

Neurosurgery for adults with brain tumours

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

This fact sheet gives an overview of neurosurgery for brain tumours and gives an idea of the processes and procedures you may experience.

It's important to remember that every hospital or surgeon may have slightly different practices, so what you experience may be different from what's described in this fact sheet. Your healthcare team will be able to explain what will or won't happen.

In this fact sheet:

- Why might I need neurosurgery?
 - Removal of the tumour (craniotomy)
 - Diagnosis of the type and grade of tumour (biopsy)
 - Other reasons
- What to expect before, during and after neurosurgery
- Answers to some common questions you may have about neurosurgery

This fact sheet is relevant to brain tumours in adults - for fact sheets and other resources for children, please see www.thebraintumourcharity.org

Why might I need neurosurgery?

There are several reasons why you might have surgery for your brain tumour:

- whole or partial removal of the tumour (craniotomy)
- diagnosis of tumour type (biopsy)
- putting chemotherapy drugs directly into the brain
- reducing associated conditions, such as hydrocephalus, by putting in a shunt.

(Hydrocephalus is a build-up of cerebrospinal fluid, increasing pressure in the skull.)

Removal of the tumour (craniotomy)

When possible, the neurosurgeon will try to remove all of your 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 brain to remove all or part of the tumour.

If all the tumour is removed, this is called a total resection. If part of the tumour is removed, this is called partial resection or de-bulking.

Removing the tumour aims to:

- reduce pressure in the brain and improve symptoms,
 e.g. headache, nausea, vomiting
- reduce brain swelling and the need to take steroids
- reduce pressure on vital nerves and improve symptoms, such as the optic nerve.
- help other treatments to work better, such as radiotherapy or chemotherapy
- increase the chances of cure (for some slow growing tumours)

A craniotomy is usually performed while you're asleep under general anaesthetic. However, sometimes it can be performed when you're awake. This is known as an awake craniotomy.

Awake craniotomy

An awake craniotomy may be performed if the tumour is close to, or involves, areas of the brain that control important functions, such as speech or movement.

By waking you during the operation, the surgeon can map out and avoid these important areas in the brain.

They do this by gently stimulating areas of the brain with a tiny electrical probe and seeing if you can still perform certain functions, such as answering questions or whether you get involuntary movement of your arm/leg or flashes of light in your vision. This tells the surgeon to avoid that area of the brain. Once they stop stimulating these areas, their function will return.

The neurosurgeon will continue to test the areas as the operation goes on to make sure they are still working.

It's important to note that the brain itself cannot feel pain, as it has no pain receptors.

The aim is to remove as much of the tumour as possible, while minimising the risks of causing any harm to these functions.

This can sound rather scary, but if this is thought to be the best option for you, your healthcare team will discuss it with you in detail, explain what is done to prevent you feeling any pain and help you mentally prepare for it.

After all types of craniotomy, 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 <u>not</u> operate to remove my brain tumour?

- The tumour is in, or too 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 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 or active monitoring.

For more information, please see the Watch and wait webpage and fact sheet.

Diagnosis of the type and grade of tumour (biopsy)

Diagnosis of the exact type and grade of your brain tumour is important because it tells your healthcare team how your tumour is likely to behave.

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

Knowing this helps your healthcare team decide on the best course of treatment for you.

An exact diagnosis can also help if you want to take part in a clinical trial, which have strict entry criteria.

For more information, see our Clinical trials and brain tumours webpage and fact sheet.

To get an exact diagnosis, the neurosurgeon operates to take a sample of your tumour. This is called a biopsy.

The sample is sent to the lab, where the tumour cells, and the genes and proteins within them, are looked at by a neuropathologist, who will tell your consultant your diagnosis.

For more information, see our Multi-Disciplinary Team for adults webpage and fact sheet.

The neurosurgeon will always take a biopsy at the same time as doing a larger operation to remove as much of the tumour as possible. (This operation is 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 get a diagnosis when it's not possible, or not advisable, to operate to remove the tumour.

