

Neurosurgery for children with brain tumours

Neurosurgery is surgery performed on the brain or spinal cord. It is performed by a highly specialised health professional called a 'neurosurgeon'.

After your child has been diagnosed as having a brain tumour, neurosurgery may be used to remove as much of the tumour as is safely possible, to diagnose the exact type of tumour or to insert devices into the brain to help with treatment or symptoms.

Any surgery on your child is scary, but when it is on their brain, it can be particularly so. This fact sheet gives an overview of surgery for brain tumours in children and helps to answer some questions you may have about brain surgery.

In this fact sheet:

- Reasons for neurosurgery
 - Removal of the tumour
 - Diagnosis of type and grade of the tumour
 - Other reasons
- What to expect before, during and after neurosurgery
- Answers to some commonly asked questions you may have about children's neurosurgery

Our series of animations includes one on neurosurgery in children. Watch/listen to them here:
thebraintumourcharity.org/jake

There are several reasons why your child may need neurosurgery.

Removal of the tumour (craniotomy)

When possible, the neurosurgeon will try to remove all of the tumour, or as much as is safe to. (Not all tumours can be operated on.)

This operation involves making a large-ish hole in the skull and is called a 'craniotomy'.

A craniotomy allows the neurosurgeon to see into your child's brain and to remove the tumour.

It is the most common type of surgery for brain tumour patients and it is used to remove all or part of the tumour.

You may hear the complete removal of the tumour being called 'total resection'. Or removal of part of the tumour as 'partial resection' or 'de-bulking'.

The aims of removing the tumour include:

- Increasing the chances of cure
- Slowing the tumour's growth
- Improving symptoms e.g. to reduce pressure on vital nerves within the brain, such as the optic nerve.
- Helping other treatments to work better such as radiotherapy or chemotherapy.

A craniotomy is almost always performed while your child sleeps under general anaesthetic. (Very occasionally an older child i.e. a teenager, may be given the option of an awake craniotomy. They would be very carefully prepared for this.)

A sample of the tumour tissue will be sent to a laboratory to be examined for diagnosis. This sample is called a biopsy.

Why might the surgeons not operate to remove my child's brain tumour?

- The tumour is in, or near, a sensitive area of the brain and the operation is likely to cause damage to this area

e.g. the brain stem (*which controls breathing*)
or the optic nerve (*responsible for sight*)

- The tumour is low grade

(*slow growing, unlikely to spread and causing relatively minor or controllable symptoms*)

- AND the risk of a major operation to remove the tumour is more likely to cause harm to the brain than not doing anything.

This is called 'watch and wait'.

For more information, please see the *Watch and wait* web page and fact sheet.

Diagnosis of the type and grade of tumour (biopsy)

Diagnosis of the exact type and grade of your child's brain tumour is important because it tells the health team about how the tumour is likely to behave.

In other words, how it is likely to grow, spread and sometimes how it may respond to certain treatments.

Knowing this helps the health team decide on the best course of treatment for your child.

An exact diagnosis can also help if you want your child to take part in a clinical trial.

Clinical trials

Clinical trials have strict 'inclusion or entry criteria'. This means there are particular requirements that your child must meet to take part in the trial.

These can include:

- Particular tumour type
- Particular tumour grade

- Age, gender etc
- Having had no previous treatment

In some clinical trials, a sample of the tumour may need to be frozen.

It is important, therefore, to discuss your wishes with your child's health team, so they are clear about what needs to be done.

See our *Clinical trials* web page and fact sheet for more information.

Diagnosis of type and grade

To give an exact diagnosis, the neurosurgeon needs to operate to take a sample of the tumour, so its cells and genes can be closely looked at under a microscope. This taking of a sample of cells is called a 'biopsy'.

The cells are then sent to a laboratory to be studied by another specialist, called a neuropathologist.

See *Your child's health team (MDT)* web page and fact sheet for more information.

The neuropathologist will give a diagnosis based on how the cells look and on the genes and proteins within the cells.

When is a biopsy taken?

Often the neurosurgeon may take the biopsy (sample) at the same time as doing a larger operation to remove as much of the tumour as possible - an operation called a 'craniotomy'.

Alternatively, the neurosurgeon will take a biopsy by making a small hole in the skull, called a 'burr hole'.

