

Neurosurgery in children

Having surgery means having an operation using equipment to manually examine or treat a disease. Neurosurgery is surgery performed on the brain or spinal cord and is conducted by a highly specialised health professional called a 'neurosurgeon'. For brain tumours, the main aims of surgery are diagnosis, and to remove as much of the tumour as is safely possible. This fact sheet gives an overview of surgery for brain tumours in children and answers some questions you may have about brain surgery.

In this fact sheet:

- Burr hole biopsy
- Craniotomy
- Insertion of chemotherapy drugs into the brain
- Shunts
- Answers to some common questions you may have about children's neurosurgery

There are two main aims of neurosurgery - to remove a small part of the tumour in order to make a diagnosis and to remove as much of the tumour as is safely possible. Neurosurgeons have two strategies for doing this:

- **Craniotomy and debulking.** This is an operation where all or almost all of the tumour is removed. During the operation, samples of the tumour (biopsies) are taken. These are then sent to a laboratory for analysis and diagnosis.
- **Burr hole biopsy.** If the surgeon feels that it is not safe or necessary to remove the tumour, they carry out a smaller operation to remove a sample of the tumour for laboratory analysis and diagnosis. It is important to realise that some tumours can be removed and others cannot.

In the vast majority of cases, your child will first have an MRI scan or CT scan (*for further information, see our Scans for children fact sheet*), the results of which will be used by the neurosurgeon to decide which of these strategies to use. This is rather than carrying out a biopsy in one operation and debulking during a separate operation.

The purpose of the scan is also to show exactly where in the brain your child's tumour is. This will help guide the neurosurgeon as to whether operating is safe and which route into the tumour is best to cause minimal damage to surrounding tissue.

Burr hole biopsy

A biopsy is a small sample of tumour tissue taken from the site of the disease, which is then analysed under a microscope by a neuropathologist (*for further information see My child's health team fact sheet*). A burr hole is a small hole that is created in order to take the biopsy sample. A biopsy would often be used to help give an exact diagnosis of the type and grade of tumour your child has. This information is used to help their health team to decide on the best course of treatment.

Biopsies may also be used to identify your child's suitability for certain clinical trials (*for more information, see our Clinical trials fact sheet*). In some instances, samples of your child's biopsy may need to be frozen for use in clinical trials. If this is the case, it is important that you discuss your wishes with your child's health team and that they are clear as to what needs to be done. You

can also ask any questions you would like to about the process, what is involved and where your wishes are recorded.

The biopsy procedure

After their scan, your child will be given a general anaesthetic before their neurosurgeon drills a small hole called a 'burr hole' into their skull. Although this may sound frightening, your child will not be able to feel anything because of the anaesthetic. They will not be aware of the procedure while it is taking place, as they will be asleep. Before the anaesthetic, your child may be given a cream to put on their hand where the anaesthetic cannula (tube) will be inserted. This cream will numb your child's hand so that they are not able to fully feel the needle. These creams do wear off after a while however, so, if there is a delay in administering the anaesthetic, your child may need more cream.

The neurosurgeon will then pass a needle through the burr hole and take a small sample of the tumour. This sample is sent to a laboratory to be analysed by a pathologist who will give a diagnosis of the exact tumour type your child has.

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.

Biopsies are not always taken through a burr hole and are often taken during the larger craniotomy procedures.

Craniotomy

'Craniotomy' literally translates as 'making a hole in the skull' and is a medical procedure that has been carried out for hundreds of years in basic forms. A craniotomy allows the neurosurgeon access to your child's brain through a hole made in the skull. It is the most common type of surgery for brain tumour patients and it is used to remove all or part of the tumour (partial removal is known as de-bulking). Removal of the tumour aims to increase the chances of cure or reduce pressure on vital nerves within the brain, such as the optic nerve. A craniotomy would usually be performed while your child sleeps under general anaesthetic.

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The craniotomy procedure

- Your child will be given an anaesthetic which will make them sleep very deeply throughout the procedure.
- Once the anaesthetic takes effect, an incision (cut) is made in your child's scalp. It may be necessary for them to have a small area of their head shaved to allow access and for hygiene reasons.
- After the skin has been cut, your child's neurosurgeon will proceed to 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.
- After accessing your child's brain, 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 the surgery is complete, 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 although, 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.
- Awake craniotomy, where the patient is carefully woken up after the first part of the operation, and asked to perform simple tasks while the surgeon removes their tumour, is not generally performed on children.

Insertion of chemotherapy directly into the brain

During the neurosurgery following a craniotomy, your child may have chemotherapy drugs inserted directly into their brain. Some chemotherapy drugs are not able to cross the blood-brain barrier (*for more information see The human brain fact sheet*), but insertion during surgery allows the health team to get round this. A further advantage of having chemotherapy in this way is that the dose can be more concentrated and effective.