Other reasons

Putting chemotherapy directly into the brain

Sometimes at the end of a craniotomy, before the surgeon closes the skull, you may have chemotherapy drugs inserted directly into your brain.

This is because some chemotherapy drugs are unable to cross the bloodbrain barrier. This is a layer of tightly-packed cells that stops harmful substances, such as viruses, from crossing from the blood into the brain. However, it also stops many drugs from entering.

Putting chemotherapy drugs directly into your brain during surgery allows your healthcare team to get round this. A further advantage of having chemotherapy in this way is that the dose can be more concentrated and potentially more effective.

There are different ways that chemotherapy drugs can be delivered directly into the brain:

Wafer implants

After whole or partial removal of the tumour, the neurosurgeon may place chemotherapy wafer implants into the space where the tumour was.

The wafers, which are coated with the chemotherapy drug carmustine, gradually dissolve over the next couple of weeks, releasing chemotherapy as they do so.

The purpose of wafer implants is to get rid of any remaining tumour cells at the site of surgery. You may also hear these implants referred to as Gliadel® wafers.

At the moment, these wafers are only licensed for people with high grade gliomas, or with glioblastomas (GBM) that have returned after treatment. Also, the surgeon must be confident that at least 90% of the tumour has been removedand that the fluid-filled spaces in the brain (ventricles) have not been affected by the tumour before they wafers can be used.

Ommaya reservoir

This is a dome-shaped device, put in during surgery, that sits underneath the scalp and allows access to deliver chemotherapy directly into the cerebrospinal fluid (CSF). This is the clear fluid within the brain and spinal cord.

Shunts

Headaches are a common symptom of brain tumours. They can sometimes 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 (sometimes called water on the brain).

To reduce this pressure, neurosurgeons can insert a tube, called a shunt, through your skull and into your brain to drain some of the excess fluid away.

You may hear the term ventricular catheter. This is the top part of the shunt that runs through the brain and into the CSF in the ventricles. (The ventricles are spaces in the brain that are filled with CSF.)

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 abdominal body cavity.

It's important to know that it doesn't go into your stomach, so does not interfere with how you eat and digest food.

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

The length of time a shunt stays in for varies.

You cannot see a shunt from outside the body, so other people won't know it's there unless you tell them. However, you may be able to feel your shunt running down behind your ear.

You may have a programmed or variable pressure shunt. This shunt can be adjusted by your surgeon with an external magnet to allow fluid to drain when pressure gets too high. If you have this type of shunt fitted, it's important to know the settings, as after each MRI scan, some programmed shunts will need to be reset, due to the effect of the magnet on the shunt setting.

What happens before neurosurgery?

Before your surgery, your neurosurgeon will discuss with you what to expect, and you'll be asked to sign a consent form stating that you understand the procedure and the risks involved.

Ask as many questions as you like - your healthcare team are used to this, so don't feel awkward or that any questions are 'silly'.

You may like to ask if there are any biomarker tests for your tumour type. Biomarkers can be a change in a tumour's genes, which can help to predict the growth of your tumour or how well you may respond to certain treatments.

For more information about biomarkers, see our Biomarkers webpage and fact sheet.

You may also like to ask if you can have a sample of your tumour tissue frozen, so you can be a candidate for clinical trials in the future and have any relevant genetic (biomarker) tests.

It can be difficult to know what to ask. To help you get started, we have a webpage on Questions to ask.

Before your surgery, you'll have a scan, or series of scans, to show exactly where your tumour is in the brain.

This helps the neurosurgeon:

- plan the best route to the tumour, to cause least damage to the healthy brain tissue around the tumour
- make sure operating is safe by using the scans during surgery for navigating round the brain.

For more information about scans, see our Scans for adults with brain tumours webpage and fact sheet.

What happens during neurosurgery?

