The Children &
Young People's
Cancer Association

A guide to brain and spinal cord tumours

Information and support for parents and carers of children and young people with a brain or spinal cord tumour

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Information
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Patient Information Forum

About this guide

This guide has been written with the help of experts and parents. It aims to help parents and carers following their child's diagnosis, and gives specific information about brain and spinal cord tumours, including treatment, possible side effects and rehabilitation.

If your child has only just been diagnosed, there may be information in this booklet that has not yet been discussed with you by the medical team looking after your child. This guide gives a general overview of brain and spinal cord tumours that occur in children and young people, and will act as a helpful reminder for any discussions you have with your child’s treatment team.

There is a lot of information in this guide and it may be helpful to read it in small sections. Much of this will be new and may feel overwhelming. We hope this guide will help answer some of your questions so that you understand more about your child's diagnosis, treatment and rehabilitation, as well as how to look after your child, yourself and your loved ones.

The experiences and tips shared throughout this booklet are from parents and carers who have been through something similar to you. We hope these will help to reassure you that you are not alone.

It is important to remember that every child is an individual, and your child’s specific diagnosis must be discussed with the treatment team caring for them.

We recommend this guide is read in conjunction with our main resource 'A parent's guide to children and young people with cancer' which is designed to accompany you through every step of the cancer experience. Available FREE of charge from your hospital or from our website: www.cclg.org.uk/publications

Contents

Beginning the journey

When you are told that your child has a tumour, it can feel as if your life has turned upside down overnight. You are likely to be going through one of the hardest things a parent can face.

You will probably be feeling scared, numb, overwhelmed, not believing that any of this is happening, angry as to why it is happening to your child or maybe guilty that your child's tumour is because of something you have or haven't done, even though that isn't true. At the same time, you may be trying to appear strong and calm for your child and other family members. All of these feelings are completely normal and many parents say that they felt the same.

Since your child's diagnosis, you may have met many new people, heard a lot of unfamiliar medical terms and your child may have undergone a series of tests. This can feel very overwhelming and daunting as a parent. Don't worry, hospital staff fully understand that it takes time for you to digest what is happening and what the next steps might be. They are there to help you through this difficult time with information and reassurance.

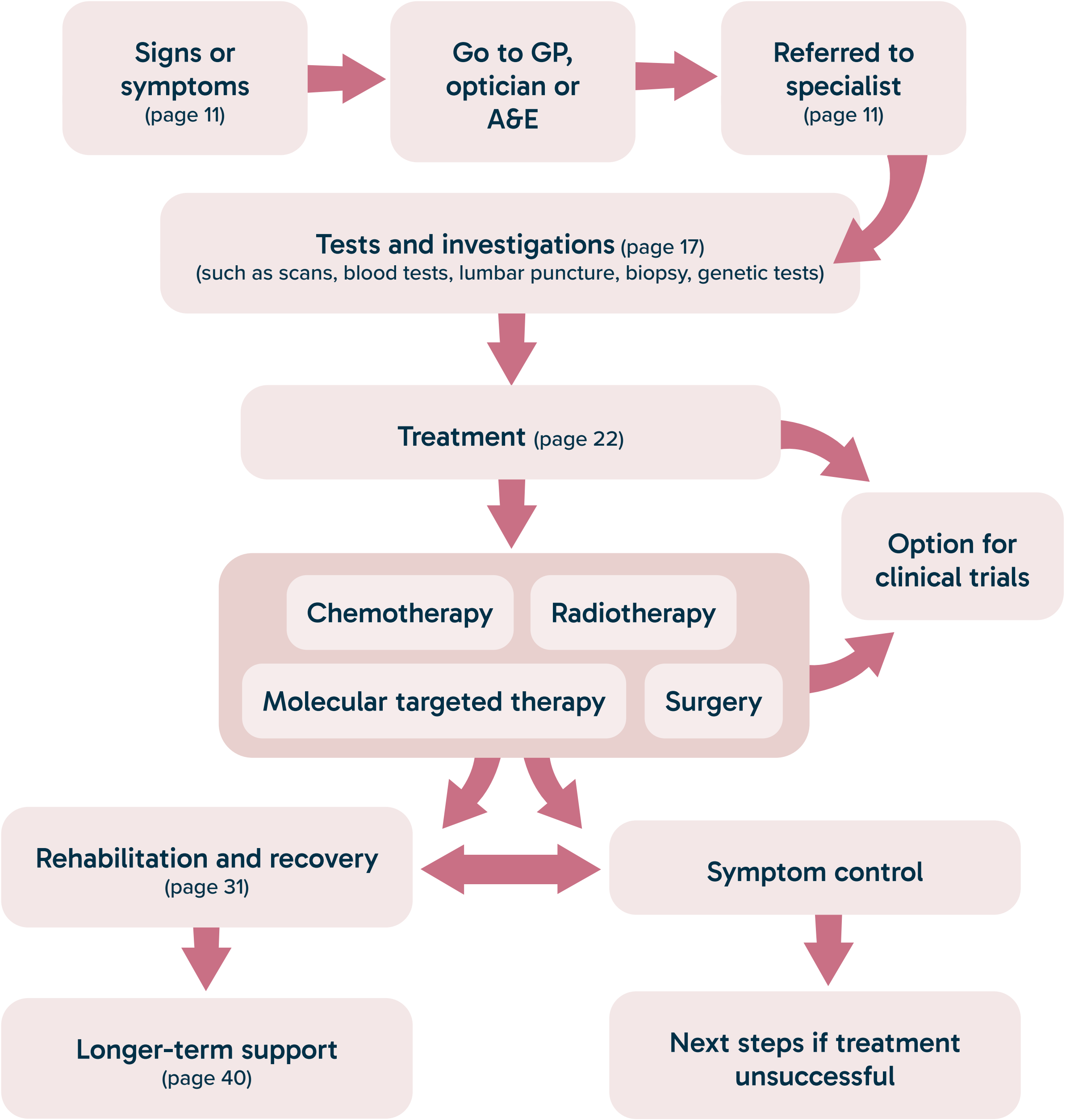
Many parents cannot think of any questions to ask during a hospital consultation but think of all sorts of things when they get home. It is a good idea to write down questions when you think of them so that you can discuss them at the next opportunity.

When a child is diagnosed with a tumour, it has a huge impact on the whole family. Your routine is likely to change due to hospital stays and regular appointments, and this can feel overwhelming for you, your child and the rest of your family.

There are many organisations who can support you through this time and some of these are listed at the end of this guide, but you should also discuss your feelings with the team looking after your child.

> “You suddenly find yourself in a world where you don't know anything, and there's so much to take in. There wasn't time to find anything out or prepare, everything moved so fast. I found it very disorientating and disempowering at first.”

Your child's healthcare journey



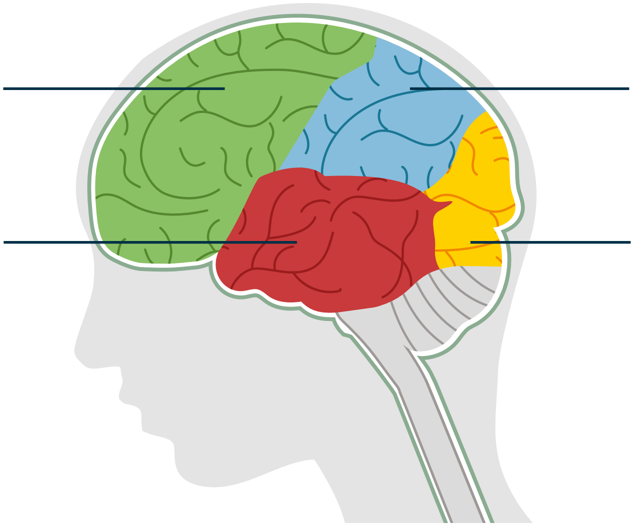
About brain and spinal cord tumours

The brain and spinal cord are two complex organs that form the central nervous system. They work together to interpret the messages from our senses and tell our bodies how to respond. There are many different parts within the central nervous system that perform different tasks.

The brain and spinal cord

The largest part of the brain is at the top of the head. This is called the **cerebrum**. It is made up of two halves (hemispheres) and is divided into lobes (frontal, temporal, parietal and occipital). It controls thinking, learning, memory, problem solving, emotions and touch. It also helps us to be aware of our body position.

Parts of the cerebrum



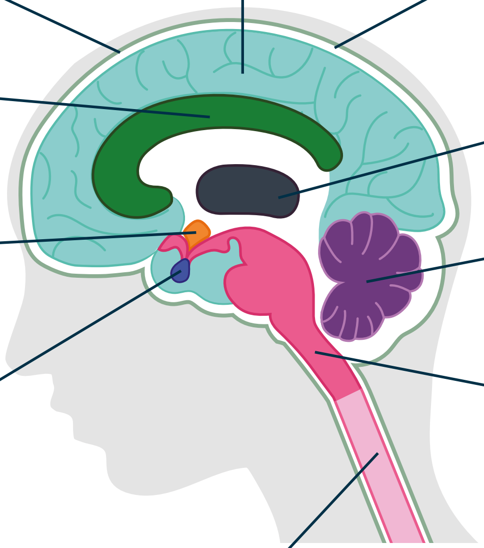
🟩 **Frontal lobe**
controls movement, decision making, behaviour regulation.

🟥 **Temporal lobe**
controls learning and memory, hearing, understanding of language.

🟦 **Occipital lobe**
controls sight and helps process visual information so that you can understand what you see.

🟨 **Parietal lobe**
controls touch, integration of information from other senses, spatial skills.

Cross-section of the brain



🟦 **Cerebrum**
the largest part of the brain at the top of the head (see previous page).

🟩 **Meninges**
membranes that protect the brain and spinal cord.

🟩 **Corpus callosum**
bundle of nerves that connects the two halves of the brain and enables them to communicate.

