
Childhood brain tumours

Our bodies are made up of billions of cells. Normally, these cells reproduce and repair themselves in a controlled way and do not cause us any problems.

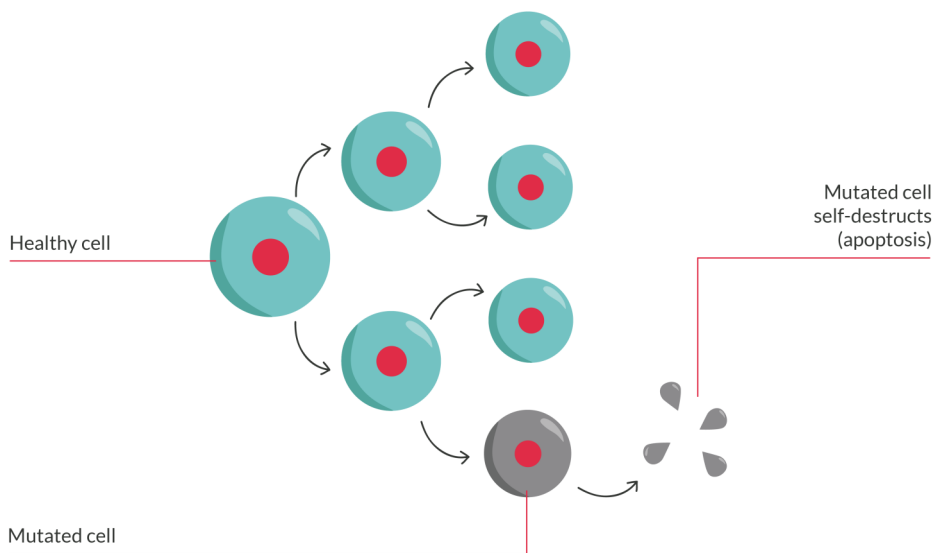
However, if this process gets disrupted for some reason, the cells can begin to grow in an uncontrolled way, creating a lump of cells called a tumour.

There are over 150 different types of brain (and spinal) tumour. They are usually named after the type of brain cell they grow from and/or where they are in the brain.

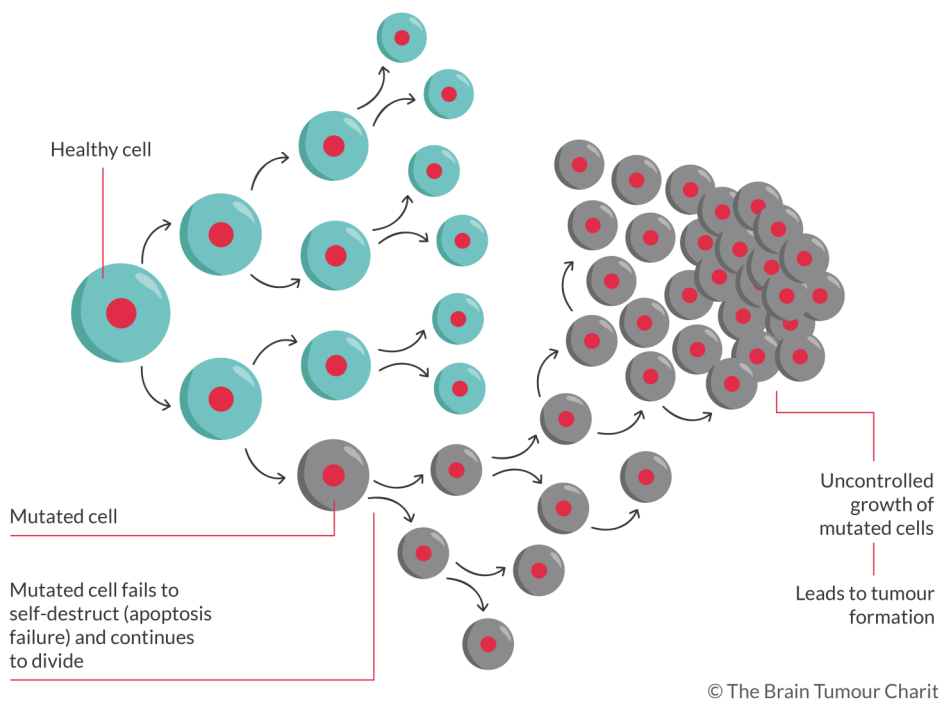
This fact sheet explains some of the terms you may hear if your child receives a diagnosis of a brain tumour.

In this fact sheet:

- ☐ What is a brain tumour?
- ☐ What are the symptoms of a brain tumour?
- ☐ What causes brain tumours?
- ☐ How are brain tumours treated?
- ☐ What are the side-effects of brain tumours?
- ☐ Some information about different types of brain tumour



Normal cell division involves destruction of mutated cells



Disrupted cell division and failure of mutated cells to self-destruct but carry on dividing, leads to formation of a tumour

What is a brain tumour?

A brain tumour is an abnormal growth caused by cells dividing in an uncontrolled way.