If you've been diagnosed with a high grade glioma, you may be given the 'Pink Drink' just before your surgery.

Otherwise known as 5-ALA, this drink (though not actually pink) makes the tumour cells glow bright pink under violet light. This helps your neurosurgeon distinguish more of the cells at the edges of your tumour, so they can remove more of the tumour.

By accurately removing more of the brain tumour, the tumour is likely to take longer to spread to other parts of the brain, there is a better response to chemotherapy and radiotherapy and there is less risk to healthy brain tissue. All of this means a longer survival time and more days feeling well.

Craniotomy procedure

Anaesthesia

• If you're having a standard craniotomy, you'll be given a general anaesthetic to make you sleep.

You may be given a local anaesthetic to the part of your scalp that the neurosurgeon will need to cut into. This is done to reduce pain after the surgery.

• If you're having an awake craniotomy, you may be put to sleep for the first part of the operation and woken later, or you may be given a local anaesthetic and sedation and be awake for parts of the operation.

The local anaesthetic will be given to any areas involved that feel pain (skin and muscle), so normally the procedure won't be painful.

It's important to know that the brain itself has no pain sensors, so cannot feel pain.

 A small area of your head may be shaved and will be cleaned. Shaving used to be done for what was thought to be hygiene reasons, but there is little evidence that shaving reduces infections, so many surgeons don't shave the head.

Operation

- Once the anaesthetic (local or general) takes effect, an incision (cut) is made in your scalp.
- After the skin has been cut, your neurosurgeon will remove a section of your skull.

This is called a bone flap and it allows the neurosurgeon to reach your brain. In a standard craniotomy, you won't be able to feel anything as you'll be asleep.

• If you're having an awake craniotomy and have been put to sleep for the first part of the operation, you'll be woken at this point.

This is to allow your neurosurgeon to map the areas of the brain and to check that your brain is functioning correctly - for example, by asking you to read something.

You may feel pulling as the neurosurgeon works, but you shouldn't feel pain due to the local anaesthetic to your scalp and the fact that the brain itself has no pain sensors.

 Once your neurosurgeon has access to your brain, they'll remove all or part of the tumour.

Very often, it's 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 as possible. Partial removal is known as debulking or partial resection and even though this doesn't 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.

For more information, see the Chemotherapy for adults and Radiotherapy for adults webpages and fact sheets.

- Removal of the tumour can take several hours, depending on the part of the brain being operated on.
- A sample will be sent to the lab for analysis and diagnosis.

Closing up

 Once the surgery is complete, your neurosurgeon will replace the bone flap and seal the wound using stitches or metal clips.

If you're having an awake craniotomy, you may be put back to sleep before this happens.

The total 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 4-6 hours. However, in complex cases, it could take significantly longer.

Done to here!!!!

Biopsy procedure

- The scan image (carried out before the operation) may be put into a computer.
 - This creates a 3D map of the brain and is used to work out the best route into the tumour. This technique is called stereotactic or image guided biopsy.
- You'll be given a general anaesthetic before your neurosurgeon drills a very small hole, called a burr hole, into your skull.
 - Although this may sound frightening, you won't be able to feel anything because you'll be asleep due to the anaesthetic.
- The neurosurgeon passes a needle through the burr hole and takes a small sample of the tumour.

- The sample is sent to a laboratory to be analysed by a neuropathologist, who will give a diagnosis of the exact tumour type you have. This can take several days.
- The skin is closed over the burr hole with staples or stitches.

A biopsy usually takes around 2 to 3 hours, including the time it takes for you to have an anaesthetic.

What happens after neurosurgery?

Where will I wake up after surgery?

Following surgery, you're likely to wake up in the recovery room of the operating theatre, where there will usually be other patients waking from their operations.

Different hospitals have different systems - some have specialist post-operative neurosurgery wards, where you may be taken for observation. In others, you may wake up in either a high dependency unit (HDU) or occasionally an intensive care unit (ICU).