🟧 **Hypothalamus**
releases hormones that help to control processes such as growth, hunger and body temperature.

🟦 **Pituitary gland**
a gland that sits underneath the brain and releases hormones into the blood that control lots of different parts of the body.

⬜ **Cerebrospinal fluid (CSF)**
fluid that flows around the hollow spaces of the brain (ventricles) and spinal cord to help protect them.

⬛ **Thalamus**
relays information from the body's senses to the brain.

🟪 **Cerebellum**
the back part of the brain that controls movement, balance and coordination.

🟥 **Brainstem**
connects the brain to the spinal cord and body. It controls heart rate, breathing and consciousness. Cranial nerves emerge from the brain stem and help control functions of the face and mouth, including eye movements and swallowing.

🟪 **Spinal cord**
a long tube of nerves bundled together that carries information between the brain and the rest of the body.

What are brain and spinal cord tumours?

‘Tumour’ is a general term for a group of cells (the tiny building blocks of our bodies) which keep multiplying in an uncontrolled way and form a lump or ‘mass’. Sometimes, a tumour develops lots of strands from it which may be described as hair-like or called diffuse.

Tumours can be cancerous (malignant) or non-cancerous (benign). Benign tumours can grow, but do not usually spread to other parts of the body. Malignant tumours usually grow faster and can spread to nearby tissue or other parts of the body.

Words used to describe brain tumours by health professionals can sometimes seem confusing. ‘High-grade’, ‘malignant’, ‘cancerous’, ‘low-grade’, ‘non-malignant’ and ‘benign’ often describe what the tumour looks like under a microscope, in terms of how invasive and fast growing it looks.

Advances in analysing the biological make-up of tumours now provide extra information, and more new tumour subgroups are being discovered. Some of these subgroups help doctors to understand how a tumour might respond to therapy.

The terms used sometimes don’t seem to match the treatment being proposed. This may be because of where the tumour is or the number of tumours found. For instance, some ‘benign’ tumours are in areas where safe surgery is difficult or can even be found in more than one location of the brain or spinal cord. In these cases, it may be safer not to remove by surgery, but to use chemotherapy, radiotherapy, or biological-targeted therapies instead.

It can be confusing to understand the terms used to describe your child’s tumour and match that with how they are going to be treated. If you are at all confused, it is very important that you speak to your child’s consultant and ask them to explain fully what your child’s tumour is and the reasons for the treatment being proposed.

Brain and spinal cord tumours can be complicated because the brain and spinal cord control so many functions of the body and mind — from physical movements to vision, hearing, memory and emotion. The tumour itself can interfere with these functions, and so can the treatment.

What causes brain and spinal cord tumours?

In most cases, we do not know what causes these types of tumour and there is nothing that could have been done to avoid them developing.

People with some genetic conditions may be at higher risk of developing a brain tumour. If this is a possibility for your child, your doctor will discuss this with you. If you want to know more about this, talk to your medical team. Brain tumours are rare, so it is very unlikely that another family member will develop one.

Signs and symptoms

As the brain and spinal cord control so much, there are lots of symptoms that might indicate a tumour. These can also occur without having a brain tumour. The difficulty for parents – and for doctors – is that many of these can seem vague. This can mean that it takes a while for parents to take their child to a doctor, and it may take a while for the symptoms to be recognised as a possible tumour. The symptoms of brain and spinal cord tumours vary depending on where exactly the tumour is, but could include:

Unusual/repeated headaches (which may wake a child or happen when they wake up)	Regularly feeling or being sick (which may wake a child or happen when they wake up)
One-sided weakness of legs, arms or face	Delayed puberty
Changes in consciousness	Seizures
Problems with speech or swallowing	Abnormal head position
Memory problems	Abnormal growth
Problems with eye movements or vision, including squint, blurred or double vision	Changes in behaviour or character, or emotional outbursts
Clumsiness or poor coordination	Problems with balance
Symptoms of spinal cord compression, which may indicate a spinal tumour: back pain, loss of sensation or disturbance of feeling, problems with bladder or bowel function, new limp or leg weakness	

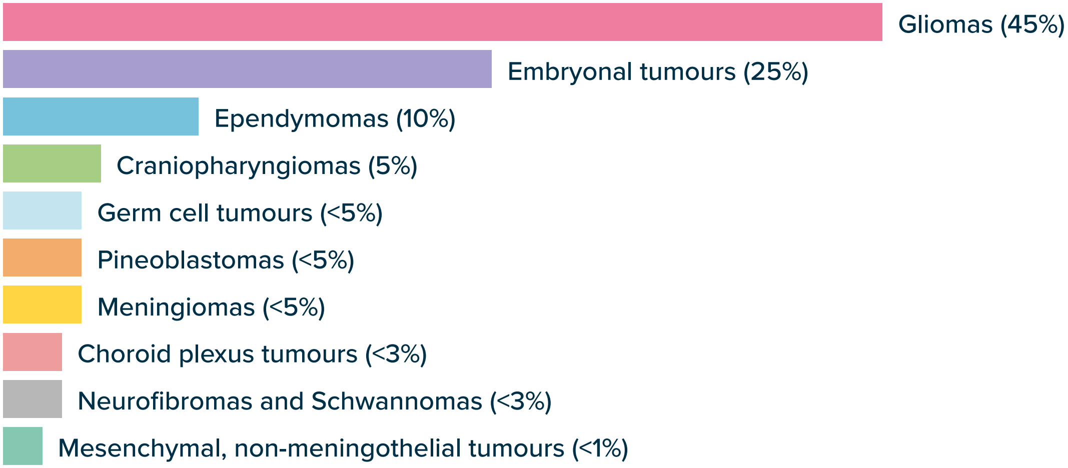
Visit **www.bettersafethantumour.com** for more information on symptoms.

Urgent referrals

The National Institute for Health and Clinical Excellence (NICE) guidelines for suspected cancer recommend very urgent referral (within 48 hours) for specialist assessment if a child has increasing head circumference, repeated/unusual headaches, abnormal coordination, walking or head position, confusion or disorientation with a headache, new bladder or bowel dysfunction, development regression, focal motor or sensory abnormalities. In the process of your child's diagnosis, you may have experienced this urgent referral. When things happen so fast this can be scary and overwhelming. Talk to your medical team if you are unsure about why or how any of this happened, or if you are unsure about anything at all.

Types of tumour

There are many different types of brain and spinal cord tumour. The chart below shows the main types, (although there are many sub-types) and the number of diagnoses as a percentage of all brain tumours.



Gliomas

The most common type of brain and spinal cord tumours found in children. They start from glial cells, which help to support the cells in the brain (neurons) that send and receive signals. Low and high grade gliomas can both occur in the spine, although this is not common. There are lots of different types of gliomas, but they can be separated into two main groups, based on the appearance of the tumour cells under the microscope and their genetic make-up. This identifies the tumour grade (according to a World Health Organisation scheme):

- **Low-grade gliomas** (including ganglioglioma, gangliocytoma, pilocytic astrocytoma, pilomyxoid astrocytoma, pleomorphic xanthoastrocytoma (PXA), subependymal giant cell astrocytoma (SEGA), dysembryoplastic neuroepithelial tumour (DNET), oligodendroglioma and diffuse astrocytoma) are benign tumours occuring mainly in the cerebellum, cerebral hemispheres or midline locations.
- **High-grade gliomas** are malignant tumours often found in the brainstem, cerebral hemispheres, or other midline locations. Modern biological testing has shown there are lots of different subtypes of these tumours, including diffuse intrinsic pontine glioma (DIPG), and other H3K27 mutant diffuse midline gliomas.

Embryonal tumours

The most common is medulloblastoma. Other types include atypical teratoid rhabdoid tumour (ATRT), embryonal tumour with multi-layered rosettes (ETMR), neuroblastoma with FOX-2 activation, and CNS tumour with BCOR-ITD mutation. These malignant tumours develop from cells left over from the early stages of a baby’s development.

Ependymomas

Low or high-grade tumours that develop from ependymal cells which line the passageways of the brain and spinal cord where cerebrospinal fluid flows. They are mainly found around the brainstem and cerebellum, or in the cerebral hemispheres or spinal cord.

Craniopharyngiomas

Benign tumours that usually develop at the base of the brain, just above the pituitary gland.

Germ cell tumours

Include germinoma, non-germinomatous subtypes, and teratomas. These tumours usually occur in adolescence or sometimes in early infancy. In older children, they are often found near the pituitary gland and/or the pineal gland. They arise from cells left over from a baby's development in the womb and mimic tumours that can be found in a testicle or ovary.

Pineoblastomas

Malignant tumours that originate from the pineal region of the brain.

Meningiomas

Low or high-grade tumours found in the lining that protects the brain and spinal cord.

Choroid plexus tumours

Benign or malignant tumours that start from choroid plexus, the tissue that produces cerebrospinal fluid. These are often found growing in the ventricles of the brain.

Neurofibromas and Schwannomas

Benign tumours that originate from the lining of cranial nerves, peripheral nerves and nerve roots. These tumours are sometimes related to genetic conditions such as Neurofibromatosis Type 1 or 2.

Mesenchymal, non-meningothelial tumours

Can be high or low grade. They include CNS sarcomas, sarcomatous tumours, vascular tumours and muscle-based tumours.

Survival

A brain or spinal cord tumour diagnosis is a serious condition that can be life threatening and life changing, but there is much cause for hope. We are finding out more every year about how the brain works and the different sub-types of tumour that exist. It is hoped that the outcomes for children with these conditions will continue to improve.

Statistics are difficult because they cannot tell you what will happen to your own child. There are many factors which vary including stage, surgery outcome and the biology of the tumour.

Going forward

Through the coming weeks and months, you and your child will attend a huge number of meetings and appointments with healthcare professionals. We have put together some tips below to help you to be prepared for these appointments.