There are over 150 different types of brain (and spinal) tumour and they are usually named according to the types of cell they start to grow from and/or the parts of the brain they grow in.

A **primary brain tumour** begins somewhere in the brain - it has not spread from elsewhere in the body.

A **secondary brain tumour** (known as a metastasis) has begun somewhere else in the body (for example, the kidney or skin) and has spread to the brain.

This fact sheet covers primary brain tumours.

For more information about tumour types, please see the sections at the end of this fact sheet.

How common are childhood brain tumours?

Childhood brain tumours are relatively rare. Around 598 children and young people in the UK are diagnosed with a brain tumour each year.

This means that, most times, the symptoms your child is showing will NOT be due to a brain tumour.

However, it is important to be aware of the symptoms, so you can go to your doctor if you are concerned.



How will I know if my child has a brain tumour?

Symptoms of brain tumours vary from child to child. Symptoms can also depend on exactly where in the brain the tumour is. They can often mimic symptoms of other, relatively minor childhood illnesses.

The presence of a symptom does not necessarily mean that your child has a brain tumour.

Common symptoms of childhood brain tumours include:

- Persistent vomiting/feelings of nausea
(over a two week period)
- Recurring headache
(over a four week period, particularly on waking)
- Abnormal eye movements
- Fits or seizures
- Behaviour change
including lethargy (severe tiredness and reduced energy levels)
and excessive sleepiness
- Abnormal balance/walking/co-ordination
- Blurred/double vision
- Abnormal head position (such as a head tilt)
- Delayed or arrested puberty
(puberty that doesn't start, or starts, but doesn't progress
as expected)



If your child has one or more of the above, you should take them to see a GP, explaining your worries about a brain tumour being present.

If they have two or more, ask for an urgent referral.

(An urgent referral means that your child will be given an appointment with a specialist who can further investigate the cause of their symptoms.)

If your child's symptoms are limited to eye problems and/or headaches, your GP will often recommend an eye test. To speed up the process, you should take your child to the opticians to have their eyes tested whilst waiting for the appointment with the GP, or around the same time.

You will find much more information about childhood brain tumours on our *HeadSmart* – be brain tumour aware website: headsmart.org.uk

Our HeadSmart campaign has helped to halve average diagnosis times for children, with the potential to save lives and reduce long term disabilities.

We have pocket-sized symptoms cards that list common signs and symptoms of childhood brain tumours that you can take with you to your family GP if you are concerned about your child. These are available to view on the **HeadSmart website** along with an animation and much more information.

BABIES UNDER 5 YEARS	CHILDREN 5 - 11 YEARS	TEENS 12 - 18 YEARS
- Persistent/recurrent vomiting - Balance/co-ordination/walking problems - Abnormal eye movements or suspected loss of vision* - Behaviour change, particularly lethargy - Fits or seizures (not with a fever) - Abnormal head position such as wry neck, head tilt or stiff neck* - Increasing head circumference (crossing centiles) 1 symptom: see GP 2+ symptoms: ask GP for an urgent referral *Starred symptoms: see GP and Optician	- Persistent/recurrent headache* - Persistent/recurrent vomiting - Balance/co-ordination/walking problems - Abnormal eye movements* - Blurred or double vision/loss of vision* - Behaviour change - Fits or seizures - Abnormal head position such as wry neck, head tilt or stiff neck* 1 symptom: see GP 2+ symptoms: ask GP for an urgent referral *Starred symptoms: see GP and Optician	- Persistent/recurrent headache* - Persistent/recurrent vomiting - Balance/co-ordination/walking problems - Abnormal eye movements* - Blurred or double vision/loss of vision* - Behaviour change - Fits or seizures - Delayed or arrested puberty 1 symptom: see GP 2+ symptoms: ask GP for an urgent referral *Starred symptoms: see GP and Optician

You can also get a link to the cards sent directly to your smartphone by texting SMART to 81400, or we can post a card to you.

Call our Information and Support Line on 0808 800 0004 or email ***support@thebraintumourcharity.org*** to request a card, or for more information.

How is a brain tumour diagnosed?

If your doctor (GP or A&E doctor) suspects your child has a brain tumour, they will refer them to a specialist. This will usually be a paediatrician (specialist in children's health) or a neurologist (specialist in brain and nerve disorders).

The paediatrician or neurologist, will give your child a series of tests to find out if they do have a brain tumour.

First they will ask questions about your child's health and give them a physical examination.

They will also test their nervous system. This is called a neurological examination.

A neurological examination involves looking at your child's sight, hearing, alertness, muscle strength, co-ordination, and reflexes.

They will also look at the back of their eyes to see if there is any swelling of the optic disc. (The optic disc is where the optic nerve from the brain enters the eye). Any swelling of the optic disc is a sign of raised pressure inside the skull. This could be a sign of a brain tumour.

Your child will then have one or more further tests.

They will need an MRI or CT scan to confirm whether a brain tumour is present.

For information about these scans, see the [Scans for children](#) webpage and fact sheet.

