



Brain tumours in children

An information guide for parents, carers and families

The purpose of this guide is to give information about brain tumours to help you understand more about the type of cancer your child has.

Information in this guide should be used to support professional advice specific to your child's diagnosis. If you have any questions, it is important to ask your child's medical team.

What are brain tumours?

Brain tumours are the most common tumours that develop in children. Children of any age may be affected. About 400 children in the UK develop brain tumours each year. Boys are affected slightly more often than girls.

A tumour in the brain can come from the brain itself (primary), or from another part of the body (secondary). This information is about primary brain tumours.

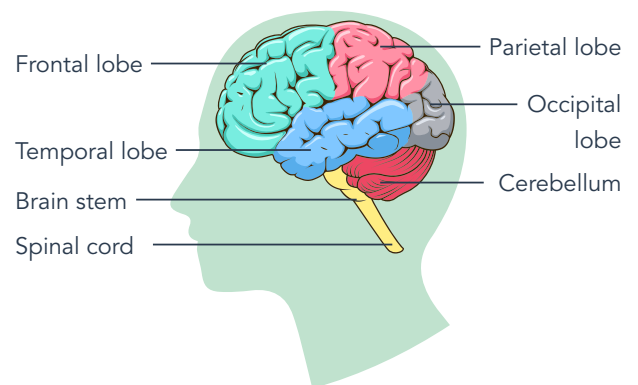
The brain

The brain sits within the skull and is part of the central nervous system which includes the spinal cord. The brain and the spinal cord are bathed in a liquid called the cerebrospinal fluid (CSF) and are surrounded by three layers of membrane.

The main parts of the brain are:

- Cerebrum - the largest part of the brain and at the top of the head. It is made up of two halves (hemispheres) and is divided into lobes - the frontal, temporal, parietal and occipital, as shown on the diagram. It controls thinking, learning, memory, problem solving, emotions and touch. It also helps us be aware of our body position.

- Cerebellum - the back part of the brain and controls movement, balance and coordination.
- Brain stem - connects the brain to the spinal cord. It is in the lower part of the brain just above the neck. It controls breathing, body temperature, heart rate and blood pressure, eye movements and swallowing.



Signs and symptoms

These will depend on the size of the tumour, where it is and how it affects that part of the brain. A growing tumour may push the brain out of the way or block the flow of fluid in the brain. Some symptoms are caused by the pressure inside the head (intracranial pressure) being higher than it should be. Brain tumours may also cause problems with balance and walking, weakness on one side of the body, or changes in behaviour.

Some common symptoms can include:

- headaches (often worse in the morning)
- being sick (usually in the morning) or feeling sick
- fits (seizures)
- feeling irritated or disinterested in day-to-day things
- abnormal eye movements, blurring or double vision
- feeling very tired quicker than usual
- feeling extremely sleepy (drowsy) for no reason

Some of these are common even without a brain tumour, and this can cause difficulties with diagnosis.

How it is diagnosed

A variety of tests and investigations may be needed to diagnose a brain tumour. Any tests and investigations that your child needs will be explained to you. Your child's doctor will ask about the problems your child has had recently. They may look into the back of your child's eyes to check for swelling, which can be a sign of raised pressure in the brain. They will usually check things like balance, coordination, sensation and reflexes. They will then arrange for further tests as below:

CT or MRI scans

Ordinary x-rays are not usually helpful for brain tumours. Most children will have a CT or an MRI scan, which looks in detail at the inside of the brain. A CT scan is quick but uses a lot of x-rays, so it is important to avoid using this too much. An MRI scan gives more detailed pictures, but takes much longer. Machines are noisy, and children may need an anaesthetic to help them stay still.

Blood tests

These are usually done to make sure it is safe to do an operation, and can also be used to help diagnose certain types of tumours.