Tips for attending appointments

- If you don’t understand the terminology, ask for an explanation
- Always bring a pen and notepad
- Bring activities for you and your child to do while you wait
- Check how and when you can contact the person you are seeing if you have any questions afterwards
- Bring plenty of refreshments in case things are running late
- Note down any questions you have and what you would like to achieve from the meeting

Diagnosis

One of the hardest things about coping with a tumour is adjusting to the unexpected new reality of your situation — the period of diagnosis can be especially demanding and may feel overwhelming. Your child will have lots of tests which may happen very quickly. This section explains the tests and procedures that your child will have and some practical steps you can take to cope during this time.

Being referred

The first stage of diagnosis will have probably involved taking your child to the GP or A&E because of some symptom or behaviour you were concerned about. If they felt these symptoms indicated a tumour, they would have referred you to the brain and spinal tumour team (the neuro-oncology team).

If your child’s symptoms are not specific, or have gradually built up over time, it may have taken you a long time to reach this point.

> “We went into A&E one night and the next morning she was scanned and they found the tumour — the following day she had surgery. You're suddenly thrown into a world you never knew existed. I'm still trying to get my head round the fact it's happened.”

If a tumour is suspected, your child will be referred by your GP or A&E staff to your nearest hospital that has a children's cancer (called paediatric oncology) centre, specialising in brain and spinal cord tumours (neuro-oncology). These Principal Treatment Centres (PTCs) are located in a network of 20 hospitals across the UK and Ireland with expertise in managing and treating all childhood cancers, including brain and spinal cord tumours.

1 **Aberdeen:** Royal Aberdeen Children's Hospital
2 **Edinburgh:** Royal Hospital for Children and Young People
3 **Glasgow:** Royal Hospital for Children
4 **Newcastle-Upon-Tyne:** Great North Children's Hospital, Royal Victoria Infirmary
5 **Leeds:** Leeds Children's Hospital, Leeds General Infirmary
6 **Sheffield:** Sheffield Children's Hospital
7 **Nottingham/Leicester:** East Midlands Integrated Service at Queen's Medical Centre, Nottingham and Leicester Royal Infirmary
8 **Cambridge:** Addenbrooke's Hospital
9/10 **London:** Great Ormond Street Hospital for Children and University College Hospital London
11 **Sutton:** Royal Marsden Hospital
12 **Southampton:** Southampton Children's Hospital, Southampton General Hospital
13 **Bristol:** Bristol Royal Hospital for Children
14 **Cardiff:** Noah's Ark Children's Hospital for Wales
15 **Oxford:** Oxford Children's Hospital, John Radcliffe Hospital
16 **Birmingham:** Birmingham Children's Hospital
17 **Liverpool:** Alder Hey Children's Hospital
18 **Manchester:** Royal Manchester Children's Hospital
19 **Dublin:** Our Lady's Children's Hospital, Crumlin
20 **Belfast:** Royal Belfast Hospital for Sick Children

Assessments and scans

The doctor will thoroughly examine your child and look carefully at their history to assess all the signs and symptoms that may indicate a tumour. Your child will then be scanned in the hospital. Younger children may be given oral sedation or a general anaesthetic to help them lie still. Sometimes, patients have an injection to highlight the tumour on the scan.

The different types of scan are:

- **CT scan (computerised tomography)** — uses x-rays to see structures and fluids within the brain. It is best used for looking at swellings, skull bones, problems with normal fluid flow or bleeding. The scan can be arranged relatively quickly and may only take a few minutes.
- **MRI scan (magnetic resonance imaging)** — the most common scan for diagnosing brain tumours. It uses a strong magnet to create very detailed pictures of the brain and spinal cord. It is painless but very noisy, so your child may be given headphones to wear. It may take up to an hour.
- **Advanced MRI scan (functional imaging)** — there have been many advances in MRI which can show more information on tumour type, how aggressive it is and whether it is close to important nerves. This can give even more detailed information about the tumour and how to treat it.
- **Positron-emission tomography (PET) scan** — mainly looks at metabolism (the chemical processes of living cells) through the brain and spinal cord, as well as through the tumour. PET scans are not part of routine clinical practice but are used in some research studies.

Tests and investigations

Once your child's medical team knows where the tumour is and how it is behaving, they often recommend immediate surgery, or they may do more tests to confirm the exact type of tumour and whether it has spread to the fluid surrounding the brain. This will enable the team to ensure the best form of treatment is offered to your child. The team may also carry out baseline tests to measure your child's progress over time. These include tests on hearing, kidneys, height, weight and the heart.

The following tests may be used:

- **Biopsy** — if the tumour cannot be removed safely, or if a diagnosis is needed before surgery, the team will remove part of the tumour for analysis – known as a biopsy. Sometimes the tumour is biopsied and removed at the same time (see surgery). The tumour sample is sent to the laboratory where cutting-edge scientific techniques are used to find out exactly what type of tumour it is and look at its biological make-up. Knowing about the tumour biology can provide important information that will help doctors to decide on the best treatment plan for your child.
- **Lumbar puncture** — involves inserting a fine needle into the spinal canal to remove some fluid, which can then be analysed. This is usually done under general anaesthetic.
- **Blood tests** — can be used to detect chemicals released by certain tumours. These are known as tumour markers.
- **Eye tests (ophthalmology)** — if the tumour is in an area that may affect the eyesight, a full visual examination will take place.

- **Cognitive assessment —** your child may have an assessment of intellectual function to check if they have any difficulties relating to learning now, and so that their progress can be monitored.

It takes a few days to accurately test tumour samples in the laboratory and this delay is a difficult time for families. But the right diagnosis is extremely important.

Receiving the diagnosis

This is an extremely difficult period. You may have very little time for the news to sink in, as your child could begin treatment immediately, and you can experience a lot of changes very quickly.

Try to have someone with you who can give you the support you need. Use this guide to help you think through what you need to put in place to cope, both practically and emotionally.

What will the diagnosis mean for my child?

Physically, tumours affect each child in a different way. Some have a short period of illness and a near-full recovery. Others are left with lasting effects, especially if part of the brain is injured. It is a sad fact that some children do not survive, but an increasing number of brain and spinal cord tumours are being cured. Research is continuing all the time to find out more about these tumours and how best to treat them.

Your doctor will talk to you about your child's possible prognosis (outcome). However, it is important to realise that prognosis is an average 'best guess'. It is different for each child.

Talking to your child

One of the hardest parts of caring for a child with cancer is knowing what to say and how much to say. Many families feel that answering questions honestly is best, giving a little information at a time.

Take your time to think about how to explain things to your child. Children often see things differently to adults, as they live more in the moment, so a few simple facts may be enough.

You will have your own way of communicating within your family. How much information you give will depend on your child and what questions they have been asking. You can help them by focusing on the positives and encouraging them to take life one day at a time.

If you are worried about what to say, or concerned about your child's emotional wellbeing, talk to your healthcare team.

> “My two year old knows she's got a thing called Timmy tumour in her head and he makes her poorly, so she goes to hospital for chemo, which is magic medicine. I feel she deals with it a lot easier because she's aware something is making her poorly and she has to have medicine, rather than not knowing what they're going to do.”

Sharing the diagnosis with others

You will need to tell other people, including family, close friends, school and work. You might like to tell people yourself, and might even find it therapeutic to talk through what is happening. If not, you could ask a friend or family member to act as a point of contact.

Some families have found setting up a closed group on social media is helpful, as it allows them to send updates out without having to talk to lots of different people individually.

The team caring for your child may be able to help you to communicate with your child's school and support you with contacting your employer.

Seeking information

You may want to find out as much as possible. The internet can be a valuable source of information, but it is important to be aware that there is much that is either incorrect or unhelpful. Always use well-known, reputable sites. Check when information was published and where a site is based as information from other countries may not always be relevant.

Don't worry that your child's doctor will be offended if you turn up with a list of questions about things you have found out online. They will take you seriously and give you honest, balanced advice based on your child's individual situation.

Using social media

Facebook, blogs and other social media offer an easy way of communicating with others. Families can tap into a supportive network of fellow parents from around the world all facing a similar journey. Regardless of what country you live in, the feelings and experiences can be the same. It is important to remember that other stories may not be relevant to your child and may not be factually accurate.

> “Some people set up a Facebook page with updates. I don't share my son's journey on Facebook. If I want to pass a message to family and friends, I'll paste it into emails. Then my family will pass it on.”

Getting the support you need

Your child's medical team will be familiar with the difficulties you might face and how these may affect you and your family. They can help and support you throughout your child's illness. You should be given a key worker or main person who you can contact with any questions. Ask for their phone number and email address. Remember, there are also helplines and support outside the hospital.

The Brain Tumour Charity has several animations for children
www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support

Young Lives vs Cancer has a storybook for young children 'Zarah has a brain tumour'.
www.younglivesvscancer.org.uk/cancer-info-support/my-child-has-cancer/storybooks

Coping with family life at diagnosis

It may feel that life is put on hold. Depending on how long your child is in hospital, you may need to rely on friends, neighbours and families to keep everything going at home. As the shock of diagnosis wears off and treatment begins, start to think carefully about the different responsibilities in your life and what you need.

Use the diagram below to help you plan what you need to put in place. In the diagram, you are at the centre, below your child. This is because although your child's needs are – rightly – at the top of everyone's agendas, it's very important your own needs are met too so that you can cope throughout this challenging time. We talk more about this in 'Caring for yourself and other family members' on page 36.