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 within the brain and spinal cord. By doing this, chemotherapy is delivered directly to the brain, which increases its effectiveness.

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 circulation. As the CSF builds up in one area, pressure rises, causing headaches. A build-up of CSF is known as hydrocephalus.

To reduce this pressure, neurosurgeons can insert a tube called a 'shunt' (which may also be called a 'ventricular catheter') into your child's skull to drain some of the excess fluid away. The shunt has valves to ensure 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.

A shunt is not a cure for a brain tumour, but it can help to improve symptoms related to increased pressure in your child's skull.

The length of time a shunt stays in varies. 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 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, however, 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 and some children may therefore need a number of shunts throughout their life.

Variable shunts

Some shunts have a variable setting and the level of drainage of fluid can be altered if needed. If your child has a variable shunt and MRI scans as part of their regular observation plan, these may cause the settings on the shunt to change. It is important that you know the settings of your child's shunt and that they know them as they grow older to help check the correct settings have been reset following scans.

Your child may also wish to wear a medical alert bracelet to inform others that they have a shunt should 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: www.theidbandco.com

What happens after my child wakes up?

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 due to the high care needs of their patients and allow for closer monitoring. When you first see your child, they may be linked to a machine that controls their breathing (a ventilator) to give their brain a chance to recover. It can be distressing to see your child in intensive care, with a bandage on their head and under medication that makes them very drowsy. If possible, try to mentally prepare yourself for this.

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

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caring for your child will carry out frequent checks (about every 15 minutes), including shining a light into your child's eyes to check that their pupils dilate and taking your child's blood pressure and heart rate. You may find it distressing to see your child roused in this way when they are resting, but these checks are very important.

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 and will be transferred to a specialist children's ward where they will be able to interact with other children and will be looked after by medics 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.

If your child's tumour has not been removed completely, another treatment, such as radiotherapy or chemotherapy, may also be given. Even if the whole tumour has been removed, another follow-up treatment may be given to target any tumour cells that may have been left behind.

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

Your child's wound will be covered with a dressing or bandage. Usually, this 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).

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 give you advice on preventing infection. They may also give your child antibiotics to prevent infection.

Why are there tubes in my child's body after surgery?

When your child awakes 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. Depending on their age, you may wish to tell them a bit about what these are and what they are for, so that they know what to expect before they go in to hospital.

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.

Some of the common tubes you could see are:

- **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. It also allows their health team to measure how much urine they are producing. This helps to determine 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** - blood pressure will usually be monitored several times throughout the day to ensure your child has a healthy blood pressure.
- **Central line** - this is a tube that is inserted under skin of the chest to a vein above the heart. It can be used to deliver chemotherapy or antibiotics and is also used to take blood samples or give blood transfusions. This tube can be inserted under a local anaesthetic, but is often inserted under general anaesthetic to reduce anxiety.

How will my child feel after neurosurgery?

Many factors 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 fatigued after surgery, so do not be alarmed if your child sleeps more than usual. Medical staff will carry out regular checks to ensure 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. They may also experience temporary worsening of the symptoms they had before the surgery. This is not unusual and is usually due to swelling in the brain following surgery.

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 awake. Your hospital may also have a play therapist who can help your child understand what is going to happen to them in the run up to their 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. Your child may have their swallowing checked by a speech therapist before they are allowed to eat or drink anything.
- New symptoms, which might include personality changes, poor balance and coordination, speech problems, weakness and epileptic seizures (fits).

They may also continue to feel tired and need a nap after a period of activity, for example, working with a therapist.

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If your child has had surgery in the posterior fossa region of their brain (the small space in the skull, near the brainstem and cerebellum) there is a small chance that they may experience posterior fossa syndrome. This is defined as 'the temporary and complete loss of speech after posterior fossa surgery'.

Other symptoms include dysphagia (difficulties swallowing) and emotional lability (uncontrolled episodes of emotion, such as crying, laughter or anger).

The above 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.

Before your child has surgery, their consultant will discuss with you what to expect and you will be asked to sign a consent form acknowledging 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 team if symptoms displayed after surgery are normal.

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 cleanse your hands with alcohol 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.

It can be distressing to see your child in intensive care, with a bandage on their head and under medication that makes them very drowsy. If possible, you should try to mentally prepare yourself for this before entering.

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. This does not mean, however, that they will not be up and walking on the ward very quickly. Your child's health team will be able to give you an indication of how long after the surgery they will be able to return home.

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.