While there, you'll have one-to-one personal care and attention.

In the first few hours, you'll have frequent neurological observations (neuroobs). They include:

- checking how alert you are
- testing your reflexes
- checking that your pupils react to light
- checking your pulse and blood pressure
- checking the amount of oxygen in your blood and the number of breaths you take each minute.

You may also be linked to a machine that controls your breathing (ventilator) to give your brain a chance to recover.

The amount of time it takes to wake up after surgery varies. Many people wake up very soon afterwards, but some people remain unconscious for a number of hours or a few days.

Why are there tubes in my body after surgery?

When you wake up after surgery, you'll have a number of tubes running in and out of your body. This unfamiliar experience can be upsetting - it can help if you know what the tubes are for.

You may be linked to the following devices:

- Drips. These are tubes that give you water and nutrients until you are able to eat normally. They may also deliver medicines into your 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 wound that drain excess blood and fluid.
- Intracranial pressure (ICP) monitor, which monitors the pressure in your brain.
- **Urinary catheter**. This goes into your bladder and gives a measure of how much urine you're producing. It's used to monitor whether you have an appropriate amount of fluid in your body and also drains urine.
- Nasogastric tube. This tube goes down through your nose to your stomach and provides liquid food.
- Blood pressure monitors.

Will I have a dressing on my wound?

When you wake up after surgery, you may have a dressing or bandage on your wound, but not always.

If a dressing is used, this usually stays on for up to about 5-10 days after surgery.

How will I feel after surgery?

Many factors will influence how you feel after surgery, including the type of surgery you've had, and the size and location of your tumour.

When you first wake up after brain surgery, you may have swelling and bruising on your face.

You may also feel some temporary worsening of the symptoms you had before the surgery. This is not unusual and is usually due to the swelling in

the brain following the surgery. You may be given steroids to help with any swelling.

For further information, see the *Steroids for adults* webpage and fact sheet.

You may 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 your breathing and oxygen levels.
- Headaches, caused by swelling in your brain. The swelling should die down within a couple of days and painkillers can be used to help relieve the headaches.
- Momentary dizziness or confusion.
- Difficulty swallowing. You may have your swallowing checked by a speech therapist before you're allowed to eat or drink anything.
- New symptoms, which might include personality changes, poor balance and co-ordination, speech problems, weakness and epileptic seizures (fits).
- You may also continue to feel tired.

For more information, see our Seizures (epilepsy) and brain tumours and our Fatigue and brain tumours webpages and fact sheets.

The list of side-effects may seem overwhelming, but it's important to remember that such effects usually disappear fairly soon after surgery and that a team of health professionals will be taking care of you.

How long after surgery will I be back on my feet?

Neurosurgery is a major operation and you'll need to rest for a number of days afterwards.

For the first few days, one of the top priorities for your healthcare team will be ensuring that the pressure in your head doesn't increase.

Nurses will also ensure that you're moving your arms and legs around enough to allow blood flow and to prevent blood clots (thrombosis) or your muscles from stiffening up.

You won't be kept in bed any longer than is necessary and hospital staff are always keen for their patients to get up and get moving as soon as is safe.

You will have physiotherapy and occupational health assessments to prepare for and support your discharge from hospital.

As a general anaesthetic is used, you'll normally stay in hospital for a few days, though some hospitals may do biopsy surgery as a day case.

I've had brain surgery - what's next?

Your consultant should talk through your treatment plan with you, so that you know what to expect.

Often after brain surgery, and if you're medically fit enough, you'll have another treatment, such as chemotherapy or radiotherapy, to get rid of any remaining tumour cells.

Due to the swelling in the brain after surgery, it's common to be given steroids. You may be prescribed a type of steroid called Dexamethasone. Steroids help to reduce the swelling and increased pressure in your head. Under the guidance of your consultant, you'll gradually be able to stop taking steroids.

