

Patient agreement to investigation or treatment

Craniotomy and resection of brain tumour in adults

Authors: Neurosurgery, Department of Neurosciences

Brief description:

Your recent tests have shown that you have a brain tumour. Your neurosurgeon has recommended a procedure called 'craniotomy and resection of brain tumour'. This is a surgical procedure that aims to take out as much tumour as is safely possible.

Here, we explain some of the aims, benefits, risks and alternatives to this procedure (operation/treatment). We want you to be informed about your choices to help you to be fully involved in making any decisions.

Please ask about anything you do not fully understand or wish to have explained in more detail.

If you would like this information in another format or language or would like help completing the form, please ask a member of our staff.

Please bring this form with you to hospital

- You will be asked to read this form carefully, and you and your doctor (or other appropriate healthcare professional) will sign it to document your consent.
- All our consent forms are available on the Addenbrooke's website: <http://www.addenbrookes.org.uk/consent>
- Guidance for health professionals can be found on the Addenbrooke's intranet site <http://nww.addenbrookes.nhs.uk/consent>
- Remember, you can change your mind about having the procedure at any time even after you have signed the form.

For staff use:

Does the patient have any special requirements? (For example: requires an interpreter or other additional communication method)

.....
.....

About craniotomy and resection of brain tumour

During a craniotomy procedure the neurosurgeon makes an incision in the scalp before taking out a small piece of the skull to expose the brain. Once the brain is exposed, the tumour is fully **resected** (removed) or **partially resected** (debulk or partially removed).

During a **resection** the surgeon performs a craniotomy and then removes as much tumour as possible before replacing the skull and stitching the skin back in place.

Sometimes it is not safe for the neurosurgeon to take out the entire tumour, for example, the edge of the tumour might be very close to vital structures. When the tumour is partially removed, this is referred to as a **partial resection** or debulking procedure.

Fluorescence-guided surgery

In some cases your consultant may feel that a more complete removal of your tumour could be achieved using a substance called Gliolan[®] (5-ALA). One of the difficulties in removing a brain tumour is knowing where the tumour stops and normal brain tissue starts. There is no sharp edge to the tumour as it merges with normal brain. Being too aggressive with tumour removal runs the risk of causing damage to parts of the brain, and not being aggressive enough runs the risk of leaving tumour behind.

5-ALA is drug that can help identify the edge of the tumour. It is drunk two to four hours before the operation. 5-ALA goes into the tumour cells of the brain but not the normal brain. In the tumour it is converted to a substance that glows pink when exposed to blue light. During the operation the surgeon will use a blue light filter on the microscope and identify remaining tumour cells which can then be removed.

Although 5-ALA is a relatively new product in the United Kingdom, it is has been used for some time in the rest of Europe.

Side-effects of 5-ALA

Like all medicines, 5-ALA can cause side effects, though they are rare.

Very common side effects (likely to occur in more than 1 of 10 patients):

- Mild alterations of blood cell counts.
- Transient alterations in blood tests of liver function.

Common side effects (likely to occur in more than 1 of 100 patients but less than 1 of 10 patients):

- Nausea (unsettled stomach) or vomiting (sickness).
- Neurological disorders including weakness of one side of the body, speech problems, seizures or some loss of vision. These problems occur because the amount of tumour removed is greater.
- Blood clots in the leg or more uncommonly the lung.

Uncommon side effects (likely to occur in more than 1 of 1,000 patients but less than 1 of 100 patients):

- Decrease of blood pressure.
- Skin reactions (for example rash, looking like sunburn).

Very rare side effects (likely to occur in less than 1 of 10,000 patients), including isolated reports:

- Decrease of your sense of touch.
- Diarrhoea.

Before your procedure

- Most patients attend a pre-admission clinic. Here you will meet a Neurosurgeon and will be given the details of your key worker. Your key worker is the person to contact if you have any questions or need advice or support.
- At this clinic, we shall ask you for details of your medical history and carry out any necessary clinical examinations and investigations. The investigations will include blood tests and skin swabs. This clinic gives you a good opportunity for you to ask us any questions about the procedure, but please feel free to discuss any concerns you might have at any time.
- You will be asked if you are taking any tablets or other types of medication - these might be ones prescribed by a doctor or bought over the counter in a pharmacy. It helps us if you bring details with you of anything you are taking (for example: bring the packaging with you). We particularly need to know about medicines that affect blood clotting for example aspirin or warfarin.
- This procedure may be performed using a general anaesthetic or a local anaesthetic. This will be discussed with you. See below for further details about the types of anaesthesia.
- Most people who have this type of procedure will need to stay in hospital for one to two days post operatively before going home or back to their local hospital.
- On the day of surgery or the day before you will be admitted to one of our neurosciences wards. On the day of admission you will be asked to telephone the admissions office on 01223 217100 to check that there is a bed available. Please do not eat or drink from midnight of the day of the operation.

During the procedure itself

You will be taken to neurosurgery theatres on your hospital bed. The surgeon shaves a small amount of hair and then makes an incision in your scalp. The size and shape of the opening will depend on the size and position of the tumour. The incision will be made behind the hairline so the scar is hidden when the hair grows back.

The neurosurgeon then takes out a small piece of the bone of your skull to expose the brain. This part of the operation is called a **craniotomy**. The surgeon will then remove as much of the tumour as possible. Sometimes it is not possible to completely remove a tumour. For example, if the tumour is in a vital structure in your brain, then removing all of it may cause severe disability or even death. Sometimes the surgeon can tell you before the operation whether they can remove the entire tumour. Sometimes they don't know until they are doing the operation itself.

After the tumour is resected the bone is replaced and the skin closed with stitches or clips (staples) and covered with a dressing. The time this takes depends upon the complexity of the procedure but you will be away from the ward for several hours.

After the procedure

- You will wake up in the recovery room after your operation. You will have an oxygen mask on your face.
- After this procedure, you will have a small, plastic tube in one of the veins of your arm. This will be attached to a bag of fluid (called a drip), which provides your body with fluid until you are well enough to drink by yourself. You may (or may not) also have a tube in the wrist called an arterial line, a tube in the neck called a central line and a urinary catheter.
- While you are in the recovery room, a nurse will check your pulse and blood pressure regularly. When you are fully conscious, you will be taken to a ward.
- Sometimes, people feel sick after an operation, especially after a general anaesthetic, and might vomit. If you feel sick, please tell a nurse and you will be offered medicine to make you more comfortable.
- You may eat and drink as soon as you feel able. It is recommended you start with clear fluids and move to light food after a few hours.
- After this procedure you are able to get up as soon as you feel well enough. Often, this is within a few hours of returning to the ward.
- Your wound will feel strange for a few weeks but pain is not usually a problem. The scar and skin may look bruised and swollen. The scar will fade to a thin pale line in three to six months. Any shaved hair will normally re-grow.
- **When you can leave hospital:** Most people who have had this type of procedure will be able to leave hospital after one to two days. The actual time that you stay in hospital will depend on your general health, how quickly you recover from the procedure and your doctor's opinion.
- Most stitches are self-dissolvable so will not need to be removed. Any clips are removed five days after surgery. If you are discharged before then, you will be asked to make an appointment with your GP surgery so they can be removed by your practice nurse.

- **When you can resume normal activities including work:** You may return to light domestic work and exercise as soon as you feel able to do so. If you intend to return to work, it is best to discuss this with your neurosurgeon and or key worker. How quickly you are able to return to work will depend upon the physical skills and demands of the job. You are advised to avoid contact sports such as boxing or rugby for at least three months.
- **Special measures you need to take after the procedure:** You are advised to avoid flying for six weeks. You can gently wash your hair as soon as the stitches or clips are removed. It is recommended you use a gentle shampoo for this. Its best to avoid hair dyes and perms for a month as this will irritate the scar.
- It is likely that you will be taking steroids (dexamethasone). It is usual to increase the dose of these around the time of surgery and then reduce them again over a few days following surgery. Sometimes it will be stopped altogether. You will receive a detailed plan of when and how many tablets to take after discharge.
- **Check-ups and results:** A sample of the tumour will be sent for analysis. The test results take about one week. When the tests are complete, you will be invited to the next available outpatient clinic. At this clinic we will check on your progress, explain the test results and will discuss any further treatment that is recommended. Please feel free to bring family and friends as appropriate.