These 'burr hole biopsies' are used to gain a diagnosis when it is not possible, or not advisable, to operate to remove the tumour.

Putting devices directly into the brain to help with treatment or symptoms

Shunts

Headaches are a common symptom of brain tumours. They can occur because of a build-up of cerebrospinal fluid (CSF) caused if the tumour is blocking its flow round the brain. As the CSF builds up in an area, pressure within the skull rises, causing headaches. A build-up of CSF is known as 'hydrocephalus'.

There are various ways of treating hydrocephalus - your child's neurosurgeon will explain which is the best course of action.

They may recommend that they operate to insert a tube, called a 'shunt', into your child's skull to drain some of the excess fluid away. (A shunt is sometimes called a 'ventricular catheter').

The shunt has valves to make sure that it takes fluid in the correct direction, away from the brain and towards other parts of the body that can easily absorb it, such as the stomach lining.

Important point to remember

A shunt is not a cure for a brain tumour, nor does it treat the brain tumour itself, but it can help to improve symptoms by relieving the pressure in your child's skull.

If your child needs to have a shunt for a long period of time they will have regular check-ups to ensure that it is still working as it should and that it has not become blocked or infected.

You cannot see a shunt from outside the body, so other people will not know it is there unless they are told. Your child may be able to feel the shunt running down behind their ear.

If a shunt is part of your child's long-term treatment plan, it will usually be inserted in a way that allows for their growth. This means that they should not require new shunts as they grow.

Shunts can, however, have complications, such as becoming blocked, so some children may need a number of shunts throughout their life.

Speak to your child's health team about safety and being aware of the signs of blockage or infection.

Variable shunts

The settings on some shunts can be changed. This is so the level of fluid drainage can be altered, if needed.

Make sure you know the settings, if your child has a variable/programmable shunt.

This can be important if your child needs an MRI scan, as the magnets in the scanner may cause the settings to change.

Knowing the settings will help you check the correct settings have been reset following the scan.

Shunt alert cards/bracelets

Your child may wish to wear a medical alert bracelet to inform others that they have a shunt, if they ever need to have a scan not related to their brain tumour.

Medical bracelets are widely available in a range of different designs. One stockist that has created designs for children is the ID band company:

theidbandco.com

The charity Shine also has a series of free shunt alert cards (available to residents in England, Northern Ireland and Wales).

shinecharity.org.uk/hydrocephalus/shuntalertcards or call 01733 555988.

What happens during surgery for a brain tumour in children?

Before your child has surgery, their consultant will discuss with you what to expect and you will be asked to sign a consent form stating that you understand the procedure and the risks involved.

You should not feel awkward about asking as many questions as you would like to before surgery. And you should not feel awkward asking your child's health team, if any symptoms your child shows after surgery, are normal.

In most cases, your child will first have an MRI scan.

(For further information, see our ***Scans for children*** web page and fact sheet).

The scan shows exactly where in the brain your child's tumour is. This will help the neurosurgeon work out if operating is safe, which type of surgery (biopsy or craniotomy) to use and also which is the best route into the tumour to cause least damage to the healthy brain tissue around the tumour.

Your child will then be given a general anaesthetic to make them sleep very deeply throughout the operation.

Having a general anaesthetic

Your child may first be given a cream or cold spray to put on their hand where a 'cannula' (tube) for giving the general anaesthetic will be inserted.

This cream/cold spray will numb your child's hand so that they are not able to fully feel the needle that is used to insert the tube. These creams do wear off after a while however, so, if there is a delay in giving the general anaesthetic, your child may need more cream.

Once the cannula is in place, your child will be given a general anaesthetic through the tube to make them go to sleep. The surgeon will then operate - either a craniotomy or a burr hole biopsy.

The craniotomy procedure

- Once the anaesthetic takes effect, an incision (cut) will be made in your child's scalp. It may be necessary for them to have a small area of their head shaved to allow easier access.
- Your child's neurosurgeon will then remove a section of their skull. This is called a 'bone flap' and it allows the neurosurgeon to reach your child's brain.

Your child will not experience any pain during this as they will be under anaesthetic.

- Once the brain has been reached, the neurosurgeon will remove all, or part of, the tumour.

Very often, it is not possible to safely remove the whole tumour. This will depend on where in the brain the tumour is and how close it is to vital areas. In such cases, the neurosurgeon will remove as much of the tumour as possible.

- Partial removal is known as 'debulking' or 'partial resection' and, even though this does not remove all of the tumour, it can help reduce symptoms caused by pressure from the tumour.

It may also make the remaining tumour cells more responsive to other treatments, such as chemotherapy and radiotherapy.

- Once as much of the tumour as possible has been removed, your child's neurosurgeon will replace the bone flap and seal the wound using stitches or metal clips.

These will usually be removed a week or two after surgery. If they are dissolvable stitches (which are often used for children), removal will not be necessary.

Over time, the bone flap should fuse with the rest of the skull.

The length of time a craniotomy takes depends on the part of the brain being operated on. As a very general guide, neurosurgery may take around 4 to 6 hours. However, in complex cases, it could take significantly longer.

The burr hole biopsy procedure

In children, biopsies are not usually taken through a burr hole, but are often taken during the larger craniotomy procedures. However, occasionally they may be taken separately.

- When they are asleep, the neurosurgeon will drill a small hole (a 'burr hole') in their skull.

Although this may sound frightening, your child will not be able to feel anything because of the anaesthetic. They will also not be aware of the procedure while it is taking place, as they will be asleep.

- The neurosurgeon passes a needle through the burr hole and takes a small sample of the tumour. They will then close the wound.

Having a biopsy means that your child is likely to spend two or three days in hospital as it involves having an operation under general anaesthetic.

The scar left from a biopsy done through a burr hole should be very small and will be easily covered by your child's hair.

To help prepare your child for neurosurgery and to explain about what happens and what to expect, The Brain Tumour Charity has produced an animation about an eight-year old boy, Jake, who has an operation to remove his brain tumour. thebraintumourcharity.org/jake

Whilst your child is having their operation

It can be a stressful time whilst your child is having their operation.

Parents who have been through this, suggest:

- Try and get out of the hospital for a while to have a break
- Try to get some food, as you will need your strength when your child comes out from the operation.

What happens after my child's operation?

Different hospitals have different procedures - your child's health team can give you details about what is likely to happen in your child's case.

In general, your child is likely to be woken up in an intensive care unit (ICU) or a high dependency unit (HDU). These units have more staff per patient than regular wards to allow for closer monitoring of each patient.

You may have many questions when your child comes out of the operation. Here are some frequently asked questions:

Can I visit my child while they are in intensive care?

Visiting hours in intensive care units are usually very flexible, especially for young children, but check with staff at the hospital where your child is being treated.

Generally, only immediate family members will be allowed to visit and very young children and babies are not allowed in.

If you have a cold, or other contagious condition, it is not advisable to visit your child in intensive care, as this could make them and others on the ward more unwell.

You can touch your child, but you will be asked to clean your hands with alcohol gel first in order to prevent the risk of infection. Alcohol gel should be provided before you enter and as you leave the intensive care unit.

What should I expect to see?

When you first see your child, they may be linked to a machine that controls their breathing. This is called a 'ventilator' and helps to give their brain a chance to recover.

They will also have a number of tubes coming in and out of their body to help with their recovery.

They will also be under medication that makes them very drowsy.

It can be distressing to see your child in intensive care. If possible, try to mentally prepare yourself.

Will there be a dressing on my child's wound?

Not necessarily, but if your child's wound is covered with a dressing or bandage, this usually stays on for around 5 days after surgery.

Stitches are usually removed 5-14 days afterwards, unless they are dissolvable (which is often the case with children).

Advice about hair washing, going back to school and swimming will be given by your child's healthcare team when your child is discharged from hospital.

Why are there tubes in my child's body?

When your child wakes after surgery, they will have a number of tubes coming in and out of their body. This unfamiliar experience can be upsetting for both you and them, particularly if you do not know what the tubes are for.