YOUR CHILD
taking care of your child
in hospital and at home;
appointments; medicines

Juggling family finances —
bills; benefits;
support and grants

Going to work —
arrangements;
adjusted hours;
taking a break

YOU
Looking after yourself
with healthy habits;
exercise; social life;
eating and sleeping well;
psychological support

Saying connected with family and close friends —
staying in contact; visiting;
practical support

Managing the home —
household chores;
pets; vehicles;
shopping

Maintaining partner relationships —
communication; helping
each other; self-care

Taking care of siblings —
school /activity arrangements;
time to talk; help with
homework; family time

“ My husband had to go back to work and I don’t know how he managed. I think he felt more pressure to hold everything together, whereas I perhaps felt there were times when I could go to bits. He said it actually helped him, because being busy gave him a little respite from thinking about the situation. He was very calm on the outside and very strong. But he went grey pretty much overnight. ”

“ My in-laws were great. They picked the kids up from school. On days when they couldn’t, or when they needed a break, there was a network of friends who would step in. I was a bit cut off from it. People just arranged all this for me. ”

“ I’ve written a journal since the day we were rushed into hospital. I don’t write it every day, Putting it on paper gets it out, so it’s not boiling up in my head. It screws your brain up trying to hold too much in your head, so finding an outlet for how you’re feeling is always a really good thing. ”

Starting treatment

The start of treatment can feel like a whirlwind. Suddenly, you are thrown into the world of cancer care, with unfamiliar language and treatments. This section explains who will look after your child, the main types of treatment, clinical trials and some of the practicalities you need to think about.

Your child's health and care team

Your child's medical team will be keen to get treatment started as soon as possible at your nearest principal treatment centre (PTC) for children's cancer. This means that your child will get highly specialised care. Your child may need to stay in hospital for a while so that they can be monitored during treatment.

Your child will be looked after by a team of professionals (known as a multidisciplinary team or MDT), who will work together to help with your child's physical and psychological recovery. Each person has their own role, but they work closely together to plan how to meet the needs of your child and your family. Who is in this team will depend on where your child is treated and what your child needs, but it will include some of the people described on the next page.

Over time, your child may also receive some treatment at your local hospital. This is called 'shared care' and allocated hospitals are known as paediatric oncology shared care units (POSCU). If your child has any shared care, the decisions about their treatment will still be made by your child's consultant at the principal treatment centre but it just means that it is easier as you may need to travel less.

> “When someone says they're in hospital with somebody, you imagine them sitting in a chair by the bed, don't you? But most paediatric units have a system of self-caring where as much as possible they get the parent to take over the care of their child to learn what to do. It's right I think, and most parents want to do that, but I was exhausted. I was doing her tube feeds and everything – so basically I was a very active carer in hospital.”

Who's who in my child's care?

Consultants are the lead doctors in your child's care. These include:

- **Paediatric oncologists** — responsible for leading your child's care and supervision of chemotherapy
- **Clinical oncologists** — radiotherapy specialists
- **Neurosurgeons** — brain surgeons
- **Neuropathologists** — scientists who make a diagnosis from tumour cells (biopsy)
- **Ophthalmologists** — eye doctors
- **Endocrinologists** — hormone doctors
- **Radiologists** — doctors who read x-rays and scans
- **Anaesthetists —** responsible for sedation during procedures
- other **doctors** work under the supervision of the consultant.

Dietitians provide advice and support to meet your child's nutritional needs during treatment and recovery.

Nurses may include clinical nurse specialists (CNS), paediatric oncology outreach nurse specialists (POONS), community nurses and other specialist nurses. Hospital care and ongoing care at home are provided by two separate nursing teams. You should have a key worker who acts as a link between all the different teams involved in your child's care.

Play specialists help make sure children's emotional and physical needs are met through play and also prepare them for unfamiliar procedures, such as lying still for radiotherapy.

Diagnostic radiographers take x-rays and scans.

Therapeutic radiographers are in charge of radiotherapy and work closely with clinical oncologists. Many centres have specialist paediatric radiographers.

Physiotherapists work with your child to restore any movement and function affected by the tumour or its treatment.

Occupational therapists support children to take part in everyday activities and enable them to regain their independence.

Clinical psychologists and **neuropsychologists** identify difficulties with learning, emotional or behavioural issues and provide support.

Social workers provide you and your child with practical, emotional and financial support throughout treatment and rehabilitation.

Speech and language therapists help with any speech, language and communication difficulty, and problems with swallowing, eating and drinking.

What your child’s care might look like:

Your local community

- Your GP for your family’s health needs
- Local charities
- Community groups for carers
- Hospice support services

Specialist children’s cancer centre

- Full team of doctors and nurses specialising in all aspects of brain and spinal cord tumour treatment
- Full range of supportive care before, during and after treatment
- Specialist wards, facilities and resources

At home

- Outreach nurse services from your hospital to support your child at home
- Local children’s community nursing

Your child's care

Shared care unit

- Access to clinical services e.g. blood transfusions, antibiotics, blood tests
- Possible access to chemotherapy services
- Local support and community services

Types of treatment

After a definite diagnosis has been made, your doctor will discuss with you which treatment is best for your child. It is possible that your child will have a combination of different types of treatments.

Surgery

The neurosurgical team will often be the first doctors that you meet, especially if your child is unwell when the tumour is identified. They will discuss surgery and other potential treatments with the rest of the MDT. Your child may receive surgery:

- **To diagnose the tumour** — scans give lots of information about a tumour but cannot tell exactly what type of tumour it is and how quickly it is growing. To do this, some of the tumour is removed and studied by the neuropathology team. Getting good quality tumour samples, either from a biopsy or as part of a bigger operation to remove the tumour, is a very important part of surgery. Detailed scans are usually used as a form of ‘sat-nav’ during the operation and this is known as ‘image-guidance’ or image-guided surgery.
- **To remove the tumour** — surgery is sometimes used to physically remove the tumour. In some cases, completely removing the tumour, if that is safely possible, greatly improves the chances of survival. Surgery may be the only treatment that is needed for certain tumours. In other cases, leaving some of the tumour behind and using other treatments may be better. Your child’s surgeon will be able to tell you afterwards how much of the tumour they have removed. They will usually do a scan after surgery within a day or two to confirm this and help with planning the next treatment stage if required.
- **To relieve pressure** related to excess fluid in the brain — some tumours can block the normal flow of fluid around the brain. If this causes a build-up of fluid in the brain, it can increase pressure which causes symptoms including headaches and drowsiness. This is called 'hydrocephalus'. This may need to be relieved by inserting a temporary external drain (EVD), or more permanently by inserting a plastic shunt tube usually down to the abdominal cavity, or having a procedure called a third ventriculostomy, which creates a new internal channel in the brain through which the fluid can drain away.

What are the risks and side effects?

The challenge for brain surgery is to remove as much tumour as safely as possible without damaging important parts of the brain or nerves that could affect the way a child functions in the longer term. Brain surgery can cause temporary effects that will settle over time, especially if there is bruising after the operation or swelling of the surrounding areas of the brain. Hydrocephalus (build up of brain fluid) can sometimes develop after surgery, even if it was not there before, and so can seizures or ‘fits’. Many children get over their surgery surprisingly quickly and can be up and about within a few days.

'Posterior fossa syndrome (PFS)' is a name given to a collection of symptoms which may occur together following surgery to the back of the brain.

Download or order FREE of charge the CCLG factsheet ‘**Posterior fossa syndrome**’.

www.cclg.org.uk/publications

Radiotherapy

Radiotherapy uses high-energy radiation to treat tumours. It is like having an x-ray taken and does not hurt. It is usually directed very accurately at the tumour to destroy the cancer cells. Radiotherapy is given as a course of daily treatments, over a period of weeks. It is usually used after surgery and sometimes with, or before, chemotherapy.

It is important for children to keep very still during treatments. The team will make a special mask to keep their head still. Young children may be treated under general anaesthetic, while older children may be helped with play therapy and distraction.

As part of preparation, your child will have a planning CT or MRI scan. The clinical oncologist uses this scan, along with any previous MRIs, to find the area they will treat, along with any important organs near to the treatment area. They then produce a radiotherapy dose map, which shows the dose of radiotherapy that should be given to all the relevant areas of the brain or spine.

There are different types of radiotherapy, such as:

- **IMRT (intensity modulated radiotherapy)** — uses X-rays to enable very accurate sculpting of the dose around the tumour while minimising the dose to the surrounding organs.
- **Proton beam therapy** — uses protons instead of X-rays, as the risk of long-term side effects may be reduced. As a highly specialised form of radiotherapy, it is only available at a limited number of facilities worldwide. In the UK, the NHS Proton Beam Centre at the Christie Hospital in Manchester has been treating patients since 2018 and the UCLH facility in London opened in 2021. Before this, some patients had to travel abroad for proton therapy via the NHS Proton Overseas Programme.

What are the risks and side effects?

Radiotherapy treatments are designed to try and limit the side effects while maximising the chance of cure. The side effects of radiotherapy vary depending on the area treated, the dose of radiotherapy required and the age of the child. Younger children are more sensitive to the long-term effects of radiotherapy. The greater the volume of tissue exposed to radiotherapy, the more severe the potential side effects.

In the short term, side effects can include tiredness, feeling sick, loss of appetite and skin soreness. These side effects may get worse towards the end of the treatment course, and often peak a few weeks after treatment ends, before fading away. Radiotherapy to the brain can cause hair loss and this is usually temporary but can occasionally be permanent.

> “While they are in surgery, it feels like the longest day of your life. We ventured out to Starbucks, because if you’re sat on a corridor waiting for eight hours it would drive you crazy. Obviously they’ve got your details if they need to call you. There were moments where it was awful then there were times when we were laughing and chatting about the stupidest of things, because you have to lighten the tone a bit at some point just to survive.”

Long-term side effects when the brain is treated can include an effect on learning, reduced growth, hormone deficiencies and an increase in the risk of developing new tumours in later life.

Radiotherapy is an effective treatment for many tumours, but it can have some permanent side effects. It's important that you talk to your child's radiotherapy team about side effects and how they may affect your child, as they can be very variable.