If, following these tests, a tumour is found, they may refer your child onto a neurosurgeon (specialist in surgery on the brain) or an oncologist (specialist in treating cancer).

To give a full diagnosis of the type of brain tumour, a small sample of the tumour (known as a biopsy) may need to be taken from your child's tumour. It is not always possible to take a biopsy - this will depend on where in the brain your child's tumour is and how safe it will be to take the sample.

A biopsy is an operation. It can take several hours. Your child's neurosurgeon will explain what happens and any risks.

If possible, as much of the tumour as possible will be removed at the same time. This is to prevent the need for a further operation. You may hear this operation called a 'resection', which means 'surgical removal'.

In both cases, cells from the tumour will be sent to a laboratory to be looked at and analysed to give a more detailed diagnosis of the exact type of tumour that your child has. This is important as it allows them to work out the best course of treatment for your child.

Opticians can also help diagnose brain tumours.

If the person who tests your child's eyesight (the optometrist) suspects or sees signs of swollen 'optic discs' at the back of your child's eye, they will send your child to the hospital for further tests.

This is because it could be a sign of increased pressure in the skull, which can be caused by a brain tumour (amongst other things).

This referral will be to a specialist 'eye doctor', called an ophthalmologist. It will usually be within 24 hours.

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

Grading of brain tumours

Brain tumours are graded from 1 to 4, according to how they look under the microscope and how they are likely to behave. This means how different they look to normal brain cells and how quickly they grow or are likely to spread within the brain.

Increasingly their genes are examined to give further information about how they are likely to behave and how they are likely to respond to certain treatments.

Brain tumours very rarely spread to other parts of the body.

Low grade tumours

Tumours graded 1 or 2 are called 'low grade' tumours. They are slower-growing and less likely to spread to other parts of the brain. There is less chance of them returning if they can be wholly removed.

They are sometimes referred to as 'benign'. The word 'benign' is used less nowadays as this can be misleading. These low grade tumours can still be serious.

This is because the tumour can cause harm by pressing on and damaging nearby areas of the brain, due to the limited amount of space in the skull.

They can also block the flow of the cerebrospinal fluid (CSF) within the brain, causing a harmful build-up of pressure on the brain.

High grade tumours

Tumours graded 3 or 4 are called 'high grade' tumours. They are faster-growing and more likely to spread to other parts of the brain or spinal cord.

They are sometimes referred to as 'malignant' or 'cancerous'. High grade brain tumours cannot usually be treated by surgery alone - other treatments, such as radiotherapy and/or chemotherapy, may also be used. They may come back, even if treated.

Within a tumour it is possible to have cells of different grades - for example, some grade 1 cells and some grade 2 cells. In these cases, the grade the tumour is given, as a whole, will be that of the highest grade of cells found. In this example, it would be called a grade 2 tumour.

It is important to know that brain tumours in children rarely change or increase in grade. This is seen more often in adults.



Gradings can be quite difficult to understand. Your child's health team can explain what it means for your child. Do ask questions if you are not clear.

What causes brain tumours?

Very often, the answer is that we just do not know. This can be one of the most difficult things to accept as a parent, as it can leave you feeling helpless.

At various times, there have been stories in the news about the possibility of mobile phones and power lines causing brain tumours, but the research remains inconclusive and, at present, there is no clear link between exposure to mobile phones or power lines and brain tumours.

Brain tumours are nobody's fault!

There is no research to show that anything you may have done during pregnancy, or in your child's early infancy, could have caused your child's brain tumour.

In addition, a tumour that has gone undetected for some time is not your fault - brain tumours can be difficult to spot, as their symptoms can be very similar, at first, to many common childhood illnesses.

The risk factors that we know about

Although we don't know what causes brain tumours, some people may have a slightly higher risk of developing them. This does NOT mean that they will develop a brain tumour.

Genetics

According to Cancer Research UK, genetics (inheriting a gene or genes that make you more likely to get a brain tumour) are thought to account for around 5% of brain tumours.

The following factors may affect your child's risk of developing a brain tumour:

- Certain genetic conditions may increase your child's risk of developing a brain tumour:
 - Neurofibromatosis type 1 and 2
 - Tuberous sclerosis
 - Li-Fraumeni syndrome
 - Von Hippel-Lindau syndrome
 - Turner syndrome
- If an immediate family member (parent or sibling) has a tumour of the CNS (central nervous system), your child may have a slightly higher chance of developing a brain tumour. However, the risk is still very low.

Radiation

We know that radiation to the head does increase the risk of a brain tumour developing.

As a result, the risk of developing another brain tumour later in life, such as a meningioma or glioma, is higher in children who have had radiotherapy to the head, than children who have not.

More information about the different types of brain tumour can be found later in this fact sheet.

This is particularly the case if they had radiation to the head before they are five years old.

Due to this known risk and the risk of developing learning difficulties, health professionals try to avoid giving radiation to a young child's brain, particularly under the age of three.

Radiotherapy is not given without very careful consideration and your child would not receive radiotherapy unless the expected benefits outweighed any potential risks to them.

More information about radiotherapy, can be found in the *Radiotherapy for children* webpage/fact sheet.



How are brain tumours treated?

The Brain Tumour Charity has a range of animations for children that explore and explain a variety of subjects relating to brain tumours and their treatment. Watch them at thebraintumourcharity.org/jake



Several factors influence the decision as to which treatment will best help your child.

A team of specialised health professionals (called an MDT or Multi-Disciplinary Team) will be involved with your child's individual diagnosis and treatment. They take account of factors such as the size and location of the tumour, the type of tumour your child has and how quickly it is growing. They will also consider your child's age and their general health.

See Your child's health team webpage and factsheet for more information.

Surgery

Surgery will often be used to remove as much of the tumour as possible. This will help to reduce pressure on the brain caused by blocked flow and build-up of the CSF (cerebrospinal fluid) that results from the tumour itself or to the brain's reaction to the tumour's growth (cerebral oedema). It is increased pressure that can cause some of the symptoms of a brain tumour.

However, depending on where in the brain the tumour is, surgery is not always possible, or necessary. Sometimes, it would be too risky to operate, as the tumour may be very close to, or wrapped around, an important part of the brain, such as the brain stem. In this case, the benefits of surgery would be outweighed by the dangers.

In other cases, such as with very slow growing, low grade brain tumours, problems with increased pressure may not develop, so your child may not need surgery straight away, or even at all.

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



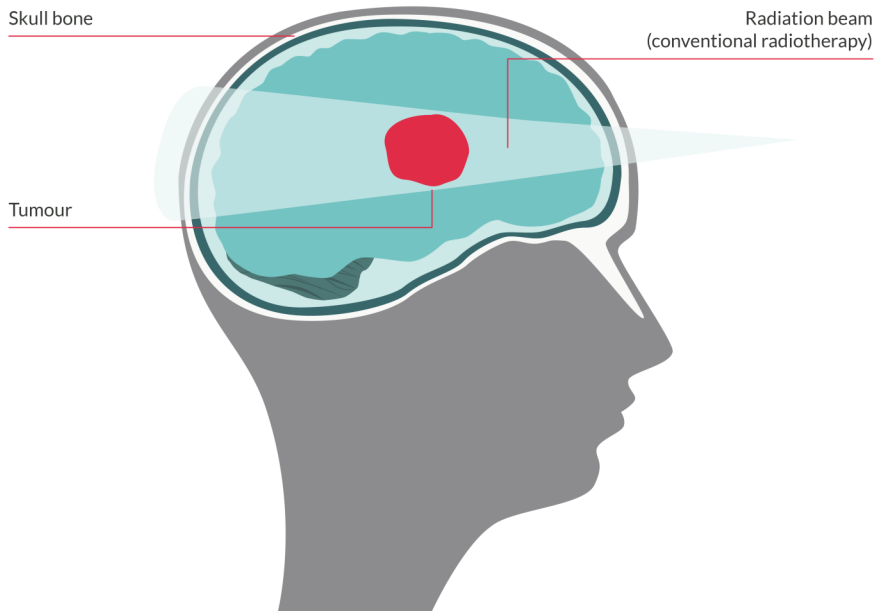
Chemotherapy and radiotherapy

Other treatments, such as **chemotherapy** and **radiotherapy** may be used on their own, in combination, or after surgery to try to remove any remaining tumour cells. Radiotherapy is generally given only to children who are at least three years old.

For more information, please see our *Chemotherapy for children* and *Radiotherapy for children* webpages/fact sheets.

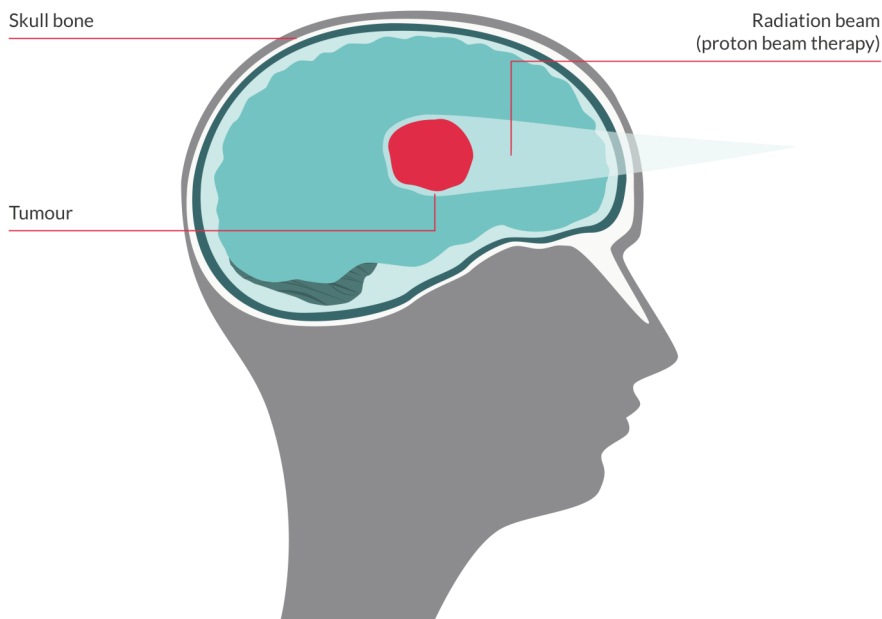
Proton Beam Therapy (PBT)

PBT is a type of radiotherapy that uses a beam of 'protons' (positively charged subatomic particles) to target the tumour in a very precise way. This means your child can have the same radiation dose to the tumour, but the effect on surrounding healthy tissue is less.



© The Brain Tumour Charity

Conventional radiotherapy beam



© The Brain Tumour Charity

Proton Beam Therapy beam

PBT is not suitable for all types of brain tumours. It works best for smaller tumours and those where the edges are clearly defined. It is also not currently available in the UK for use in brain tumours. However, if this treatment is right for a child, the NHS will send them to centres outside the UK.

It is important to note that there are specific referral criteria for PBT and if your child does not meet these criteria they will not be referred on the NHS.

The Department of Health has announced two Trusts in England that have been chosen to develop PBT centres - The Christie NHS Foundation Trust Hospital in Manchester and University College London Hospitals NHS Foundation Trust (UCLH).

Given the complex nature of the treatment and facilities, PBT won't be fully available until 2018 at The Christie and 2020 at UCLH.

Several private centres are also being developed in England and Wales, which are due to open from 2018 onwards.

Until there are centres in the UK, the NHS will continue to fund patients to receive treatment abroad.

For further information, see the *Proton Beam Therapy* webpage and fact sheet.

Summary

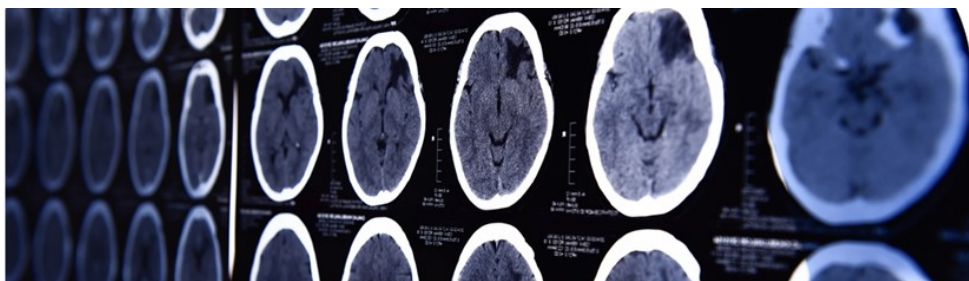
It is important to know that your child's medical team will tailor your child's treatment to provide the treatment that is the best for your child.

This could mean that you meet other families whose children have the same tumour, but who are receiving different treatments. The reasons for this could be due to several factors that are individual to your child.

If you are worried or concerned at all, you should speak to your child's medical team, who will be able to help you understand the treatment decisions that have been made.

If you feel your child is not getting the correct treatment you can ask for a second opinion. More information about this can be found on The Brain Tumour Charity website :

thebraintumourcharity.org/understanding-brain-tumours/navigating-the-system/getting-a-second-opinion



Will my child have learning difficulties as a result of their brain tumour?

Children who have had a brain tumour may experience learning difficulties to some degree.

These difficulties can be due to a number of factors, such as the tumour itself, the impact of treatment, or the fact that they have had to take time out of school and therefore miss lessons.

Unfortunately, it is generally the case that the younger a child is when they have a brain tumour, the higher the likelihood that they will need specialist educational input to support their learning.

For example, radiotherapy is generally given only to children who are at least three years old. However, radiotherapy may need to be given to under threes in certain circumstances, where the benefits are felt to outweigh the risks. A very young brain (under three years) is less developed and changing fast and so more likely to experience long-lasting damage from radiation. This poses an increased risk of long-term social and educational learning difficulties.

If your child receives radiation at any age, you may not be aware of difficulties straight away and they may only become apparent as your child gets older.

It is important to remember that any learning difficulties may be mild, and there is much help to overcome learning difficulties of any level.

For further information, see our *Education resources*, to help make sure that support is put in place to help your child in school, college or nursery, and the *Learning difficulties and childhood brain tumours* and *Radiotherapy for children* webpages and fact sheets.

What other long-term effects might my child have?

Long-term effects from a brain tumour vary from child to child and depend on the exact location of the tumour within their brain, and the treatment given.

Your child's medical team will be able to talk you through the possible long-term effects they might experience. You should be able to ask any questions of them that you would like to.

Some possible long-term impacts include:

- **Sight problems**

Sight loss may be partial, children may experience double or blurred vision, or sometimes they may lose all their sight.

Sight loss depends on the area of the brain where the tumour grows and also the areas that receive radiation. As a general rule, radiologists plan radiation to avoid the optic nerves if possible.