Your child may be linked to one, or a number, of the tubes listed below:

- **Drips** - these are tubes that give your child water and nutrients until they are able to eat normally. They may also deliver medicines into your child's blood stream.
- **External ventricular drain (EVD)** - this drains fluid from the brain to prevent the build-up of cerebrospinal fluid (CSF), which can cause hydrocephalus.
- **Tubes from your child's wound** to drain excess blood and fluid
- **An intracranial pressure (ICP) monitor**, which monitors the pressure in your child's brain.
- **A urinary catheter** - this goes into your child's bladder and allows your child to pass urine (to wee). It also allows their health team to measure how much urine your child is producing and whether there is an appropriate amount of fluid in their body.
- **A nasogastric tube** - this tube goes down through your child's nose to their stomach and provides liquid food.
- **Blood pressure monitors** - your child's blood pressure will usually be monitored several times throughout the day.
- **Central line** - this is a tube that is put under skin of the chest to a vein above the heart.

This is usually done under general anaesthetic to reduce anxiety, but can be put in under a local anaesthetic

It is used to deliver chemotherapy or antibiotics, or to take blood samples or give blood transfusions, if required.

See *Chemotherapy for children* web page and fact sheet for more information.

Depending on your child's age, and unless the operation is an emergency, you may wish to tell them a bit about what these are and what they are for, before they go in to hospital, so that they know what to expect .

Equally, depending on your child's age, to help them to prepare for their hospital visit, you may wish to put some tubes on a toy or teddy bear to help them understand.

A play specialist from the hospital can also help with this. Ask your child's health care team.

How long will it take my child to wake up?

The amount of time it takes to wake up after surgery varies. Your child may wake very soon afterwards or they may remain unconscious for a number of hours or a few days.

In the first few hours after your child wakes up, health professionals caring for your child will carry out frequent checks (about every 15 minutes).

These include shining a light into your child's eyes to check that their pupils dilate (get larger) and taking your child's blood pressure and heart rate. You may not like to see your child roused in this way when they are resting, but these checks are very important.

How long will my child stay in intensive care (ICU or HDU)?

Brain surgery is a significant operation and your child will need to stay in hospital for at least a few days afterwards.

They will not remain in the ICU or HDU for this time, but will be transferred to a specialist children's ward where they will be able to see and talk to other children. They will be looked after here by healthcare professionals who specialise in treating children.

In some hospitals, you may be able to stay with your child on the ward. If not, the hospital will usually be able to help you find suitable accommodation, or may have its own limited accommodation where parents/carers can stay.

Could my child's wound become infected?

Although infection is a possibility, it is very uncommon. Your child's health team will check the wound after surgery and also regularly during your child's stay in hospital.

They will also give you advice on preventing infection, when you take your child home. They may also give your child antibiotics.

How will my child feel after neurosurgery?

Many things will influence how your child feels after surgery, including the type of surgery they have had and the size and location of their tumour.

It is very common to feel very tired after surgery, so do not be alarmed if your child sleeps more than usual. Medical staff will carry out regular checks to make sure that everything is as it should be.

When your child first awakes after brain surgery, they may have swelling and bruising on their face, which can be very upsetting for them, and for you.

The symptoms they had before the surgery may also get worse temporarily. This is quite common and is usually due to swelling in the brain following surgery. These symptoms will get better during recovery.

It can be helpful to talk about this before your child has surgery, so that they know what to expect and are not frightened when they wake.

It can also be useful to plan ways of communicating beforehand in case they are unable to speak when they wake up, as happens sometimes. For example, thumbs up and thumbs down.

Your hospital may also have a play therapist who can help your child understand what is going to happen, both before and after surgery.

Your child could also experience some or all of the following temporary effects:

- **Sickness and nausea**
Due to the anaesthetic. Anti-sickness tablets can be given to help with this.
- **Sore throat**
Due to the tube used during surgery to regulate breathing and oxygen levels.
- **Headaches**
Caused by swelling in their brain. The swelling should die down within a couple of days and painkillers can be used to help relieve headaches.
- **Momentary phases of feeling dizzy or confused**
- **Difficulty swallowing ('dysphagia')**
Your child may have their swallowing checked by a speech therapist before they are allowed to eat or drink anything.
- **Ongoing tiredness**
Your child may continue to feel tired and need a nap after a period of activity (for example, working with a therapist).

- New symptoms

These might include personality changes, poor balance and co-ordination, speech problems, weakness and epileptic seizures or fits.

This list can feel overwhelming, but it is important to remember that such effects usually disappear fairly soon after surgery and that a team of highly qualified health professionals will be taking care of your child.