Biopsy

A small operation is done (under anaesthetic) to remove a piece of the tumour. The sample is looked at in the laboratory to find out exactly what type of tumour it is. A biopsy isn't always done as it is sometimes better to remove the whole tumour in one operation. In this case, it will be a few days before the exact type of tumour is known. Occasionally, because of the position in the brain and what the scan pictures show, your child's doctor may start treatment without a biopsy or surgery.

Eye tests

These are useful as part of diagnosis and also for monitoring response to treatment. Tests will look at

how well your child can see, including any double-vision, eye movements and blind spots.

Types of brain tumours

There are different types of brain tumours and they are usually named after the type of cells they develop from. The main types are **astrocytoma**, **ependymoma**, and **medulloblastoma**, but there are many other, less common types. Brain tumours can be non-cancerous (benign) or cancerous (malignant).

Non-cancerous brain tumours

It is unusual for benign brain tumour cells to spread into other areas. However, they can have serious effects if they continue to grow, so it is still important to take an active approach to treatment. Sometimes, it may be difficult to remove a benign tumour, because of where it is, so other treatments may be needed.

The most common benign brain tumours are **low-grade astrocytoma** (also called **low-grade glioma**) and **craniopharyngioma**.

Cancerous primary brain tumours

Malignant primary brain tumours are most likely to cause problems by causing pressure and damage to the areas around them and by spreading to the normal brain tissue close by. Sometimes, they spread to other areas distant to the original tumour.

The main types of malignant tumours that affect children are **high-grade gliomas**, **ependymomas** and **medulloblastomas**.

Medulloblastomas are the most common malignant brain tumours found in children. They usually develop in the back of the brain (cerebellum). They may spread to other parts of the brain or into the spinal cord, and treatment must include the whole of the central nervous system.

Treatment

Treatment will depend on the type of brain tumour, its size and where it is in the brain. Surgery, radiotherapy and drugs are used to treat brain tumours. Your child may have one treatment or a combination of treatments.

Surgery

Usually, a specialist surgeon will operate to remove as much of the tumour as possible. Operations can be long and often last more than six to eight hours.

Sometimes, the fluid in and around the brain does not flow freely, as a result of the tumour or brain swelling. In this case, it may be necessary to place a fine tube (shunt) to drain excess fluid from the brain and into the lining of the tummy area (abdomen). You cannot see the shunt outside of the body. Another way of treating this is to create a drainage route for the fluid to bypass the obstruction.

After the operation, your child may spend some time in an intensive care ward or high dependency unit, so nurses and doctors can keep a close eye on them.

Once the type of tumour is known, a plan to treat any tumour left behind can be made. For benign tumours, no further treatment may be needed.

Radiotherapy

Radiotherapy treats cancer by using high-energy radiation beams to destroy cancer cells whilst doing as little harm as possible to normal cells.

Radiotherapy is delivered carefully and accurately, and lots of preparation is required before treatment can start. Radiotherapy is given in a number of daily treatments (or fractions) for up to six weeks. Each treatment usually takes only a few minutes.

Sometimes more specialised types of radiotherapy may be used. Your child's doctor will explain more about this.

Drug treatments

These include chemotherapy and targeted drugs. Chemotherapy is the use of anti-cancer drugs to destroy cancer cells. The combination of drugs and the length of treatment will depend on your child's particular type of tumour.

Other medicines

Your child may need to take medicines for a while to reduce or control the symptoms of the brain tumour:

- steroids – reduce swelling and inflammation in the brain and can help with symptoms.
- anticonvulsants – help prevent fits, which can be a problem before or after operations on the brain. They may only be necessary for a short period.

Side effects during treatment

Treatment for brain tumours can cause side effects, and your child's doctor will discuss these with you before the treatment starts. Any side effects will depend on the part

of the body that's being treated and what treatment is being used.

Most side effects are short-term and gradually disappear once treatment stops. Side effects can include:

- feeling sick (nausea) and being sick (vomiting)
- temporary hair loss
- tiredness
- low blood count leading to an increased risk of infection and bruising and bleeding (sometimes blood and/or platelet transfusions are needed)
- a sore mouth and tummy
- diarrhoea

Radiotherapy can make your child feel tired, and the skin in the area that's being treated may go red or get darker.

Clinical trials

Many children have their treatment as part of a clinical research trial or study. Trials and studies are carried out to try to improve our understanding of the best way to treat an illness. There are better results for curing children's cancers compared with just a few years ago because of clinical trials. Your child's medical team will talk to you about taking part in a clinical trial and will answer any questions you have. Taking part is completely voluntary, and you'll be given plenty of time to decide if it's right for your child. You may decide not to take part, or you can withdraw from a trial at any stage. Your child will still receive the best standard treatment available.

National treatment guidelines

Sometimes, clinical trials are not available for your child's tumour. In this case, your doctors will still offer the most appropriate treatment, using guidelines which have been agreed by experts across the UK. Children's Cancer and Leukaemia Group (CCLG) is an important organisation which helps to produce these guidelines.

Donating to a tissue bank

Brain tumours are rare and more research is needed to help doctors develop better treatment for the future. Your child's hospital team will offer you the opportunity to anonymously donate tissue left over from tests, for example, a biopsy or bone marrow test, to the tissue bank. This sample of tissue can then be used by scientists to learn more about brain tumours and how best to treat them. This is voluntary, and you will have plenty of time to decide if you wish to take part.

Late side effects

Months or years later some children may develop late side effects from the treatment they have had. These may include a reduction in bone growth, a change in the way the heart, lungs and kidneys work, a risk of infertility and a small increase in the risk of developing another cancer in later life. It is important to understand that not all side effects will happen to all patients. Please visit www.cclg.org.uk/life-after-childhood-cancer for more information.

Your child's doctor or nurse will talk to you about any possible late side effects and will keep a close eye on possible long-term side effects in follow-up clinics.

Follow-up care

Once treatment has finished, the doctors will monitor your child closely with regular appointments to be sure that the cancer has not come back and there are no complications. After a while, you will not need to visit the clinic so often. If you have specific concerns about your child's condition and treatment, it's best to discuss them with your child's doctor, who knows the situation in detail.

Your feelings

It's devastating to hear that your child has cancer and you may feel overwhelmed but there are many professionals and organisations to help you through this difficult time. You may have many feelings, such as fear, guilt, sadness, anger, and uncertainty. These are all normal reactions and are part of the process that many parents go through.

It's not possible to address in this guide all of the feelings you may have. However, the CCLG booklet 'A parent's guide to children and young people with cancer', talks about the emotional impact of caring for a child with cancer and suggests sources of help and support. Your child may have a variety of powerful emotions throughout their experience of cancer. The Parent's Guide discusses these further and talks about how you can support your child.



The CCLG booklet 'A parent's guide to children and young people with cancer' is available **FREE** of charge from your child's hospital

All CCLG booklets and leaflets can be downloaded or ordered from our website:

www.cclg.org.uk/publications

i USEFUL ORGANISATIONS

Children's Cancer and Leukaemia Group (CCLG) publishes a variety of free resources to order or download.

www.cclg.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to their families.

www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer.

www.macmillan.org.uk

The Brain Tumour Charity funds research and offers support and information to people affected by brain tumours.

www.thebraintumourcharity.org



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Patient Information Forum

With thanks to Dr Nicky Thorp, Consultant Clinical Oncologist, (The Clatterbridge Cancer Centre, Liverpool) and CCLG member, who reviewed this factsheet on behalf of the CCLG Information Advisory Group, comprising multi-professional experts in the field of children's cancer.

Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

Our work is funded by donations. If you would like to help, text 'CCLG' to 70300 to donate £3. This will cost £3 plus a standard rate message.

We are grateful to all those who have contributed to this publication. We make every effort to ensure that this information is accurate and up to date at the time of printing. CCLG does not accept any responsibility for information provided by third parties including those referred to or signposted to in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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