If the sight problems develop immediately, you can ask to be referred to an ophthalmologist to see if there is any treatment available. Some side-effects develop over years and regular visits to the opticians can help to monitor and possibly prevent or treat them.

- **Impacts on puberty and fertility**

Treatments, such as radiotherapy and chemotherapy, can delay puberty and/or affect fertility.

Effects on puberty can be treated with an artificial hormone replacement.

Girls who have radiotherapy to the head as a child may begin puberty earlier. However, medication can be used to stop this until your daughter is the right age to go through puberty.

Speak to your child's health team - they may be able to refer your child on to an 'endocrine' team who deal with hormonal issues.

- **Impacts on fertility**

Your child's future fertility may be affected. Possible options to deal with this, such as sperm banking (boys) or egg freezing (girls) will depend on whether your child has reached puberty. For girls, it will also depend on how urgently they need to start treatment for their brain tumour.

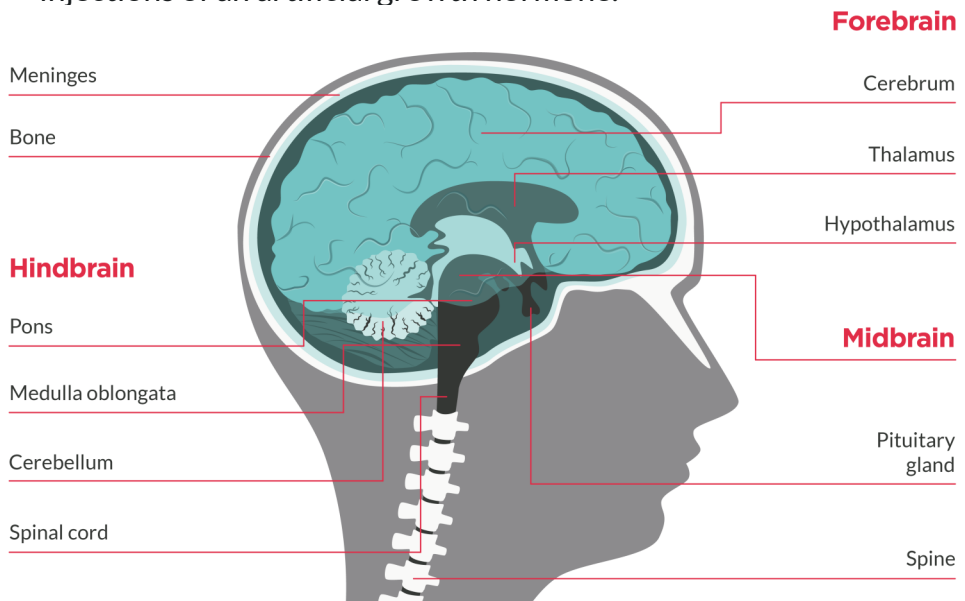
Other treatments you may have heard of, such as freezing their ovarian tissue (girls) or testicular tissue (boys), may be available for children who have not reached puberty, but may not be available in all NHS trusts.

Speak to your health team for more information.

- **Impacts on growth**

If your child receives radiotherapy to, or near, the pituitary gland at the base of the brain, their growth may be slowed. (This is because the pituitary makes and releases chemicals responsible for growth.)

If your child's growth is affected, this can be treated with injections of an artificial growth hormone.



Your child's growth may also be affected if your child receives radiotherapy to their spine, as this may prevent the spine growing normally as your child develops.

- **Physical problems**

Some children who have had a brain tumour will be left with a long-term physical effect, such as weakness in a limb (hemiplegia), or difficulties with balance. Physiotherapy is one possible treatment that may help children to adapt.

- **Emotional difficulties**

Children who have or had a brain tumour may experience emotional difficulties.

This can be due to a number of factors, including changes to areas of the brain that control emotions, the emotional impact of a serious illness and also to the treatment itself.

In addition, your child may experience emotional impacts from social changes, loss of contact with their friends and being different to their friends, as well as fears of their tumour returning or of dying.

Most health teams will include a psychologist who can help with these difficulties., or will be able to signpost you to similar help for your child.

Coping as a family

Coping with the diagnosis of a child's brain tumour can have a huge impact on you and on the rest of your family.

It could be that, although your child is treated on a children's ward, they may be the only child on the ward with a brain tumour. This could feel lonely for them and for you.

The Brain Tumour Charity has a variety of services to give help if you or your child need it .

For example, we run Family Days, which provide children affected by brain tumours the opportunity to meet other children in similar circumstances in a social situation.

For further information, visit our website:
thebraintumourcharity.org/familydays



You may also find it helpful to join one of our closed Facebook groups. They offer a safe space to gain peer support.

As well as our general group and our carers group, we also have one specifically for parents.

bit.ly/FBSupportGroups

If you have questions or would like to talk to a member of our Information and Support team, please phone 0808 800 0004 or email support@thebraintumourcharity.org.