The radiographers will give advice about what to expect and will answer any queries that arise during radiotherapy. Your child will also be reviewed by their clinical oncologist on a regular basis during radiotherapy. Generally, children tolerate radiotherapy very well in the short term and you may be encouraged to send your child to school during radiotherapy to maintain some normality if they are well enough.

Chemotherapy

This treatment uses anti-cancer drugs that disturb the cells' ability to divide and reproduce. It affects all dividing cells, including some normal cells – but while normal cells can repair the damage, cancer cells cannot. So, they become damaged and eventually die.

Chemotherapy can be given by mouth, into a vein (usually by a drip), or as a spinal fluid injection. The drugs are absorbed into the blood (except for spinal fluid injections, which are absorbed into the brain and spinal cord), so they can reach all the cancer cells. This is particularly useful when cancers have spread to different areas of the body.

Each person's chemotherapy is different. How often and for how long it is given will depend on several things, including the type of tumour and your child's age. It can be given in high doses over a short period, or in lower doses over a longer period. After each dose, there is usually time for your child's normal cells to recover before the next cycle.

What are the risks and side effects?

Some chemotherapy drugs cause short-term side effects, such as hair loss, feeling or being sick, tiredness, increased risk of infection, sore mouth and tummy, and diarrhoea. These are usually temporary, and there are effective ways of making these manageable. Some treatments can have longer term effects. These may include effects on fertility, hearing, and the way the lungs, kidneys or heart work. These are not always obvious at the time, so your child will have appointments to check for these after treatment has finished. The side effects that your child may have will depend on the specific drugs that they are given. Your doctor will explain these side effects in detail.

> “The first couple of radiotherapy sessions were hard because you can't stay in the room. But we all got into a routine of it and it became a fun thing. My daughter had a sticker chart, so she could see how she was working through the 31 sessions. It didn't particularly make her feel poorly, so she would go to radiotherapy and then go off to school.”

Targeted molecular therapy

The understanding of the steps involved in brain and spinal cord tumour growth has improved in recent years. As a result, new drugs have been developed which target and block genetic pathways thought to be crucial to tumour growth.

Some of these drugs have shown promising results in childhood brain tumours, particularly low grade gliomas. However, for other tumours, these new therapies have not improved survival or quality of life for those affected.

Nevertheless, new drugs continue to be developed for a range of tumours and, if appropriate, certain children may be eligible to try them under clinical trial supervision.

Taking part in clinical trials?

Every cancer treatment in current use began its life in a clinical trial. Many children are offered cancer treatment within a clinical trial. Research trials and studies are regularly carried out to try and find new and better treatments for cancer, such as a new drug or combination of treatments. These trials often build on existing knowledge and treatment protocols and ask specific questions aimed at improving treatments further. By doing this through clinical trials, we can make sure that comparisons are measured consistently and reliably over times to see if one treatment is better than another.

Your child will receive the best possible treatment regardless of whether they are on a trial or not. If your doctor believes a trial would be applicable to your child's individual condition they will discuss this with you and you will be given information about what is involved.

Giving your consent

Before your child is asked to take part in a clinical trial, your child’s medical team will explain what the trial is aiming to achieve and the risks and benefits of taking part. Once you have considered everything you need to know, you will be asked to give your consent for your child to take part and to sign a form. There is no pressure to take part and your child will receive the best treatment available whatever you decide.

When deciding whether to take part in a trial, it can add to the stress of coping with your sick child and to the bewildering range of processes associated with treatment. It may seem as though the treatment team is passing over responsibility for deciding what treatment your child should be given.

However, in practice, the treatment team will only invite you to join a trial when it is considered in the best interests of your child and where both you and your child are likely to benefit.

Randomisation

For some trials, a process called randomisation is carried out. This means a computer will randomly allocate your child to have a particular treatment in the trial. This is done so that each treatment group has a similar mix of children with different ages, sex and general health. It makes sure that researchers and doctors can’t decide who should get which treatment to avoid bias that could skew the findings.

Safety

The safety of children in clinical trials is the top priority. All trials are approved by ethics and regulatory committees, and are reviewed on an ongoing basis.

Donating to a tissue bank

Your child's hospital team will offer you the opportunity to anonymously donate tissue left over from tests, such as a biopsy or bone marrow test, to the national children's and young people's cancer tissue bank called VIVO Biobank (www.vivobiobank.org). This sample of tissue can then be used by scientists to learn more about your child's type of tumour and how best to treat it. This is voluntary and you will have plenty of time to decide if you wish to take part.

If treatment doesn't work

In some cases, parents are told the devastating news that their child's disease cannot be cured. In this situation, your child's care will change to focus on giving them the best quality of life and managing their symptoms. There is a huge amount of practical and emotional support for families at this time, such as from your child's hospital, local hospice and charities.

If treatment is not successful, your child's doctor will talk to you about the options. They will be able to refer you for support where you feel most at ease, whether in hospital, a hospice or at home.

CCLG has a range of resources to help parents to prepare and plan if treatment doesn't work. These can be found at **www.cclg.org.uk/about-cancer/my-child-and-cancer/my-child-cannot-be-cured**

Coping with family life during treatment

Once your child starts treatment, the period of change during diagnosis becomes a more long-term situation. You may be spending a lot of time in the hospital, so you will need to think about who will manage the rest of family life while you are focusing on your child.

If you are working, you will need to discuss this with your employer, as you may be eligible for financial or practical support during this time. You can talk to your Young Lives vs Cancer social worker or contact their welfare advice line to find out about employment rights, benefits for carers and disability benefits for your child. There may be local schemes which entitle you to get help with parking, transport and food.

Think also about yourself and what you need to be able to cope emotionally. You will need to look after yourself so that you can cope – not just in the coming days and weeks, but perhaps in the months and years ahead too. Enjoying a little time to yourself or with a close friend or partner may help you.

Don't be scared or shy of asking for or accepting help. People are often keen to help but may not know what to say or do. Be prepared to ask for specific help and tell them what you need. Here are some ideas:

- Ask other family members to help with household tasks, such as washing, gardening or shopping.
- Ask a friend if they can coordinate a rota so you get the help you need.
- If you have a partner, chat through your calendar commitments to see how you can share the load.
- If you don't want to leave the hospital, ask a friend to meet you there for a quick coffee.
- Your child's school, neighbours, community organisations and clubs are often keen to help with tasks from cooking to school drop offs.

Supporting your child during treatment

Through their treatment, your child will have many different needs, and these will change over time. There is lots of support available, from the hospital team and from other cancer organisations, and – perhaps most importantly – from other parents. Over time, you will develop your own ways of coping and finding some balance. Here are some things that you may come across:

Anxiety or low mood?

...the play team and clinical psychologists can help your child manage difficult feelings.

Fatigue and low motivation?

...your clinical team can explain the patterns of fatigue over the course of treatment to help you plan. They can also give advice around fatigue management and can prescribe medication to help.

Boredom?

...the play team and schools team can help your child engage with activities that interest and challenge them.

Challenging behaviour?

...if your child starts to communicate stress or anxiety through challenging behaviour, the psychology and therapy team can help you and your child to find ways to manage these.

Side effects?

...your team can offer a wide range of treatments and strategies to help cope with side effects.

Isolation or loneliness?

...your child may feel lonely, especially if they have times in isolation to protect them from infection. The play team and clinical psychologists can help, but you can help too. Think about how your child can stay in contact with friends, including social media and messaging apps.

Eating and weight problems?

...dietitians can help with appetite loss or weight gain. If your child cannot eat or drink, they may be given high-calorie drinks and milkshakes or be tube fed if necessary. Speech therapists can help with problems with swallowing.

Having a tumour, and the associated treatment, uses up a lot of the body's energy. It is important your child has a well-balanced diet so they are best able to respond to treatment, tolerate chemotherapy, fight infection and repair damaged cells from radiotherapy or surgery. Your child's medical team includes a specialist paediatric dietitian who can provide free personalised nutrition and diet plans for your child.

After treatment

The end of cancer treatment feels like an important milestone, and rightly so. But while it is the end of one journey, it is the start of another one: recovery. Once your child goes home, life may feel more normal but your child will still need care. You will need to feel able to cope at home, away from the hospital.

For many parents, reaching the end of treatment can bring mixed emotions. You may feel relieved and happy your child has completed treatment, but you may also feel anxious that the tumour may come back and about ongoing support. It can be a very unsettling time. It is important to accept that it will take time to recover physically and emotionally. In this section we talk about ongoing support, rehabilitation, going back to school and timescales for recovery.

> “It would have helped if someone had said ‘Don’t think it’s all over once you get home’. Leaving hospital was so euphoric, but at home it was more difficult than I anticipated. My child was unwell, still on medication and tube fed, so we were responsible for everything that in hospital the nurses did.”

Ongoing support

The hospital team will start preparing for your child to go home soon after they are admitted, as it can take time to arrange the right support. They will involve you in your child’s care so that you learn how to meet their needs. The medical team works closely with other professionals (see page 23) to assess what support your child needs, both in the short and longer term. Your child may need ongoing support in these areas:

- **Medical —** If your child is having ongoing treatment, you will be given information on how to care for them at home, including what to do if they become unwell, and how to give medicines and any special feeds. The community nursing team will help you with this. If your child has nursing needs that are too much for you to manage, your child may receive ongoing nursing support.
- **Physical —** If your child has physical difficulties, they will be assessed to check how they will cope at home with things like climbing stairs, getting into bed and going to the toilet. The occupational therapy team will order equipment if it’s needed.

- **Psychological and practical —** Before going home, it's important to put emotional and practical help in place so that you don't have any time unsupported. This help may come from professionals such as outreach nurses, social workers, psychologists and support groups, while family, friends and voluntary agencies may also be able to help you.

If your child has ongoing complex needs, you may be referred to a community paediatrician once appointments with the hospital team become less frequent. Ask your team about this.