For further information, see the *Steroids for adults* webpage and fact sheet.

Some people experience seizures (fits) after brain surgery.

You may be given anti-epileptic medication. The length of time people take this for varies from person to person, but it's not uncommon to take anti-epileptics for up to a year after brain surgery. You may need to stay on them for life.

For more information, see our *Seizures* (epilepsy) and brain tumours webpage and fact sheet.

The clips or stitches will usually be removed 1-2 weeks after surgery. If you have dissolvable stitches, they don't need to be removed.

Over time, in most cases, the bone flap will fuse with the surrounding skull.

Other questions after neurosurgery

Will my wound become infected?

Infection is a possibility after surgery, so your healthcare team will check your wound and give you advice on preventing infection.

Will my hair grow back?

If you've had an area of your hair shaved before surgery, it normally grows back relatively quickly.

Will I be able to fly after brain surgery?

If you wish to travel by plane after brain surgery, you should ask for advice from your healthcare team. Normally, you wouldn't be able to fly for a little while after neurosurgery.

The Civil Aviation Authority, which is responsible for air travel safety, advises avoiding air travel for approximately 7 days following neurosurgery. This is because neurosurgery may leave gas trapped within the skull, which may expand at altitude.

Travel insurance may also be more expensive or difficult to obtain following neurosurgery. It's essential that you make sure you are fully covered to travel before you do so, to prevent incurring heavy costs if you fall ill while away. There are some specialist insurers who may insure you to travel.

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

Will I be able to play sport after brain surgery?

If you wish to play sport after your surgery, ask for advice from your doctor. Once you've recovered from surgery, it should be fine for you to play sport, though you may need to avoid sports that involve significant physical contact between players (contact sports), such as rugby and wrestling.

Your healthcare team will be able to advise you on when you can begin playing sport again after brain surgery.

How will I know if the surgery has been successful?

You're likely to have a brain scan a few days after surgery. This will give your healthcare team a good idea of whether any of the tumour remains and how much swelling of the brain you have.

The success of surgery is measured on the aim of the surgery and not on curing a tumour. Even if all of the visible tumour is removed, this may or may not mean that all of the actual tumour has been removed.

Will surgery cure my tumour?

Surgery as a cure depends on tumour type and your individual case. Before surgery, your consultant will discuss with you what to expect from surgery and whether they are hoping to remove all or part of the 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.

Are there any long-term difficulties associated with surgery?

Long-term difficulties after surgery are possible. Nerves, or the brain itself, can be damaged during surgery, affecting the functions that they control within our bodies.

The nature of these will depend on which part of the brain has been operated on, or which nerve has been affected.

The result of this damage is sometimes called a deficit and can be permanent or temporary. Such difficulties could include problems with speech and movement or problems with thought processes.

Before you have surgery, where possible, a health professional from your healthcare team will talk to you and/or your carer about what to expect and the risks involved.

It's important that you fully understand the level of risk, so you can make an informed decision about whether to agree to the surgery.

The exact level of risk depends on the exact procedure performed, but any surgery on the brain does carry risks, some of them serious. You should have been given a key worker within your healthcare team who you can contact - feel free to ask them as many questions as you wish, at any point.

If you're left with any long-term difficulties, professionals, such as speech and language therapists, physiotherapists and clinical psychologists, can work with you to improve these functions. Don't be afraid to ask for such support if you feel it's necessary.

For more information, see the Cognition and brain tumours and Communication difficulties and brain tumours fact sheets.

What if I'm told I can't have surgery?

Surgery is not always the preferred option to treat a brain tumour - it depends 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. In this case, the benefits of surgery would be outweighed by the dangers.

If your consultant doesn't think surgery is appropriate for you, you may like to ask them to explain their decision.

If you're still unhappy with their decision, you could ask for a second opinion from another consultant. Your current consultant or your GP can help to arrange this.

For more information, see our Getting a second opinion webpage.

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 or 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

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

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