Intended benefits of the procedure

The aims of this procedure are:

- To find out what kind of cells are causing the tumour. This is called a **histopathology diagnosis**.
- To remove as much of the tumour as possible.

Taking out as much tumour as a possible may have the following benefits:

- Better survival outlook
- Fewer symptoms
- It means other treatments may be safer for example radiotherapy, causes swelling (oedema). By creating space in the brain, the risk of severe complications is reduced.

Who will perform my procedure?

This procedure will only be performed by a consultant neurosurgeon or neurosurgery specialist registrar operating under the supervision of a consultant.

Alternative procedures that are available

There are generally three treatment options for brain tumours:

- **Brain tumour biopsy.** During this procedure a very small amount of the tumour is removed and sent for analysis. Once a diagnosis is known, further treatment options can be discussed. This is a safer, less intrusive procedure but the benefits may not be as good.

- **Craniotomy and resection with intra-operative chemotherapy.** For some types of tumour it is possible to use chemotherapy that is placed directly into the tumour cavity at the end of the procedure. This carries a higher risk and is not always possible but there is evidence that it can increase survival.
- **You may decide not to have surgery at all.** This may also prevent you from having other types of treatment such as radiotherapy or chemotherapy as these depend upon having a tissue diagnosis. The full implications of deciding not to have surgery will be discussed with you.

Serious or frequently occurring risks

There are risks of surgery in general and risks associated specifically with the craniotomy. The risks of surgery in general include problems with the wound (for example infection), problems with breathing (such as a chest infection) and blood clots for example in the legs or less frequently the lungs.

- Infection in the brain: one in 100 people
- Leakage of brain fluid (CSF): one in 100 people
- Bleeding (haemorrhage) into the brain: four in 100 people
- Superficial wound infection: two in 100 people
- Permanent 'neurological deficit' such as speech, visual, arm or leg weakness if the tumour is away from a critical area of the brain: three in 100 people
- Permanent 'neurological deficit' such as speech, visual, arm or leg weakness if the tumour is in or close to a critical area of the brain: ten in 100 people
- Death: 1 in 100 people

The risks of this surgery depend very much upon which part of your brain the tumour is in. Your surgeon will discuss your particular risks with you.

If you do wake up with a new neurological deficit then remember that most patients with a new neurological deficit following this procedure will improve over a few days. Some will resolve completely.

Warnings

After administration of this medicine, you should avoid strong light for 24 hours (for example direct sunlight or brightly focused indoor light).

Do not take 5-ALA

- If you are allergic to 5-aminolevulinic acid hydrochloride (5-ALA) or porphyrins.
- If you have or are suspected to have acute or chronic types of porphyria.
- If you are or might be pregnant.

5-ALA should be used with caution if:

If you have a heart disease or had heart disease in the past

You should tell your doctor. In this case, this medicine should be used with caution because the blood pressure may be decreased.

Women who are breastfeeding

It is not known whether this medicine enters breast milk. Breast-feeding mothers should not breastfeed for 24 hours after treatment with this medicine.

If you are taking other medicines

Please tell your doctor or pharmacist if you are taking or have recently taken any other medicines, particularly medicines that may cause skin problems when the skin comes under strong light (for example some types of antibiotics), but also medicines obtained without prescription (for example hypericin or Saint John's wort extracts). You should not take any such products up to two weeks after you have taken 5-ALA.