Rehabilitation and recovery

Rehabilitation is an important part of the recovery process for brain and spinal cord tumour patients. This is because of how the tumour and treatment may have affected the functions of the brain and therefore your child's ability to carry out daily activities. Rehabilitation is about regaining and maintaining skills and abilities. The team will have started working on your child's rehabilitation when they were diagnosed, and this will continue throughout treatment and ongoing recovery.

Once your child goes home, their rehabilitation care will be transferred to a community team. Professionals such as physiotherapists, speech and language therapists, play specialists and clinical psychologists will continue to work with your child – at home or in a local clinic – to help them regain and maintain their skills and abilities.

Therapy sessions with the community team will be less often than the hospital sessions. If you feel that your child's needs are not being met, talk to your keyworker or doctor who will discuss your concerns with the hospital rehabilitation team.

Post-treatment therapy

You may need to practice rehabilitation exercises with your child at home. At first, this can be challenging and frustrating but rehabilitation works best when activities or exercises are part of everyday tasks. This gives your child more practice and can be made fun by using games and activities that your child enjoys. It also helps to get into a routine so that it becomes something they automatically do at certain times of the day. Your child's therapist will give you ideas about how to do this.

Try to be encouraging and positive about the efforts your child makes. Focus on raising the level of effort rather than the level of achievement, as this may vary depending on their health.

Recovery does not always progress smoothly. At times, your child may seem to be making extremely encouraging progress, but at others things may seem to hit a standstill.

During intensive periods of treatment, a child may even seem to regress. This can be very frustrating for both you and your child. It's important to keep going with rehabilitation during these times to get things back on track as quickly as possible.

The rehabilitation team may also have details about local charities who may be able to offer help. Please talk to your team about what is available in your area.

> “My son sees a physio and has hydrotherapy at hospital. He has orthotics on his splints. We see an occupational therapist and a social worker as well as a psychologist to help with his eating. We still have lots of appointments.”

Education

Going to school or college is an important step in getting life back to normal. Your child may breeze through the experience but, depending on their type of tumour and treatment, their return to education will still need careful planning.

You child may have developed difficulties with learning, concentration, coordination and fatigue. A cognitive assessment conducted by the clinical psychologist or neuropsychologist can help to identify any specific learning issues and if additional support is needed. Your child may find school hard for emotional reasons – they have been through a lot and life may have changed in many ways.

Being away from school can affect friendships and confidence. Your child's abilities, appearance or mood may have changed during their illness, and they may feel self-conscious. School is important for children with cancer. School helps them to feel 'normal', rebuilds their confidence and reduces the isolation and loneliness which many children with tumours face. The process of returning to school can be made easier through planning and preparation. Communication between school, hospital and families is key in making sure a child's education and social needs are met.

While in hospital

Your child may have attended the hospital school depending on their treatment and length of stay as an in-patient. The hospital school will support them to keep up with their school work if possible and can play an important part in their rehabilitation. The teachers will keep in close contact with your child's usual school to stay in step with the rest of their class. Your child may be able to sit exams at the hospital school if it is a registered exam centre.

Getting support in school

Every school has a special educational needs coordinator (SENCO) who is responsible for making sure that every child's needs are met. It's a good idea to involve school early, so that they can plan to meet your child's needs. Your specialist/outreach nurse or clinical psychologist should be involved in the planning and your child may be visited at school by community therapists – for example, in occupational therapy or speech and language.

If you and your child's school work closely together, there is much you can do to encourage your child to feel positive, reconnect with their friends, and find ways to adapt learning to meet their needs.

> “In some ways, when my daughter went back to school, she'd become a bit of a celebrity. It's been a very slow, phased return, building the time back up. She's still tired from treatment even all these months afterwards. She still has naps and gets tired more easily than the average six year old.”

Some schools are better at adjusting to children's individual needs than others. If you feel your child is not getting the support and understanding you need, talk to your keyworker or nurse specialist. Part of their role is to help your child integrate back into school and they can help facilitate discussions with the school.

Your child may need an education, health and care (EHC) plan, which looks at all your child's needs across education, health and social care to make sure your child receives the right amount of support. An assessment has to be requested by the school, hospital or you and is carried out by the local authority. Whether or not your child has an EHC plan, their progress and level of support should be regularly reviewed.

> “I found getting my daughter the care and equipment she needed was a real struggle actually, a bit of a fight… I think it's made me quite combative and a bit aggressive sometimes. That's probably not a good thing, but it was necessary and I did get what I wanted in the end.”

Further resources

- The Children's Trust Brain Injury Hub – advice for families and education resources. **www.thechildrenstrust.org.uk/brain-injury-information/info-and-advice/return-to-education**
- The Royal Marsden – 'Returning to school: A teacher's guide for pupils with brain tumours'. **patientinfolibrary.royalmarsden.nhs.uk/returning-school-guide-teachers-students-brain-tumours**
- CCLG – 'A school's guide to supporting a pupil with cancer'. **www.cclg.org.uk/publications**
- Young Lives vs Cancer – Cancer and school life pack. **www.younglivesvscancer.org.uk/cancer-info-support/education/my-student-has-cancer**
- The Brain Tumour Charity – resources for returning to education. **www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support/children-and-families-service/education-resources**

Timescales for recovery

All parents want to know how long recovery will take, but unfortunately this is something the team cannot predict. They can make an educated guess, but each situation is so different that it is impossible to know how long it will take to regain a skill, or whether some changes may be permanent. This can be very difficult to hear. Many parents cope by not looking too far ahead and taking things one day at a time.

Lots of encouragement and determination can help progress. You can also help by ensuring that the level of support is appropriate for your child's individual health and abilities.

Managing family life after treatment

Once your child goes home, it's helpful to avoid having fixed expectations about how things will be. This will be a period of adjustment for you all. Try to be realistic about how much care your child will need, who will provide it, and extra help you may need.

Talk to your child about what help they would like. For example, if they feel isolated, your focus might be inviting friends round. If they are worried about hobbies or regaining skills, you might prioritise that instead. Make sure you have all the benefits, equipment and support you need.

Who can help?

Ask your specialist nurse or Young Lives vs Cancer social worker for details of support groups, charities and any other agencies that can help.

- If you are caring at home, you could ask a friend or relative to come over so you have a chance to get out.
- If you are worried your child is anxious or low, contact your community team or your consultant.
- If you feel you are not getting the support you need at home or school, talk to your medical team. It may help to bring someone to meetings if you find them difficult.
- Sometimes progress can be slow and inconsistent. It helps to take one day at a time, and remember it does not mean things are not improving overall.

> “I would recommend having low expectations for recovery time. My daughter is several months down the line, and we still live with the consequences of treatment in terms of her energy levels and her physical frailty. I think it's important to set expectations.”

> “There are things I cared about before that I don't care about any more: what people think about the state of my house or what I'm doing. You've got to live your life. You're grateful you've still got your child and you've got through it. You don't waste time anymore on things that don't matter.”

Caring for yourself and other family members

This section is all about looking after your own health and wellbeing. This is important to help you to cope with the challenges that you are facing during this time.

Your feelings

It is natural to feel a range of different feelings at different times through your child's journey — from anger or fear to despair. Of course, there will also be times of hope, relief and joy. It is important to find some way of coping with difficult feelings.

Some parents might find these things helpful:

- meeting friends or family you trust
- journalling thoughts and feelings
- connecting with other parents in similar situations
- distracting yourself with activities you enjoy

Anxiety and depression

It is normal to feel emotional when your child is seriously ill. If you find your emotions overwhelming and are struggling to cope, you may need extra support. Anxiety, low mood or depression are very common and most parents will experience these. If these are not manageable, or you have symptoms such as nightmares or flashbacks, speak to your GP or healthcare team.

Feeling anxious includes a constant sense of worry or fear, sometimes with panic attacks.

Low mood or depression include lack of motivation, feelings of hopelessness and difficulty sleeping or concentrating.

Things that help include:

- **Psychological therapy** — includes psychotherapy, counselling, or cognitive behavioural therapy (CBT), a talking therapy that helps identify thought patterns and break unhelpful habits. Time and space to process difficult feelings is often helpful.
- **Mindfulness** — training the brain by focusing on the present and learning to let go of persistent thoughts. Visit the Mental Health Foundation www.mentalhealth.org.uk or NHS Every Mind Matters www.nhs.uk/every-mind-matters for more information.

- **Medication** — can help in the short term with depression and anxiety, stress and sleeping problems.
- **Complementary therapies** — such as massage or reflexology may help. Some organisations offer these free of charge to people caring for others with cancer. Ask your team for more information.

Your relationships with others

An important part of looking after yourself involves spending time with other people, including friends and family. You may not feel like seeing people during difficult times in your child's journey, but the important people in your life can make a big difference.

Your partner

Having a child who is unwell or having treatment can be very challenging. The worry, stress and constant demands can put a lot of strain on a relationship.

If you feel the need to take time out as a couple away from everything, try not to feel guilty. Taking time to reconnect and care for each other can help you to stay resilient and better support the whole family.

> “I think this is something parents can feel guilty about, because obviously everything focuses on your child, and that's all you care about. But on the sidelines you've got a couple of adults whose lives have imploded, and they are a secondary issue. You are secondary to everything.”

Friends and family

Often family and friends want to help but aren't sure how, so think about what would make a difference — a babysitter, a shopping trip, a glass of wine or a school pick up. Don't be afraid to let them know how they can help.

A friendly ear is just as valuable as practical help, so make time to stay in touch. If you don't feel like talking, doing something together can be a good distraction.

Some people will be more comfortable with talking about your situation than others. Some don't know what to say or do to help. Don't be scared to tell them to help them understand what support you need. Try to learn who you can trust to support you on a bad day. It doesn't mean that the others aren't important too — just that you may choose not to share your feelings with them when you are feeling vulnerable.

This may be a time where you make new friends too. Other parents who have been through similar experiences can become valuable connections. Talk to your treatment centre to find your local group.

Your other children

If you have other children, they will be greatly affected by their sibling's illness. Their world has turned upside down and they may not understand why this is happening. They will naturally have lots of questions and fears, although they may not want to worry anyone at this anxious time.

An honest approach is nearly always best, but if you don't feel able to tell siblings what is happening, there may be staff at the hospital who can advise.

Brothers and sisters are likely to have a lot of the same emotions as parents which can seem overwhelming or wrong. However, all feelings are normal and there is no wrong or right way to feel. All siblings will react differently but the following are some of the issues that may arise:

- **Grief and fear** — they may be scared and worried about their sibling and what is happening to them, and missing them.
- **Guilt** — sometimes siblings blame themselves and feel it is their fault. They may feel guilty for being healthy and carrying on with normal activites when their sibling can’t.
- **Feeling jealous and left out** — siblings may feel jealous of everyone worrying about their brother or sister, and that they seem to have more attention from everyone, more treats than they do or don’t get told off for behaving badly. If they experience feelings of jealousy, they may also feel guilty about this.
- **Broken routine** — daily life may become disrupted and unpredictable if other people have been looking after them while you are involved in your child’s hospital care and the normal family routines and organisation disturbed.
- **Craving attention** — they may worry that they are no longer important and they need attention themselves, especially as you are likely to have had less time and energy to focus on them.
- **Anger** — siblings may feel angry about many things, such as their brother or sister’s illness and how family life has changed.
- **World view** — seeing their sibling in a vulnerable state may shake their own sense of security and lead them to feel fragile, anxious or depressed.

Try to make a regular time to spend with each child so they feel reassured that you love them even if they are not seeing you as often. They need to know that they are important too.

Help other children to understand what is happening to their sibling and to feel part of things. Sometimes, playing an active role by helping out helps them to feel involved and valued.

Many siblings keep their feelings bottled up to avoid worrying their parents. For siblings to be open and honest, talking to another family member or friend may be best. Often the place where they may show how they feel is at school. This may result in behavioural issues, difficulties with school work or being withdrawn and emotional. It is important that the staff at any sibling’s school know what is happening at home so that appropriate support can be given.

> “Suddenly, we were at the hospital all day, every day. Our daughter was recovering from surgery, while our son was being passed around family and friends. He did well, but would often be upset. We made Saturday morning his time to play rugby so we could watch him and that’s been a good thing. Now they’re happily squabbling away together again.”

Managing family life at home

Take a moment to think about each person in the family, what their needs are, and how they can be met. That includes parents, siblings, and of course your child with cancer. This can give you some clues about what help you need to put in place.

For example:

- If your child had really enjoyed after-school chess club, can they play against a friend online while they are in hospital?
- If their sibling is eager to keep going to Scouts, can you organise a regular lift?
- If your partner seems very tired and stressed, can you help them find a regular activity that gives them a change of scene?
- If you are struggling to care for your child as well as managing the household tasks, can you talk to a social worker to see if you are entitled to support as a carer?
- Try to notice how you are feeling and notice when things are too much.
- Try to encourage everyone to talk honestly about how they are feeling from time to time – and to think about something completely different too.
- Reassure everyone in your family that no feelings are 'bad' – feelings of frustration, jealousy or resentment are natural and talking can help.
- Don't be afraid or embarrassed to go to your GP if anyone in your family is finding things too much. Sometimes the strongest thing to do is to ask for help.

Even during difficult times, there are ways to enjoy your family time together and still have fun. It can help to find a balance so you and your children can focus on other things too. Talk to other parents in similar situations for ideas to manage this.

> “ My son has young carers support because he does so much with his little brother, even though he's only eight. He'll get up and decide to empty the dishwasher and look in on his brother. I'm sad for him sometimes because this is his childhood, and he's had to do a lot of growing up. But in other ways I think, he's just a lovely boy. It's made him even more kind and caring than he already was. We always make sure he's got people he can talk to, and try and give him lots of normality too. ”

Looking to the future

This final section looks at what a tumour may mean for your child and the rest of your family going forward.

Children can have an amazing ability and desire for recovery. How long this will take, and the nature of your child's recovery, depends on their individual circumstances. This can be unsettling and cause an ongoing feeling of uncertainty, especially at first — but many families are able to adapt and adjust over time.

Long-term care

As time goes on after treatment has finished, your child's team will monitor their health and well-being. The team will continue to assess the area where the tumour was found, along with any other areas that may have been damaged by the tumour or treatment.

As your child gets older, the team may monitor with tests and scans and check things like weight, appetite, blood counts, kidney function, mobility, hearing, vision and hormone levels.

They are also there to talk through concerns about rehabilitation, school or employment, so it's a good idea to bring a list of concerns to appointments. Families will usually feel anxious about follow-up appointments and scans, bringing up memories of treatment and fears of the tumour returning. This is understandable and normal and is often called scanxiety. You may find it helpful to find ways to prepare — especially for your child — and talk these feelings through with the team.

> “Our daughter is scanned every three months now. We just had clear results so we can breathe again – but only for three months. We try to get to some kind of normality, but it's at the back of my mind all the time – and often at the front of my mind.”

Long-term effects

A tumour in the brain and spinal cord can have wide-ranging effects because of the damage it may have caused. If your child is affected in the longer term, there might be areas that they need help with, depending on their particular situation. Some can be simply addressed with medical treatment, while for others you need to develop strategies and find ways to adapt and adjust.

The areas where your child may need help include:

- **Growth and hormone levels –** metabolism, growth, puberty and fertility, and response to stress or illness can be affected. Your child's growth and hormone levels will be monitored by a specialist department called endocrinology. Hormones are available in a synthetic form and may be given as medication if required.
- **Hearing/eyesight and other senses –** there is a small risk that these may be affected. Your child will be monitored and referred to specialist doctors for help if required.
- **Neurological issues –** symptoms such as weakness down one side, difficulty balancing or a drooping face can occur. These often disappear over time. Some children have problems with fine motor control and find it hard to do up buttons or complete fiddly tasks and will need support.
- **Difficulties with learning –** learning and social skills can be affected. Your child may have challenges with behaviour, language, memory and attention span, and the ability to reason and problem solve. It may take them longer to do things. A neuropsychological assessment can identify your child's difficulties and strengths.
- **Independence –** within teenage years and young adulthood, often more complex skills such as learning to go out and about, road safety and managing money can be more difficult and take longer to learn. It is really important your child is able to develop their independence as far as they can; regular practice and gradually reducing the amount of support you give can be helpful. More advice can be given by the multidisciplinary team.
- **Emotions and behaviour –** some children develop emotional difficulties as a result of the illness and trauma of having treatment. They need support to process what they have been through and to cope with difficult feelings.
- **Fertility –** there are fertility preservation services which are potentially available, and your child may have been offered these depending on age and treatment given. Please discuss this further with your consultant or keyworker.

> “We made an effort to get our son out in the fresh air, even though it meant working around the difficulties and adapting things. He just wants to be a normal boy who plays with his friends without all of these restrictions. We're trying to keep him safe but with the balance of getting him to do things and enjoy his life.”

Emotional or behavioural challenges

Not every child who has had treatment for a brain tumour will be emotionally distressed by the experience. But because they have been through so much, it is important that you and your child talk things through regularly and that they feel they can express their fears. The healthcare team can support you with this, so try not to worry.

If your child's behaviour becomes more challenging, this could be for several reasons. It could be a sign of anxiety, stress or frustration. Their behaviour may also be affected by neurological changes as a result of the cancer or their treatment. These might affect their impulse control or their ability to regulate their emotions.

If you are finding their behaviour difficult to manage, there are strategies that can help you work with your child on their behaviour over time. These are similar to standard parenting strategies, but may need to be more intensive and consistent. Talk to your child's healthcare team and ask for support.

In the meantime, it can help to think of challenging behaviour as your child trying to tell you something, rather than simply 'behaving badly'. Sometimes it helps to make a note of what was happening before each episode and what happened afterwards. You may be able to identify triggers that are causing distress. It can then be possible to make simple changes to the environment or routine to avoid these situations or to help your child manage these situations differently. It might also help to take regular breaks and get in the habit of slow breathing or walking away when things get difficult, to help you keep calm in conflict situations.

A new reality

Finding a new 'normal' family life can take time for everyone in the family. Both you and your child may need to process the difficulties, experiences and emotions you have encountered but were not able to think about at the time. Everyone needs time to adjust to things being, or feeling, different from how they were before. Many parents feel extremely protective of their child and constantly look for symptoms of the tumour returning. Some families feel grief at the loss of aspects of their child or their lives that have been changed by the experience. Depending on your child's needs, you may need to reconsider options for school, college or even employment for your child. This means revising your ideas of how you had expected life to be. This can be difficult, but many parents say it becomes easier to cope with over time.

When a child has a brain or spinal cord tumour, this can create major life changes in the long term. Of course, there are the practical changes – a new schedule of attending clinics, and getting support and therapy. But it can also change people's philosophy of life and provide a new world view, with a clearer sense of what really matters in life and a determination to focus on the positives and to make the most of the time we have.

“Now she’s coming up to three and she’s due to start nursery, I’m very scared of leaving her with someone else. I’m looking forward to a little break and her having a bit of a life, but I’m also absolutely terrified.”

“I don’t need to go on holiday to Mauritius to be happy. I can appreciate just sitting down to breakfast with my boys or taking them out for a day out. My husband is the same. We sit and say ‘Isn’t this lovely? We’ve come out to a freezing cold beach – but we got here!”

“You realise your happiness actually doesn’t depend on anything other than the people who matter to you. You become sure of that, and that makes you more sure about the decisions you make in life and the reasons you’re making them. That’s a good thing.”

“I feel really lucky. It’s been a tough time and we don’t know what the future holds — he could always have an abnormal scan — but it gives you a lot of clarity about your priorities.”

Glossary

AFP
Alphafetoprotein is a chemical released by certain tumours into the blood. High levels of AFP may be used as a marker to suggest the presence of the tumour.

Anaesthetic
A general anaesthetic makes you unconscious. A local anaesthetic stops feeling in part of the body but you are still awake. Both stop feeling, especially pain.

Astrocytoma
Tumour of the astrocytes (star shaped glial cells). Glial cells help to support the cells in the brain that send and receive signals. The most common type of glioma.

Ataxia
Jerky, erratic movements probably caused by damage to the cerebellum.

Benign
Low-grade or less aggressive tumours, which don't usually spread.

Beta HCG
Beta human chorionic gonadotrophin is a chemical released by certain tumours into the blood. High levels of this may be used as a marker to suggest the presence of the tumour.

Biopsy
Taking a small sample of the tumour, to be analysed by a histopathologist to give a diagnosis.

Blood brain barrier
System where the composition of the membranes around the central nervous system (CNS) protects the brain by not allowing some chemicals to cross it.

Bone marrow
The substance at the centre of long bones that makes blood cells.

Brain stem
Controls the basic functions essential to life, including blood pressure, breathing, heartbeat, eye movements and swallowing. It is the bottom part of the brain and connects the cerebral hemispheres to the spinal cord.

Cannula
A fine tube inserted into a vein to give drugs through or to take blood.

Catheter
Tube that is passed into the body to drain fluid.

Central venous line (central line)
Long plastic tube that is inserted into a large vein near the heart, under anaethetic. It is used to take blood samples and give drugs.

Cerebellum
The back part of the brain concerned with balance and coordination.

Cerebral cortex
Four lobes on each side of the upper brain that process information and maintain our bodily functions.

Cerebrospinal fluid (CSF)
Fluid that circulates around the brain and spinal cord.

Chemotherapy
Drugs that interfere with the ability of a cancer cell to divide and reproduce itself.

Clinical Psychologist
Advises on managing behaviour or strong feelings and identifies difficulties with learning or memory.

Clinical trials
Research on patients to find new and better treatments.

Cognitive or neuropsychological assessment
Assessment of your child's intelligence and memory.

Craniopharyngioma
Benign tumour that develops from tissue behind the pituitary gland.

CT scan
Computerised tomography scan that uses X-rays to create detailed images of the body.

Ependymoma
Tumour of the ependymal cells, which line the passageways of the brain.

External ventricular drain (EVD)
Temporary way of draining CSF from the ventricles in the brain.

Fine motor skills
Small precise movements such as those involved in feeding, dressing and writing.

Frontal lobe
Part of the brain responsible for movement and cognitive abilities such as decision-making, influencing behaviour and personality.

Gastrostomy tube (PEG tube)
Tube inserted directly into the stomach for feeding.

Glioma
Tumour of the glial (supportive cells) of the brain.

Haemogloblin (HB)
The substance in red blood cells that carries oxygen around the body.

Hemiparesis
Weakness on one side of the body.

High-grade tumours
Malignant or aggressive tumours that can spread easily.

Histopathologist
The doctor who analyses the tumour under a microscope to give a diagnosis.

Hormones
Chemical messengers released from glands e.g. growth hormone, which control growth and development.

Hydrocephalus
Blockage within the brain leading to a build up of CSF and thus raised intracranial pressure.

Hypothalamus
Part of the brain that controls body function (such as temperature and hormone levels), emotional expression (such as pleasure and anger) and the sleep wake cycle.

Immune system
The body's defence against infection, disease and foreign substances.

Immunosuppressive
Lowering the body's ability to fight infection.

Intracranial
Inside the main part of the brain.

Intrathecal
Giving drugs by injection into the spinal fluid.

Intravenous (IV)
Giving drugs by injection into a vein.

Keyworker
Named nurse who liaises with all the different teams involved in your child’s care.

Low-grade tumours
Benign or less aggressive tumours, which rarely spread.

Lumbar puncture
Needle inserted into the spine to remove some of the CSF fluid for analysis.

Malignant
Growth with tendency to invade and destroy nearby tissue and spread to other parts of the body.

Medulloblastoma
Tumour arising in the nerve cells in the cerebellum.

MRI scan
Magnetic resonance scan that uses strong magnetic fields and radiowaves to create detailed images. It is particularly useful for imaging the central nervous system (brain and spine).

MRS
A magnetic resonance spectroscopy image is like an MRI scan but gives more information about chemicals in the brain and workings of the tumour cells.

Nasogastric tube (NG tube)
Thin tube that is put down the nose and throat into the stomach and can be to give feeds, usually used for a short time.

Nausea
Feeling sick.

Neuro-oncology
The diagnosis and treatment of brain and spinal cord tumours.

Neuroscience
Field that is devoted to the scientific study of the nervous system.

Neurosurgery
Surgical treatment of diseases of the brain and spinal cord.

Neutropenia or neutropenic
Low levels of neutrophils.

Neutrophils
A type of white blood cell that fights infection.

Occipital lobe
One lobe of the cerebrum where visual understanding and perception are controlled.

Occupational therapist (OT)
Helps to redevelop skills needed to manage daily activities. They provide practical advice and help for your child to be as independent as possible.

Oncologist
Doctor who specialises in treating people with cancer.

Oncology
The study and treatment of cancer.

Paediatric
To do with children.

Palliative
Relief of a symptom (for example, pain) rather than cure of the disease.

Parietal lobe
Part of the brain controlling touch and other senses, and spatial awareness.

PET scan
Positron-emission tomography scan that looks at blood flow and can identify active cancer cells.

Physiotherapist (physio)
Therapist who helps with exercise and other physical treatments to regain normal movement.

Pituitary
Small organ that lies underneath the brain and produces hormones.

Platelets
A type of blood cell that helps the blood to clot.

Posterior fossa
Region at the back of the brain that houses the brain stem and cerebellum.

Prognosis
The outlook or expected outcome of a disease and its treatment.

Proton beam therapy
Radiotherapy that uses protons instead of x-rays to destroy cancer cells.

Radiotherapy
Treatment using high-energy rays to destroy cancer cells.

Raised intracranial pressure
Increased pressure in the skull caused by excess fluid in the brain or the presence of a tumour.

Randomisation
Process that randomly allocates patients to have different treatments in a trial to ensure that no treatment is favoured.

Relapse
The return of symptoms of a disease after a period of good health; re-occurrence of a tumour after treatment.

Remission
When there is no longer any visible cancer.

Stem cell
Early (immature) blood cell from which other blood cells are made.

Therapy
Treatment.

Shunt
A device which allows CSF to be diverted from the brain to the abdominal cavity.

Spinal cord
Connects the brain to the lower back and carries signals between the brain and the body.

Temporal lobe
Part of the brain involved in learning, memory, understanding language and hearing processing.

Total parenteral nutrition
Nutrition (feed) given via a central line.

Tumour
Group of cells that multiply in an uncontrolled way.

Ventricle
Fluid filled cavity in the brain.

Ventriculostomy
Creation of another drainage route from the ventricles for the CSF fluid.

White blood cells (WBC)
Blood cells that help fight infection.

Whole genome sequencing (WGS)
Test looking at all genetic changes in a tumour.

Help and support

CCLG: The Children & Young People's Cancer Association

www.cclg.org.uk

Information on childhood cancer, funding of research, and a full range of award-winning patient information resources, including Contact magazine for families of children with cancer

Join our closed Facebook group just for parents and carers of a child with cancer: **www.facebook.com/groups/cclgparentcarergroup**

Scan to order or download this booklet or any other CCLG publications FREE of charge: **www.cclg.org.uk/publications**

Better Safe Than Tumour

www.bettersafethantumour.com

National awareness campaigns of symptoms of brain tumours in children and young people

Brain and Spine Foundation

www.brainandspine.org.uk

FREE helpline: 0808 808 1000

Support for anyone affected by neurological issues

Brainbow

www.cuh.nhs.uk/our-services/childrens-services-paediatrics/childrens-services-a-z/brainbow-paediatrics

Rehabilitation service at Addenbrooke's Hospital in Cambridge for children based in the East of England

The Brain Tumour Charity

www.thebraintumourcharity.org.uk

FREE helpline: 0808 800 0004

Information and support for those affected by brain tumours

Child Brain Injury Trust

www.childbraininjurytrust.org.uk

FREE helpline: 0303 303 2248

Information on children's acquired brain injury and training and support for professionals including school staff

Children's Brain Tumour Research Centre

www.cbtrc.org

Committed to improving understanding of childhood brain tumours

The Children's Trust Brain Injury Hub
www.thechildrenstrust.org.uk
Information on acquired brain injury. Offers rehabilitation and education services.

The International Brain Tumour Alliance
www.theibta.org
Global network for brain tumour patient and carer groups around the world

Young Lives vs Cancer
www.younglivesvscancer.org.uk
FREE helpline: 0300 330 5220
Advice and support for families affected by childhood cancer

Cancer Research UK
www.cancerresearchuk.org
Information and statistics on all cancer types and a funder of research into cancer

Macmillan Cancer Support
www.macmillan.org.uk
FREE helpline: 0808 808 0000
Practical, financial and emotional support for anyone affected by cancer

Notes:

CCLG

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Trusted Information Creator
Patient Information Forum

We are CCLG: The Children & Young People's Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care, and outcomes.

Our expert information helps children and young people, and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

Our work is funded by donations. If you would like to help, visit **www.cclg.org.uk/donate** or text '**CCLG**' to **70085** to donate **£3.** You may be charged for one text message at your network's standard or charity rate. CCLG will receive 100% of your donation.

We want our information resources to be relevant and useful. Tell us what you think by scanning this code to complete a short survey, or contact us at publications@cclg.org.uk