Occasionally some of these symptoms may persist for longer periods.

How long will it be after surgery before my child is back on their feet?

Neurosurgery is a major operation and your child will need to rest for a number of days afterwards.

For the first few days, one of the top priorities for your child's health team will be ensuring that the pressure in their head does not increase and that infections are prevented.

Nurses will help to ensure this by checking that your child is lying in a suitable position and by checking the wound regularly.

They will also ensure that your child is moving their arms and legs around enough to allow blood flow and to prevent thrombosis (blood clots) or muscle stiffening.

Your child will most likely be given socks to wear in bed, which help to prevent thrombosis, or could be given an injection each day to help with prevention.

This does not mean, however, that they will not be up and walking on the ward very quickly.

Your child will not be kept in bed any longer than is necessary and hospitals are always keen for their patients to get up and get moving as soon as is safe.

Parents sometimes worry that their child is up and about too soon. If you feel this, it is important that you talk with the health team to get a better understanding of why this is.

Your child will be seen by members of their health team, such as a physiotherapist and an OT (occupational therapist), to help with their rehabilitation and assess when they can safely go home.

They may be referred to community physiotherapy or OT, if this is required.

How will I know if the surgery has been successful?

Your child is likely to have a brain scan a few days after surgery. Having a brain scan so soon after surgery can feel like a burden, but it is important. It will give the health team a good idea about whether any of the tumour is still there and how much swelling of the brain there is.

Will surgery cure my child?

Before surgery, your consultant will discuss with you what to expect and whether they are hoping to remove all or part of your child's tumour. Often, surgery does not cure a tumour completely, but removing part of it can make any remaining tumour cells more responsive to other treatments, such as radiotherapy and chemotherapy.

The success of surgery is measured against the aim of the surgery and not on curing a tumour. You will need to keep in mind what these aims were when hearing the scan results.

Will surgery cure my child?

Before surgery, your consultant will discuss with you what to expect and whether they are hoping to remove all or part of your child's tumour. Often, surgery does not cure a tumour completely, but removing part of it can make any remaining tumour cells more responsive to other treatments, such as radiotherapy and chemotherapy.

My child has had neurosurgery - what's next?

After the operation, your child's health care team (MDT) will meet to discuss your child's recovery and next steps. (MDT = Multi-Disciplinary Team).

Please see *The MDT* webpage/fact sheet for more information.

Using scans taken after the operation and the results of the tests of the tumour tissue in the lab, the MDT will discuss what type of tumour your child has and what should happen next. For example, whether your child will require further treatment, such as chemotherapy or radiotherapy.

After their meeting, the MDT will arrange to meet with you and your child to discuss with you what the treatment plan will be, so that you know what to expect.

Other treatments

After brain surgery, it is likely that your child will have another treatment, such as radiotherapy and/or chemotherapy, to get rid of any remaining tumour cells. (Radiotherapy is usually given only to children who are at least three years old.)

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

Steroids

Due to the swelling in the brain after surgery, your child may be given steroids. The most common steroid used is called Dexamethasone.

Steroids help to reduce the swelling and increased pressure in your child's head.

Unfortunately, steroids can have side-effects on emotions and might make your child irritable and bad tempered whilst they are taking them.

Under the guidance of their consultant, your child will gradually be able to stop taking steroids.

It is very important that your child does NOT suddenly stop taking the steroids.

It takes some time for the body to start making its own steroids again. So stopping steroids needs to be done through gradually reducing the dose.

For further information, see our *Steroids in children* web page and fact sheet.

Anti-epileptic medicine

Some people experience seizures ('fits') after brain surgery, due to increased pressure in the head. Your child may be given anti-epileptic drugs (AEDs) as a preventative measure.

The length of time people take this for varies from person to person, but it is not uncommon to take anti-epileptics for up to a year after brain surgery.

In some cases your child will need to take AEDs for the rest of their life. A psychologist may be able to help them come to terms with this as they get older.

What are the possible side-effects of surgery?

Will my child's hair grow back?

It may be necessary for your child to have some of their hair shaved before brain surgery. This is to allow the neurosurgeon access to their brain and can also be for hygiene reasons.

Hair generally grows back quite quickly and will cover the wound, but hair will not grow back along the wound itself.