Information and support

- If you have any questions or anxieties, please feel free to ask your key worker or any other member of staff at any time even after discharge.
- Brain Tumour UK – for regular meetings, phone pals, information and advice.
Tel: 0845 450 0386 Email: www.braintumouruk.org.uk
- Macmillan Cancer Support (now merged with CancerBackup) – for online information, advice and support: www.macmillan.org.uk or via Cancerbackup on www.cancerbackup.org.uk Tel: 0800 500 800

Your anaesthesia

Local anaesthetic

You may be having this procedure under local anaesthetic. This means you will be awake during the procedure. The skin is numbed by injecting local anaesthetic directly at the site of the operation. The anaesthetist is still present to monitor you during the procedure and will talk to you throughout the procedure. Please feel free to bring your choice of music if you wish.

General Anaesthesia

During general anaesthesia you are put into a state of unconsciousness and you will be unaware of anything during the time of your operation. Your anaesthetist achieves this by giving you a combination of drugs.

Before your operation

Before your operation your anaesthetist will visit you in the ward. The anaesthetist who looks after you on the day of your operation is the one who is responsible for making the final decisions about your anaesthetic. He or she will need to understand about your general health, any medication that you are taking and any past health problems that you have had. Your anaesthetist will want to know whether or not you are a smoker, whether you have had any abnormal reactions to any of the drugs or if you have any allergies. They will also want to know about your teeth, whether you wear dentures, have caps or a plate. Your anaesthetist needs to know all these things so that he or she can assess how to look after you in this vital period. Your anaesthetist may examine your heart and lungs.

Do not be worried about your anaesthetic. When your anaesthetist visits you before your operation, this is the time to ask all the questions that you may have, so that you can forget your fears and worries.

Before your operation you will usually be changed into a gown, wheeled to the operating suite and into an anaesthetic room. This is an ante-room outside the theatre. The anaesthetist, his or her assistant and nurses are likely to be present. An intravenous line (drip) may be inserted. Monitoring devices may be attached to you, such as a blood pressure cuff or a pulse oximeter.

A pulse oximeter is a small box which is taped to your finger. It shows how much oxygen you have in your blood and is one of the vital monitors that an anaesthetist uses during your operation to ensure that you remain in the best of health. You may be given some oxygen to breathe.

During your operation

While you are unconscious and unaware, your anaesthetist remains with you at all times. He or she monitors your condition and administers the right amount of anaesthetic drugs to maintain you in the correct level of unconsciousness for the period of the surgery. Your anaesthetist is constantly aware of your condition and trained to respond. Your anaesthetist will be monitoring such factors as heart rate, blood pressure, heart rhythm, body temperature and breathing. He or she will also constantly watch your need for fluid or blood replacement. If you have any other medical conditions, your anaesthetist will know of these from your pre-operative assessment and be able to treat them during surgery.

After your operation

After your operation your anaesthetist continues to monitor your condition carefully. You will be transferred to a recovery ward where specially trained nurses, under the direction of anaesthetists, will look after you. Your anaesthetist and the recovery nurses will ensure that all the anaesthetic effects are reversed and that you are closely monitored as you return to full consciousness. You will be given some oxygen to breathe in the recovery area, and may find that intravenous drips have been inserted whilst you are unconscious in theatre and that these will be replacing fluids that you might require. You will be given medication for any pain that you might feel.

You are likely to feel drowsy and sleepy at this stage. Some patients feel sick; others may have a sore throat related to the insertion of the breathing tube during surgery. During this time it is important that you relax as much as you can, breathe deeply, do not be afraid to cough, and do not hesitate to ask the nursing staff for any pain relief, and about any queries you may have. You are likely to have hazy memories of this time and some patients experience vivid dreams. Once you are fully awake you will be returned to the ward. Do not expect to feel completely normal immediately!

What are the risks of general anaesthesia?

In modern anaesthesia, serious problems are uncommon. Risks cannot be removed completely, but modern equipment, training and drugs have made it a much safer procedure in recent years. The risk to you as an individual will depend on; whether you have any other illness, personal factors (such as smoking or being overweight) or surgery which is complicated, long or done in an emergency. Please discuss any pre-existing medical condition with your anaesthetist.