Brain tumour types in children

Brain tumours in children are rare, but they do happen. There are many different types of brain tumour and their names can sound long and complicated.

As a general rule though, tumours are named according to the type of cell they start from and/or where in the brain they are located.

For example, you may hear the term 'posterior fossa'. This is the area inside the back of the skull, which contains the cerebellum, the medulla and the brainstem. Tumours in these regions may, therefore, be called posterior fossa tumours. About 60% of childhood brain tumours occur in the posterior fossa.

The following is not an exhaustive list.

Common childhood brain tumours

Gliomas

Around half of all childhood brain tumours are a type of 'glioma'. This means they grow from a type of cell in the brain called a 'glial cell'. There are different types of glial cells, so there are different types of gliomas.

Glial cells

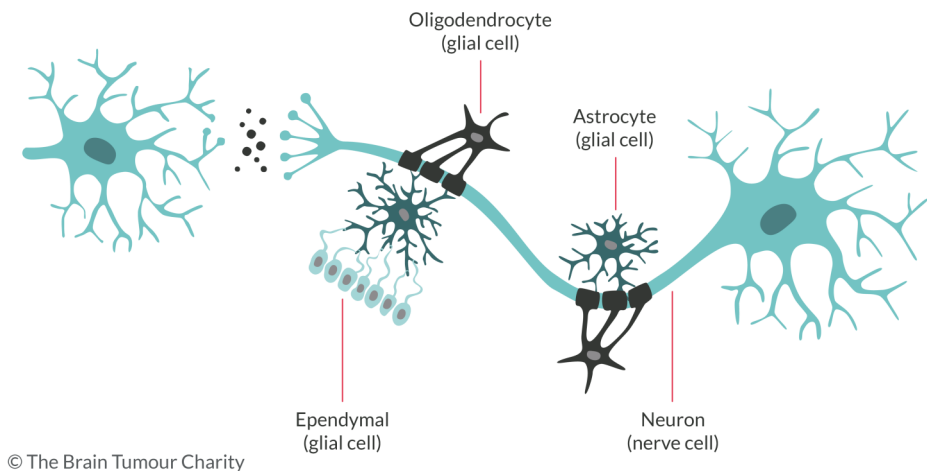
Glial cells support and protect the nerve cells in the brain, called neurons. They do this by providing the neurons with oxygen and nutrients and by removing dead cells.

There are 3 main types of glial cells:

- Astrocytes
- Ependymal cells
- Oligodendrocytes

Brain tumours which grow from these cells are named after them. Respectively:

- Astrocytoma
- Ependymoma
- Oligodendroglioma



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Astrocytomas

Astrocytoma are the largest subgroup of gliomas. They make up over two-fifths (43%) of all childhood brain/spinal tumours.

In children, they tend to be slow growing (73% are low grade) and are diagnosed throughout childhood at all ages. They occur equally in boys and girls.

Pilocytic astrocytoma is a type of astrocytoma common in children. It is a grade 1 brain tumour that occurs in the cerebellum. This is the structure at the back of the brain that is responsible for balance, movement and co-ordination.

You may hear it referred to as a 'posterior fossa' tumour. This is because the cerebellum is in the posterior fossa (a cavity inside the posterior/back of the skull).

They can usually be operated on and the prognosis tends to be very good.

DIPG, or Diffuse Intrinsic Pontine Glioma, is another type of astrocytoma. It accounts for approximately 10-15% of childhood brain tumours in the UK and is the second most common high grade brain tumour in children.

Recently its name has changed to '**diffuse midline glioma**', though you may still hear or see it being called by its old name.

Diffuse midline glioma (DIPG) is a fast growing, high grade brain tumour that originates from astrocytic cells in the pons or other parts of the brain stem. The brain stem controls many of the functions we do not have to think about e.g. breathing, swallowing, blood pressure and digestion.

Often appearing in children aged around six years old, DIPG's fast growth can mean they can be quite large and cause significant symptoms within a few days of their onset. Unsteadiness, squints and swallowing symptoms are common.

Unfortunately, due to their location in a critical part of the brain, DIPGs cannot usually be operated on. And chemotherapy has been found to not be very effective in treating childhood DIPGs.

Treatment therefore is generally by radiotherapy.

Ependymomas and Choroid plexus tumours

Other types of glioma include ependymomas and choroid plexus tumours. These make up about 10% of childhood brain tumours.

Both grow from ependymal cells, which line the ventricles (fluid-filled spaces) within the brain. They occur most often in the ependymal cells of the cerebellum at the back of the brain.

These types of tumours can block the cerebrospinal fluid (CSF) from circulating and draining, causing the pressure in the brain to increase. This is called 'raised intracranial pressure'. The first symptoms therefore may be pressure headaches, particularly in the mornings.

They occur most often in one year olds, where the signs of the raised intracranial pressure may be vomiting and lethargy (drowsiness), rapidly increasing head size and an inability to look upwards.



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Embryonal tumours

Embryonal tumours develop from embryonic (foetal) cells that remain in the brain after birth. These are cells that are left over from the earliest stages of our development, while we are still growing in our mother's womb as an embryo.

