The CNS may also be able to give you guidance about some of the non-medical support you may need, such as financial benefits that may be available to you.

(They may be called a key worker - though the key worker could be anyone in the health team).

Additional staff who may work with your child

In addition to the 'core' staff who make up your child's health team, they may receive care from the following professionals who, when involved, play a key role in your child's care.

It is important to note that the team caring for your child may be made up of different healthcare professionals.

Radiographer

If your child needs radiotherapy, the radiographer is the person who actually administers the radiotherapy (sometimes called radiation treatment) that your child's clinical oncologist prescribes.

Radiographers work with other professionals who help plan your child's treatment, including radiotherapists and medical physicists.

Whilst your child is receiving radiotherapy, they will see radiographers daily, or as often as your child's radiotherapy treatment plan requires.

For more information, see our [Radiotherapy for children](#) web page and fact sheet.

Health play specialist

Health Play Specialists are specialists who use play to help your child in various ways:

- understand and prepare for treatment
- express and explore their feelings
- feel more in control of what is happening.

For example, they can work with your child to help reduce their fear of the machines used for treatment, which can be large, noisy and intimidating.

Or they could help your child prepare for having a radiotherapy mask of their face made and for wearing the mask during treatment. This may include letting your child play with the material used for making the mask, or making a mask for their favourite toy.

A health play specialist may also help your child come to terms with having a cannula or central line fitted if they have a fear of needles.

They could also help them speak about feelings that they may not want to talk about with mummy and daddy.

They may also give out Beads of Courage for each treatment, blood test, scan etc. These build into a string of beads that help children to take ownership of their 'journey' and explain it to others in a visible way. They have been found to help reduce illness-related distress.

Health play specialists work with children across the age ranges - from birth to 16 years.

Physiotherapist

Children with brain tumours are often referred to a physiotherapist because of difficulties with balance or muscle weakness caused by the tumour or treatment.

A physiotherapist helps with the recovery of your child's movement and muscle strength by using exercises, massage and other treatments, such as ultrasound or heat and cold.

The physiotherapist may put together a programme for your child that includes exercises at home, the gym or in a hydrotherapy pool.

Occupational therapist (OT)

An occupational therapist helps with day-to-day tasks and activities at home and at school - for example getting dressed, writing and moving around.

They may suggest certain aids or equipment around the home to make life easier for your child.

These aids could be temporary to help with some of the immediate side-effects of treatment or could be long-term, updated as your child grows.

Speech and language therapist (SLT or SALT)

If your child's tumour affects an area of the brain that is involved with language, your child will be referred to a speech and language therapist (SLT).

They will work with your child to help them improve their speech or develop ways of communicating that does not involve speech.

Speech and language therapists can also help with difficulties relating to swallowing, which can be caused by the brain tumour.

Dietitian

When your child is having treatment for their brain tumour, it is quite likely that their appetite will be affected at some point. This could be due to stress and anxiety, or to the treatment itself.

Some treatments for brain tumours, such as chemotherapy or radiotherapy, can cause appetite loss - by affecting taste, making the mouth or throat sore, causing nausea or vomiting, or just simply making them feel tired and unwell.

Alternatively, steroids may cause your child to put on weight.

A dietitian specialises in food and nutrition and can work with you to plan a diet to suit your child and their nutritional needs. This can help your child stay well during their treatment and make sure they are getting a good balance of nutrients.

For more information, see our *Helping your child to eat* web page and fact sheet.

Clinical psychologist

Clinical psychologists are concerned with reducing psychological distress and promoting psychological well-being.

Psychologists may meet with your child, or with the whole family, to help work through difficult or stressful issues, or to help with feelings. They can also help with anxiety, fear and depression.

They can help your child to prepare mentally for treatment.

A clinical psychologist could be part of your child's long-term health team - to help them cope with different stages in life following treatment.

They may carry out tests as your child grows. This is to help establish any long-term difficulties your child may experience and plan interventions to support them through these difficulties.

For children who have been given a poor prognosis, a clinical psychologist can support your family to work out and express any thoughts, fears and questions you may have.

Clinical psychiatrist

Like a clinical psychologist, a clinical psychiatrist helps with mental health issues, such as anxiety and depression.

They differ from a clinical psychologist in that they are a medically qualified doctor (who has specialised in psychiatry). This means they are able to prescribe medication and certain other treatments.

Your child may not see a clinical psychiatrist immediately, or even at all, but may see them at a later date if your child experiences long-term emotional or behavioural difficulties.

Educational psychologist

Educational psychologists (or 'Ed Psychs') can help if your child is having problems at nursery/school/college that affect their learning or taking part in social activities.

It is important to be aware that different schools have different arrangements with the Educational Psychology Service in their area and the waiting time for an appointment with a local authority EP can be long.

Ed Psychs use a range of tests and watch how your child deals with things so they can work out the different types of support that may help your child. For example, one-to-one support in certain subjects, giving extra time, breaking down tasks into small chunks.

They can also advise teachers on teaching styles and techniques that may help, or refer on to another health professional, such as a speech and language therapist .

For more information, see our *Education resources* and our *Learning difficulties and brain tumours in children* web page and fact sheet.

Social worker

Social workers can look at the needs of the family, both at home and in hospital. They can provide emotional and practical support, such as helping you with financial concerns, and co-ordinate care between hospital and home.

Some centres have their own social workers, provided by the Local Authority but employed by the hospital.

Other centres have social workers provided by charities such as CLIC Sargent. This is a national charity for children affected by cancer.

CLIC Sargent have eligibility criteria for their services. If you have been told by the treating doctor that your child has a high grade tumour, OR that they are being treated as if the tumour is high grade, though they are not sure if it is, then your child/family can receive their services. (Your child must also be under 24yrs at diagnosis and eligible for free NHS treatment).

Other staff

Although technically not part of the MDT, two types of healthcare professional may have been involved with assessing your child's first symptoms and referring them for more specialist help - your GP (family doctor) or an optometrist (at your opticians).

These professionals may also be involved in your child's care during treatment for a brain tumour.

General Practitioner (GP)

Your child's GP (family doctor) may be the first person you seek medical advice from when your child experiences symptoms or side-effects of any kind - from the tumour itself or from treatment.

Your child's GP may already be involved with your child's treatment, as they may have suspected the presence of a brain tumour and referred your child for a brain scan, or for a consultation with a more specialised health professional, such as a neurologist or a paediatrician.

Your child's GP will also receive updates from the hospital about their treatment.

Optometrist

If you take your child for an eye test, the optometrist will look at many things. These may include your child's eye movements, the reactions of their pupils, visual acuity, and into the back of their eyes to see if there is any swelling of the optic disc. The optic disc is the area where the optic nerve enters the eye. Swelling of the optic disc can be a sign of raised pressure inside the skull (intracranial pressure).

Raised intracranial pressure can be caused by many things, not just brain tumours.

If there are signs of swollen discs, the optometrist will send your child to the hospital, usually within 24 hours, to be examined by a specialist 'eye doctor' (ophthalmologist).

If the ophthalmologist suspects a brain tumour, they may refer your child to a neurologist or send them for a scan directly.

If your child is diagnosed with a tumour, the tumour or its treatment may affect their vision, such as loss of their peripheral (outer) field of vision. Your optometrist may be able to provide them with glasses, visual aids and information about organisations that can help your child adjust to changes in their vision.

What if I have further questions or need other support?

You can contact our Information and Support Team in the following ways:

- Call 0808 800 0004 (free from landlines and most mobiles including 3, O2, EE, Virgin and Vodafone)
- Email: support@thebraintumourcharity.org
- Live Chat: Get in touch with us online via thebraintumourcharity.org/live-chat
- Join one or more of our closed Facebook groups: bit.ly/FBSupportGroups
- Website: thebraintumourcharity.org/getsupport

Disclaimer

This resource contains information and general advice. It should not be used as a substitute for personalised advice from a qualified specialist professional. We strive to make sure that the content is accurate and up-to-date, but information can change over time.

Patients must seek advice from their medical teams before beginning or refraining from taking any medication or treatment.

The Brain Tumour Charity does not accept any liability to any person arising from the use of this resource.

About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard – an NHS standard that allows the public to identify reliable and trustworthy sources of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology.

Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you have already been given. Please do continue to talk to your medical team if you are worried about any medical issues.

If you would like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on **0808 800 0004** or support@thebraintumourcharity.org

About us

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research worldwide, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

We wouldn't be able to make the progress we have without the incredible input we receive from you, our community.

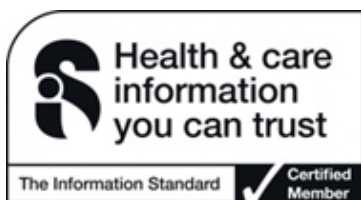
Whether it's reviewing our information resources, campaigning for change, reviewing research proposals or attending cheque presentations, everything you do helps to make the difference.

To find out more about the different ways you can get involved, please visit thebraintumourcharity.org/volunteering

We rely 100% on charitable donations to fund our vital work. If you would like to make a donation, or want to find out about other ways to support us including leaving a gift in your will or fundraising through an event, please get in touch: Visit thebraintumourcharity.org/get-involved, call us on 01252 749043 or email fundraising@thebraintumourcharity.org

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Your notes



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