- Very common and common side effects (1 in 10 or 1 in 100 people)
Feeling sick and vomiting after surgery, sore throat, dizziness, blurred vision, headache, itching, aches, pains and backache, pain during injection of drugs, bruising and soreness, confusion or memory loss.
- Uncommon side effects and complications (1 in 1000 people)
Chest infection, bladder problems, muscle pains, slow breathing (depressed respiration), damage to teeth, lips or tongue, an existing medical condition getting worse, awareness (becoming conscious during your operation).
- Rare or very rare complications (1 in 10,000 or 1 in 100,000)
Damage to the eyes, serious allergy to drugs, nerve damage, death, equipment failure.

Local anaesthesia

Sometimes, while you are asleep a local anaesthetic drug is injected into the skin and tissues around the site of the operation. This helps with pain relief once you are awake.



We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169

Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or patient.information@addenbrookes.nhs.uk

Polish

Jeżeli chciałbyś uzyskać te informacje w innym języku, w dużej czcionce lub w formacie audio, poproś pracownika oddziału o kontakt z biurem Informacji Pacjenta (Patient Information) pod numerem telefonu: 01223 216032 lub pod adresem patient.information@addenbrookes.nhs.uk

Portuguese

Se precisar desta informação noutra língua, em impressão de letras grandes ou formato áudio, por favor peça ao departamento que contacte a secção de Informação aos Doentes (Patient Information) pelo telefone 01223 216032 ou através do e-mail patient.information@addenbrookes.nhs.uk

Arabic

إذا كنت تود الحصول على هذه المعلومات بلغة أخرى، بالأحرف الكبيرة أو بشكل شريط صوتي، يمكنك أن تطلب من القسم الاتصال بمعلومات المريض على الرقم: 01223216032 أو عبر البريد الإلكتروني: patient.information@addenbrookes.nhs.uk

Cantonese

如您需以另一語言版本、特大字體或錄音形式索取本資料，請要求部門聯絡病人諮詢服務：電話 01223 216032，電郵地址 patient.information@addenbrookes.nhs.uk

Turkish

Eğer bu bilgileri başka bir dilde veya büyük baskılı veya sesli olarak isterseniz, lütfen bulunduğunuz bölümdeki görevlilere söyleyin Hasta Bilgilendirme servisini arasinlar: 01223 216032 veya patient.information@addenbrookes.nhs.uk

Urdu

اگر آپ کو یہ معلومات کسی دیگر زبان میں، بڑے الفاظ میں یا آڈیو طریقہ سے درکار ہوں تو برائے مہربانی اس شعبہ سے پیشینٹ انفارمیشن سے ذیل کے ذریعہ رابطہ کرنے کی درخواست کریں: 01223 216032 یا patient.information@addenbrookes.nhs.uk

Bengali

আপনি যদি এই তথ্য অন্য কোন ভাষায়, বড় অক্ষরে বা অডিও রেকর্ডিং পেতে চান তাহলে 'প্যাশেন্ট ইনফরমেশন' এর সঙ্গে 01223 216032 নম্বরে ফোন করে বা patient.information@addenbrookes.nhs.uk ঠিকানায় ই-মেইল করে যোগাযোগ করার জন্য ডিপার্টমেন্টটিতে অনুরোধ জানান।

Document history

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Version number/Ref	3/CF385

Consent form 1

For staff use only:
Surname:
First names:
Date of birth:
Hospital no:
Male/Female:
(Use hospital identification label)

Patient agreement to investigation or treatment

Responsible health professional/job title

Special requirements
 (For example, other language/other communication method)

Name of proposed procedure or course of treatment

Craniotomy and resection of brain tumour Side (left/right).....

Statement of health professional

(To be filled in by a health professional with an **appropriate knowledge of the proposed procedure**, as specified in the Hospital's consent policy)

I have explained the procedure to the patient. In particular, I have explained:

The intended benefits of the procedure

- Curative** – to give you the best possible chance of being cured
- Palliative** – the aim is not to cure, but to control or shrink the tumour. The aim is to keep you well for as long as possible and increase the likelihood that you can have other treatment.
- Diagnosis**
 - Any serious or frequently occurring risks from the procedures including those specific to the patient: Problems with the wound (for example infection); problems with breathing (such as a chest infection); and blood clots; infection in the brain; leakage of brain fluid (CSF); bleeding (haemorrhage) into the brain; superficial wound infection; permanent 'neurological deficit'; permanent 'neurological deficit'; death. Other (please state):

- Any extra procedures that might become necessary during the procedure.....