Embryonal tumours are the second most common subgroup of brain tumours in children (20-25%) and are more frequent in younger children - usually diagnosed in the under 10s.

They used to be called PNETs (Primitive NeuroEctodermal Tumours). There are different types of embryonal tumour, and they are usually high grade in children.

Medulloblastomas

Nearly three-quarters of embryonal tumours are medulloblastomas. These are the most common high grade (grade 4) tumour in children (20%). They are more common in boys than girls and are most commonly diagnosed around the age of five.

They develop in the cerebellum - the structure at the back of the brain involved in co-ordination and movement - but may spread to other parts of the brain and spinal cord.

Treatment depends on many factors (including the age of your child and the size, location and molecular/genetic make-up of their tumour), but may involve surgery, radiotherapy and chemotherapy.

Embryonal tumour with multi-layered rosettes (ETMR)

ETMRs used to come under the name of CNS PNET tumours. They are high grade (grade 4) and can develop almost anywhere in the brain. They occur most commonly in young children under the age of 4 years.

Rarer childhood brain tumours

Craniopharyngiomas

Craniopharyngiomas in children and young people are usually diagnosed between the ages of 5 and 14, and account for 8% of childhood brain tumours.

They grow near the base of the brain on the stalk of the pituitary gland. They are low grade (grade 1) and do not usually spread.

However, they are near important structures in the brain and can cause problems as they grow, such as changes in hormone levels, problems with eyesight, weight gain and growth problems.

Pineoblastomas

Pineoblastomas account for 3-8% of childhood brain tumours.

They are tumours which develop in the pineal region at the base of the brain, just above the pituitary gland. The pineal gland produces melatonin, a substance that helps control our sleep cycle.

They are usually high grade (grade 4), and are slightly more common in males.

Treatment is similar to that for embryonal tumours.

Astrocytoma (high grade)

In children, high grade astrocytomas are much less common than low grade astrocytomas. They account for about 8% of childhood brain tumours. They include anaplastic astrocytomas (grade 3) and glioblastoma (grade 4, and sometimes referred to as GBM).

These are fast-growing tumours, with glioblastomas being the quickest growing type of brain tumour. They usually develop between the ages of 5 and 9 years.

Glioblastoma are rare in children.

Germ cell tumours

Germ cell tumours represent between 4 – 11% of childhood brain tumours across the world.

Germ cells are primitive, undeveloped cells that develop into the reproductive system, but occasionally they can occur in the brain. They are most commonly found near the base of the brain in the pineal region - the area above the pituitary gland.

Atypical teratoid/rhabdoid tumour (AT/RT)

AT/RTs are a high grade (grade 4) embryonal tumour, which account for 1-2% of childhood brain tumours. However, because they usually develop in children under 3 years old, they account for about 10% of brain tumours in infants.

They mostly occur in the posterior fossa (back of the brain) and can spread to the spine.

Oligodendrogliomas

Oligodendrogliomas are very rare in children, accounting for less than 1% of brain tumours in children under 15 years, and less than 2% in adolescents (15 – 19 years).

They can be grade 2 or grade 3 and tend to occur in the frontal or temporal lobes. They are far less common in children than astrocytomas and ependymomas.

Meningiomas

Meningiomas develop in the membranes covering the brain, called the meninges. They are slow growing tumours.

They are rare in children, but may occur in children who have the genetic condition called neurofibromatosis type 2 , that causes tumours to grow along your nerves.

Alternatively, they may be associated with radiotherapy given at a young age.

The usual therapy is surgery.

This list of tumours is not exhaustive and there are other rare brain and spinal tumours in childhood. The list of names for the tumours is expanding due to continuing developments in the understanding of the microscopic structure and genetics of tumour cells.

For further information about areas of the brain, see *The human brain* webpage and fact sheet.



What if I have further questions or need other support?

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



0808 800 0004

(Free from landlines and most mobiles:
3, O2, EE, Virgin and Vodafone)



support@thebraintumourcharity.org



Live Chat

Get in touch with us online via
thebraintumourcharity.org/live-chat



Join one (or more) of our
closed Facebook groups:
bit.ly/FBSupportGroups



thebraintumourcharity.org/getsupport

Disclaimer: This resource contains information and general advice. It should not be used as a substitute for personalised advice from a qualified specialist professional. We strive to make sure that the content is accurate and up-to-date, but information can change over time. Patients must seek advice from their medical teams before beginning or refraining from taking any medication or treatment. The Brain Tumour Charity does not accept any liability to any person arising from the use of this resource.

About this information resource

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

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

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

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

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

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

About The Brain Tumour Charity

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

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

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

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

We rely 100% on charitable donations to fund our work.

If you would like to make a donation, or find out more about other ways to support us, including leaving a gift in your Will or fundraising through an event, please get in touch:

Visit

thebraintumourcharity.org/get-involved

call us on 01252 749043 or email

fundraising@thebraintumourcharity.org



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