If your child has a particularly short hair cut, such as a shaved head, then their wound may be visible as a pink raised line. Eventually it will become a white line as it fades.

Will my child be able to play sport after brain surgery?

Yes, once your child has recovered from surgery, there should be no problem with their playing most sports.

Your child's consultant or doctor will be able to advise you on when your child can begin playing sport again after brain surgery.

It is important to speak with your child's health team about any concerns you have rather than preventing them from doing activities they may well be able to do.

After surgery, part of your child's emotional and social recovery will involve being a 'normal child' and playing with friends and siblings, in a way that is safe, will be good for them.

The Children's Cancer and Leukaemia Group (CCLG) booklet '***Sport and Exercise for Children and Young People with Cancer: A Parent's Guide***' also gives a lot of information on the topic.

An electronic copy is available at:

[cclg.org.uk/write/MediaUploads/Publications/PDFs/Sport_and_exercise_\(Nov_13\).pdf](http://cclg.org.uk/write/MediaUploads/Publications/PDFs/Sport_and_exercise_(Nov_13).pdf)

Or you can request a free hard copy from CCLG on 0116 252 5858.

Will my child be able to fly after neurosurgery?

It is strongly advised that you seek advice from your child's doctor before booking any travel arrangements.

The Civil Aviation Authority is responsible for air travel safety. It states that because neurosurgery may leave gas (air) trapped within the skull, which may expand at altitude, it is advisable to avoid air travel for approximately seven days following this type of procedure.

Cancer Research UK advises that it can take up to 10 days for the air to dissolve away, whilst the NHS Choices website suggests you should allow six weeks after a craniotomy and four weeks after a brain biopsy.

Different airlines may also have different rules, so it is advisable to talk to both your consultant and your airline first.

Travel insurance can be more expensive or difficult to obtain following neurosurgery. It is essential that your child is fully covered for travel to prevent you from having to pay very high costs if they do fall ill when away.

There are some specialist insurers who may insure your child to travel.

For further information, see our *Travelling and brain tumours* web page and fact sheet.

When will my child be able to go back to school?

This will be specific to your child, depending on the operation they had, how it went and their individual recovery.

It may be that your child will need to go back part-time, at least initially, and that they will need extra support.

Speak to your child's health team - they should be able to give you advice and talk to your child's school to co-ordinate this.

We have also developed a suite of *Education resources* giving information about what to expect and how to help you, your child, and the school work together to provide the support your child needs.

Are there any long-term difficulties associated with surgery?

It is possible that your child will have some difficulties long-term after surgery, but each child is different. Some may only have mild difficulties that can be helped with extra support, whilst others may have none at all. Others may have more severe difficulties.

What the difficulties might be, will depend on which part of the brain has been operated on. As mentioned, such difficulties could include problems with speech, movement and thought processes e.g. memory or reasoning.

Fatigue is also a common side-effect.

For further information, see our web pages and fact sheets on *Cognition and brain tumours*, *Communication difficulties and brain tumours* and *Fatigue and brain tumours*.

If your child has any of these difficulties, there are a variety of professionals, such as speech and language therapists, physiotherapists and clinical psychologists, that can work with them to improve their capabilities.

Your child may also continue to need extra help at school or college in the future. Don't be afraid to ask the health, social and educational professionals looking after your child for such support .

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

Posterior fossa syndrome (PFS)

If your child has had surgery in the 'posterior fossa' region of their brain (the cerebellum or brain stem), particularly to remove a type of tumour called a 'medulloblastoma', there is a small chance that they may develop 'posterior fossa syndrome'.

The 'posterior fossa' is the small space in the back of the skull, near the brain stem and the cerebellum.

Posterior fossa syndrome (PSF) is a group of symptoms that can appear a few days after surgery and include:

- Difficulty speaking

Speech may be slow, slurred or your child may not speak at all. This is why PFS is sometimes called 'cerebellar mutism'.

- Difficulty with movement

Your child may develop poor 'muscle tone' making them unsteady on their feet or unable to walk. They may be unable to sit or hold their head up, or develop difficulty with swallowing.

- 'Emotional lability ' Uncontrolled displays of emotion, such as crying, laughter or anger
- Slowed thinking and reasoning

How severe the symptoms are will vary from child to child, as will how well and how long it takes them to recover. If your child develops PFS, they will be given ongoing rehabilitation. And support for months or even years.

The cause of PFS is not known.

For more information, please see the Posterior Fossa Syndrome fact sheet produced by the Children's Cancer & Leukaemia Group (CCLG).

cclg.org.uk/write/MediaUploads/Publications/PDFs/Posterior_Fossa_Syndrome_Factsheet.pdf

Can neurosurgery cause brain injury?

Neurosurgeons are highly skilled professionals and will remove as much of the tumour as possible whilst avoiding damage to healthy brain tissue.

However brain surgery does carry risks. This could include injuring the blood supply to healthy brain tissue, causing a type of stroke.

Depending on which part of the brain is being operated on, an injury to healthy brain tissue could cause problems with speech, memory, muscle weakness, balance, vision or co-ordination.

Your child's consultant can give you more information about the potential risks to your child specifically. You should feel free to ask them any questions that you would like.

This is important before you sign the consent form to show that you have fully understood the risks and are agreeing to the procedure.

What if the tumour comes back?

Unfortunately, sometimes tumours do come back. They may come back in the same place or in a different part of the brain.

Treatment for these recurring tumours will be personal to your child, depending on where the initial tumour was and how it was treated.

Further surgery to remove the tumour may not be possible. In this case, chemotherapy may be the treatment option.

In some cases, surgery may be used to place the chemotherapy drugs directly into the brain.

Placing chemotherapy directly into the brain

Some chemotherapy drugs are not able to cross the blood-brain barrier. Putting the chemotherapy drugs directly into the brain during surgery allows the health team to get round this barrier.

Blood-brain barrier

This is a membrane which surrounds the brain and helps to protect it from harmful substances in the blood, such as bacteria or viruses, that could cause infections.

For more information, see *The human brain* web page and fact sheet.

The most common way for children to have chemotherapy directly to the brain is via an 'Ommaya reservoir'.

This is a dome-shaped device that sits underneath the scalp and delivers chemotherapy directly into the cerebrospinal fluid (CSF) - the clear fluid in the brain and spinal cord.

By delivering chemotherapy directly to the brain, rather than having it go round the whole body affecting other organs, the dose can be more concentrated, which increases its effectiveness.

What if I am told that my child can't have neurosurgery?

Surgery is not always the best way to treat a brain tumour - it depends on where in the brain the tumour is.

Sometimes, it would be too risky to operate, as the tumour may be very close to, or wrapped around, an important structure in the brain, such as the brain stem, which controls breathing. In such a case, the benefits of surgery would be outweighed by the dangers.

The decision not to operate is taken by your child's multi-disciplinary team (MDT) after much careful consideration. If the MDT does not think surgery is appropriate for your child, they will talk you through their decision to explain it to you.

If surgery is not an option, your child will still continue to be monitored or may have other treatment, such as chemotherapy or radiotherapy.

If you are unhappy with their decision, you could ask for a second opinion from another consultant. Your child's current consultant or GP can help to arrange this and will not be offended by your request.

For more information, see the *Getting a second opinion* web page.

Disclaimer: The Brain Tumour Charity provides the details of other organisations for information only. Inclusion in this fact sheet does not constitute a recommendation or endorsement.

What if I have further questions or need other support?

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

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

Disclaimer

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

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

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

About this information resource

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

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

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

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

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

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

About us

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

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

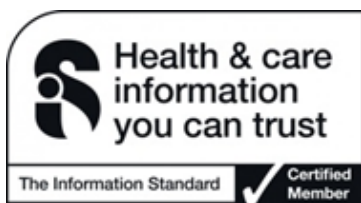
Whether it's reviewing our information resources, campaigning for change, reviewing research proposals or attending cheque presentations, everything you do helps to make the difference.

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

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

Neurosurgery for children with brain tumours

Your notes



Hartshead House
61-65 Victoria Road
Farnborough
Hampshire
GU14 7PA
01252 749990
enquiries@thebraintumourcharity.org
www.thebraintumourcharity.org

© The Brain Tumour Charity 2018. Registered Charity Number 1150054 (England and Wales) and SC045081 (Scotland).

Version 2.0 (clear print). First produced in standard print format February 2018. Review date, February 2021.