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

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 burdensome, but it is important as it will give the health team a good idea as to whether any of the tumour remains and how much swelling of the brain there is. 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?

Your child's consultant should talk through their treatment plan with you so that you know what to expect. After brain surgery, it is likely that your child will have another treatment, such as radiotherapy (usually given only to children who are at least three years old) or chemotherapy, to get rid of any remaining tumour cells.

Due to the swelling in the brain after surgery, your child may be given steroids, such as 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 (*for further information, see our Steroids in children fact sheet*). It is very important that your child does not suddenly stop taking the steroids, as it takes some time for the body to adjust and this is done through gradual reduction of dose.

Some people experience seizures (or 'fits') after brain surgery due to increased pressure in the head. Your child may be given anti-epileptic medication 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 anti-epilepsy drugs for the rest of their life. A psychologist may be able to help them come to terms with this as they get older.

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Will my child's hair grow back?

It is usually 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 relatively 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 and eventually a white line as it fades.

Can neurosurgery cause brain injury?

Neurosurgeons are highly skilled professionals and will remove as many of the tumour cells as possible while avoiding damage to healthy brain tissue. Nonetheless, as with any operation, brain surgery does carry risks and this could include injuring the blood supply to healthy brain tissue - 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 and co-ordination.

Your child's consultant can give you more information about the potential risks in relation to your child specifically and you should feel free to ask them any questions that you would like to. Before your child has surgery you will be asked to sign a consent form to indicate that you have fully understood the risks and are agreeing to the procedure.

Are there any long-term difficulties associated with surgery?

Long-term difficulties after surgery are possible, but the nature of these 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. If your child experiences these effects, professionals, such as speech and language therapists, physiotherapists and clinical and educational psychologists, can work with them to improve these functions. *(For further information, see our fact sheets on Cognition and brain tumours and Communication problems and brain tumours).*

If your child has long-term effects as a result of their brain surgery, they may need extra help at school in the future. Do not be afraid to ask the health, social and educational professionals looking after your child for such support *(for further information, see our Learning difficulties and brain tumours in children fact sheet).*

Will my child be able to fly after neurosurgery?

Advice on this matter should be sought from your child's doctor. As a general rule, anyone who has had brain surgery should not fly for around three months afterwards. This is because of changes in air pressure and oxygen levels when you fly.

After this period it should be safe for your child to fly. 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 incurring heavy 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 fact sheet).*

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 sport, though they should avoid sports that involve significant physical contact between players ('contact sports'), such as rugby and wrestling.

Your child's consultant or doctor will be able to advise you on when your child can begin playing sport again after brain surgery. The Children's Cancer and Leukaemia Group (CCLG) publication 'Sport and Exercise for Children and Young People with Cancer: A Parent's Guide' also gives a lot of information on the topic. You can access an electronic copy at: www.cclg.org.uk/products_files/CCLG-SportExercise.pdf or you can request a free hard copy from CCLG on 0116 249 4460 or through CLIC Sargent on 0300 330 0803.

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 should be encouraged.

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

Surgery is not always the preferred option 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, and the benefits of surgery would be outweighed by the dangers.

If your child's consultant does not think surgery is appropriate for your child, you may like to ask them to talk you through their decision to explain it to you. 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.

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

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What if I have further questions?

If you require further information, any clarification of information, or wish to discuss any concerns, please contact our Support and Information Team, which includes a dedicated Children and Families Worker.

Call: 0808 800 0004

(Free from landlines and most mobiles:
3, O2, Orange, T-Mobile, EE, Virgin and Vodafone)

Email: support@thebraintumourcharity.org

Join our online forums at:
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About us

The Brain Tumour Charity makes every effort to ensure that we provide accurate, up-to-date and unbiased facts about brain tumours. We hope that these will add to the medical advice you have already been given. Please do continue to talk to your doctor if you are worried about any medical issues.

We are the UK's leading brain tumour charity. We fund scientific and clinical research into brain tumours and offer support and information to those affected, whilst raising awareness and influencing policy.

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 fundraising, leaving a gift in your will or giving in memory, please visit us at thebraintumourcharity.org, call us on **01252 749043** or email fundraising@thebraintumourcharity.org

About this fact sheet



This fact sheet has been written and edited by The Brain Tumour Charity's Support and Information Team and is supported by the Children's Cancer and Leukaemia Group (CCLG).

The accuracy of medical information has been verified by a paediatric neurosurgeon. Our fact sheets have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence. If you would like a list of references for any of the fact sheets, or would like more information about how we produce them, please contact us.

The **BRAIN** **TUMOUR** **CHARITY**

Neurosurgery in children

Your notes

**Saving lives through research,
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