I have discussed what the treatment / procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient.

- The following information leaflet has been provided: Craniotomy and resection of brain tumour'.Version/Date/Ref: 3/July 2010/CF385

This procedure will involve:

- General and/or regional anaesthesia Local anaesthesia Sedation

Health professional's signature:Date:

Name (PRINT): Job title:

Contact details (if patient wishes to discuss details later)

- I have offered the patient information about the procedure but s/he has declined information.

Statement of the interpreter (if appropriate)

I have interpreted the information to the best of my ability, and in a way in which I believe s/he can understand:

Interpreter's signature..... Date:

Name (PRINT):

Important notes: (tick if applicable)

- The patient has withdrawn consent (ask patient to sign/date here)
- See also advance directive/living will

Copy accepted by patient: yes / no (please circle)

For staff use only:
Surname:
First names:
Date of birth:
Hospital no:
Male/Female:
(Use hospital identification label)

Statement of patient

Please read this form carefully. If your treatment has been planned in advance, you should already have your own copy, which describes the benefits and risks of the proposed treatment. If not, you will be offered a copy now. Do ask if you have any further questions. The staff at Addenbrooke's are here to help you. **You have the right to change your mind at any time before the procedure is undertaken, including after you have signed this form.** Training doctors and other health professionals is essential to the continuation of the Health Service and improving the quality of care. Your treatment may provide an important opportunity for such training, where necessary under the careful supervision of a senior doctor. You may, however, decline to be involved in the formal training of medical and other students without this adversely affecting your care and treatment.

Please read the following:

I understand that I will have the opportunity to discuss the details of anaesthesia with an anaesthetist before the procedure, unless the urgency of my situation prevents this. (This only applies to patients having general or regional anaesthesia.)

I understand that you cannot give me a guarantee that a particular person will perform the procedure. The person undertaking the procedure will, however, have appropriate experience.

I understand that any procedure in addition to those described on this form will only be carried out if it is necessary to save my life or to prevent serious harm to my health.

I have been told about additional procedures which may become necessary during my treatment. I have listed below any procedures that **I do not wish, without further discussion, to be carried out.**

I understand that any tissue (including blood) removed as part of the procedure or treatment will be anonymised and may be used for teaching or quality control, and stored or disposed of in a manner regulated by appropriate, ethical, legal and professional standards.

I understand that all research will be approved by a research ethics committee and undertaken in accordance with appropriate ethical, legal and professional standards.

I understand that the research may be conducted within a hospital, university, not for profit organisation or a company laboratory.

Please tick boxes to indicate you either agree/disagree to the three points below. Yes No

I agree that tissue (including up to 20ml blood that would not otherwise be taken) not needed for my own diagnosis or treatment can be used for **research which may include genetic research.** **If you wish** to withdraw your consent for the use of your tissue (including blood) for research, please contact the Patient Advice and Liaison Service at Addenbrooke's Hospital.

I agree to the use of photography for the purpose of diagnosis and treatment.

I agree to anonymised photographs being used for medical teaching.

I confirm that the risks, benefits and alternatives of this procedure have been discussed with me and I have read and understood the above and agree to the procedure (or course of treatment) on this form.

Patient's signature:..... **Date:**

Name (PRINT):

If the patient is unable to sign but has indicated his/her consent, a witness should sign below. Young people may also like a parent to sign here (see guidance notes).

Witness' signature: **Date:**

Name (PRINT):

Confirmation of consent (to be completed by a health professional when the patient is admitted for the procedure, if the patient has signed the form in advance)

On behalf of the team treating the patient, I have confirmed with the patient that s/he has no further questions and wishes the procedure to go ahead.

Signature Date:

Name (PRINT): Job Title: