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.

More children than ever are surviving childhood cancer. There are new and better drugs and treatments, and we can now also work to reduce the after-effects of having had cancer in the past.

It is devastating to hear that your child has cancer, and at times it can feel overwhelming, but there are many healthcare professionals and support organisations to help you through this difficult time.

Understanding more about the cancer your child has, and the treatments that may be used, can often help parents to cope. We hope you find the information here helpful. Your child’s specialist will give you more detailed information and, if you have any questions, it is important to ask the specialist doctor or nurse who knows your child's individual situation.

This factsheet is published in conjunction with CCLG’s booklet entitled: ‘Children and Young People with Cancer: A Parent’s Guide’.

Brain tumours

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.

Signs and symptoms

These will depend on the size of the tumour, where it is and how it affects that part of the brain. Most commonly, children present with symptoms described below. These are caused by the pressure inside the head being higher than it should be: a growing tumour may push normal brain out of the way, or block the flow of fluid in the brain. Doctors call this raised intracranial pressure, and it can cause symptoms such as:
- headaches (often worse in the morning)
- vomiting (usually in the morning) or feeling sick
- fits (seizures)
- feeling very irritated or losing interest in day-to-day things
- eye problems, such as abnormal eye movements, blurring or double vision feeling very tired much more quickly than usual
- feeling extremely sleepy (drowsy) for no reason.

Brain tumours can also cause problems with balance and walking, weakness down one side of the body, or changes in behaviour. Some of these symptoms are common even without a brain tumour, and this can cause confusion in the early stages.

The brain

The brain is contained within the skull, which protects it. Between the brain and the skull, there are three layers of membrane called the meninges. These completely cover the brain and spinal cord and help to protect it. Between two of these layers is a space that contains a fluid called cerebrospinal fluid (CSF), which circulates around the brain and spinal cord.
What happens when a brain tumour is suspected

Knowing what a test involves can make things a bit easier. The specialist doctor and nurse will explain things but don’t be afraid to ask questions.

Your doctor will want to hear about the problems your child has had recently, and will examine him or her properly. This will include looking into the back of your child’s eyes with an ophthalmoscope to check for swelling, which can be a sign of raised pressure in the brain. They’ll usually check other things like balance, coordination, sensation and reflexes.

CT or MRI scan
Most children will have a CT or an MRI scan, which looks in detail at the inside of the brain.

A CT scan uses X-rays. It is quick and often is the best first-line investigation, but it does not give as detailed pictures as an MRI. It uses quite a lot of X-rays, and so it is important to make sure we do not use it on too many people if it can be avoided.

An MRI scan uses no X-rays, and gives more detailed pictures, but takes much longer. Machines are noisy, and often children cannot lie still long enough to get proper images. It is sometimes necessary to have an anaesthetic for this scan.

Ordinary X-rays are not usually helpful for brain tumours.

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 tumour.

Biopsy
It is often necessary for doctors to remove a small part of the tumour (biopsy) to find out exactly what type of tumour it is. It means your child will need to go into hospital for an operation under general anaesthetic. The piece of tumour removed is then examined under a microscope by an specialist doctor called a pathologist.

A biopsy isn’t always done; 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.

Sometimes, it may be safer to do the operation in two stages. Part of the tumour might be removed in the first operation and the rest a few days later.

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 either benign (non-cancerous) or malignant (cancerous).

Benign brain tumours
These remain in the part of the brain that they started in and do not usually spread into other areas. Sometimes it may be difficult to remove a benign tumour, because of where it is and, in this situation, other treatments may be needed.

The most common tumour of this type is a low grade astrocytoma (also called low grade glioma).

Malignant primary brain tumours
These are most likely to cause problems by causing pressure and damage to the areas around them and possibly by spreading to the normal brain tissue close by.

The main types that affect children are:

High grade astrocytoma and ependymoma
These tumours develop from the supporting cells of the brain known as glial cells, and are sometimes also called gliomas.

Medulloblastomas
These usually develop in the lower part of the brain, the cerebellum. They may spread to other parts of the brain or into the spinal cord, and treatment must include the whole of this.

Treatment

Because there are different types of brain tumours, treatment will not be the same for everyone. The doctors will look at the type of brain tumour, its size and where it is in the brain before deciding on the best treatment.

These are the main treatments used to treat brain tumours. Your child may have one treatment or a combination of treatments:

Surgery
Usually, a neurosurgeon will operate to remove as much of the tumour as possible. Operations can be very long – it is not uncommon for these to be more than six or eight hours – so you should not become unduly worried by this.

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 the body. Another way of treating this is to create another drainage route for the fluid around the obstruction (called a ventriculostomy).

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

Once a diagnosis is known, a plan to treat any tumour left behind can be made. For benign tumours, there may be no further treatment, but for some, radiotherapy or chemotherapy will be required.

**Radiotherapy**
Radiotherapy treats cancer by using high energy radiation beams. These are exactly the same as visible light, but instead of reflecting from the surface, the energy passes inside the body, where it causes damage to tumour cells.

Radiotherapy is delivered extremely carefully, using machines linked to the MRI scans of your child's brain. The process usually takes a few minutes each time, but often needs to continue for five or six weeks.

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

**Chemotherapy**
Chemotherapy uses drugs to get rid of cancer cells. Chemotherapy is given into the veins, and sometimes as a liquid or tablets by mouth. Treatment is often quite prolonged, with periods of time in hospital and gaps when you will be able to return home. This part of the treatment is planned by an oncologist.

The specialist doctor and nurse will explain your child’s treatment and answer your questions so that you understand what is involved.

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

**Steroids**
These are medicines that reduce swelling and inflammation in the brain and can help with symptoms.

**Anticonvulsants**
These are medicines that help prevent fits, which can be a problem before or after operations on the brain. They may only be necessary for a short period, but sometimes are needed for longer.

**Side effects of treatment**
Your child's doctor and specialist nurse will explain more about what to expect. Always let them know about any side effects your child is having. Many side effects can be well controlled or made easier.

Some possible common side effects of radiotherapy and chemotherapy include:

**Hair loss**
Both radiotherapy and chemotherapy can cause hair loss. Your child’s hair will usually grow back again after chemotherapy, although it may not after radiotherapy.

**Tiredness**
Tiredness is very common with both treatments and may continue for weeks after chemotherapy or radiotherapy finishes.

**Feeling sick**
Radiotherapy and chemotherapy may make your child feel sick. This can usually be controlled well with anti-sickness drugs, which the oncologist will prescribe for your child.

**Increased risk of an infection**
Chemotherapy can increase the risk of infection, so it is important to contact the oncologist or specialist nurse straightaway if your child has a temperature, any signs of infection or suddenly feels unwell.

**Skin changes in the treated area if your child is having radiotherapy**
Radiotherapy can cause a mild form of sunburn. Skin may become red, flaky or sore if your child has fair skin and may become darker and flaky if your child has dark skin. You’ll be given advice on looking after the skin in the treated area.

**Clinical trials**
Trials aim to improve our understanding of the best way to treat an illness, usually by comparing the standard treatment with a new or modified version. It is important to realise that a clinical trial is not an ‘experiment’, and your doctor will always offer you what is believed to be the best available treatment. Clinical trials are usually offered to explore ways of making new improvements to treatment, beyond what is already known.

Specialist doctors carry out many trials for brain tumours. If appropriate, your child’s medical team will talk to you about taking part in a clinical trial, and will answer any questions you have. Written information is often provided to help explain things.

Taking part in a research trial is completely voluntary, and you’ll be given plenty of time to decide if it is right for your child. You can also join a trial, and then withdraw if you change your mind at a later date.

**Treatment guidelines**
Sometimes, clinical trials are not available for your child’s tumour. This may be because a recent trial has just finished, or because the tumour is very rare. In these cases, you can expect your doctors and nurses to offer treatment which is agreed to be the most appropriate, using guidelines which have been prepared by experts across the country. The Children’s Cancer and Leukaemia Group (CCLG) is an important organisation which helps to produce these guidelines.

**Follow-up care**
After treatment is over, your child will be seen regularly by specialists. This is to check their progress and how well they’re recovering from treatment. It is also to check that they don’t have any long-term problems from treatment.

You can contact your child’s specialist doctor or nurse at any time if you have any worries about their health.
**Long-term side effects**

Sometimes treatments may cause possible long-term side effects that may develop later. Your child’s oncologist or specialist nurse will explain the possible risk of any long-term effects in your child’s situation. Children are monitored for any long-term problems following treatment so that they can be picked up and managed early on.

**Your feelings**

As a parent, the fact that your child has cancer is one of the worst situations you can be faced with. You may have many emotions, such as fear, guilt, sadness, anger and uncertainty. These are all normal reactions and are part of the process that many parents go through at such a difficult time. It is not possible to address in this factsheet all of the feelings you may have. However, the CCLG booklet ‘Children & Young People’s Cancer: A Parent’s Guide’, 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.

**Useful organisations**

**Children’s Cancer and Leukaemia Group (CCLG)**

www.cclg.org.uk

CCLG supports the 1,700 children who develop cancer each year in the UK. It gives support to healthcare professionals involved in caring for children with cancer and is instrumental in the development of high standards of care.

**CLIC Sargent**

www.clicsargent.org.uk

CLIC Sargent offers practical support to children and young people aged 21 and under, with cancer or leukaemia, and to their families.

**Macmillan Cancer Support**

www.macmillan.org

Offers support and advice to those affected by cancer.

**The Brain Tumour Charity**

www.thebraintumourcharity.org

The Brain Tumour Charity funds research into brain tumours and offers support and information to people with brain tumours, and their families.

**References**

This factsheet has been compiled using information from a number of reliable sources, including: