Patient information and consent to endoscopic hypophysectomy / transphenoidal hypophysectomy

Key messages for patients

- Please read your admission letter carefully. It is important to follow the instructions we give you about not eating or drinking or we may have to postpone or cancel your operation.

- Please read this information carefully, you and your health professional will sign it to document your consent.

- It is important that you bring the consent form with you when you are admitted for surgery. You will have an opportunity to ask any questions from the surgeon or anaesthetist when you are admitted. You may sign the consent form either before you come or when you are admitted.

- Please bring with you all of your medications and its packaging (including inhalers, injections, creams, eye drops, patches, insulin and herbal remedies), a current repeat prescription from your GP, any cards about your treatment and any information that you have been given relevant to your care in hospital, such as x rays or test results.

- Take your medications as normal on the day of the procedure unless you have been specifically told not to take a drug or drugs before or on the day by a member of your medical team. If you have diabetes please ask for specific individual advice to be given on your medication at your pre-operative assessment appointment.

- If you have any questions or concerns about this procedure or your appointment, please call the clinical nurse practitioner on telephone number 01223 245151 and ask the switchboard operator for bleep 152-423 or 154-175.

After the procedure we will file the consent form in your medical notes and you may take this information leaflet home with you.

Important things you need to know
Patient choice is an important part of your care. You have the right to change your mind at any time, even after you have given consent and the procedure has started (as long as it is safe and practical to do so). If you are having an anaesthetic you will have the opportunity to discuss this with the anaesthetist, unless the urgency of your treatment prevents this.

We will also only carry out the procedure on your consent form unless, in the opinion of the health professional responsible for your care, a further procedure is needed in order to save your life or prevent serious harm to your health. However, there may be procedures you do not wish us to carry out and these can be recorded on the consent form. We are unable to guarantee that a particular person will perform the procedure. However the person undertaking the procedure will have the relevant experience.

All information we hold about you is stored according to the Data Protection Act 1998.
About endoscopic hypophysectomy / transphenoidal hypophysectomy

- You have been recommended to have an operation to remove your pituitary tumour by using Endoscopic Hypophysectomy or Transphenoidal Hypophysectomy approach.
  Endoscopic Hypophysectomy: A surgeon uses an instrument called an endoscope. Hypophysis is another name for Pituitary. Ectomy means removal. Trans is a Latin noun meaning ‘across or beyond’. Sphenoid is a bone at the base of the skull.
- The surgeon gains access to the small bony dish at the base of the brain where the pituitary gland and tumour are located by passing either a microscope or endoscope through the nose. The decision to offer you this operation will be based on the results from a variety of investigations, including MRI scan, CT scan, eye tests and blood tests.
- This surgery is the best and safest way of removing the majority of pituitary tumours.

Intended benefits

The aim of the surgery is to remove the abnormal tumour tissue, leaving as much normal pituitary tissue as possible.

Who will perform my procedure?

This procedure will be performed or supervised by a consultant neurosurgeon and otoneurology (ENT) surgeons where the endoscopic approach is used.

Before your procedure

Most patients attend a pre-admission clinic, when you will meet either the consultant neurosurgeon, specialist registrar or clinical nurse specialist. At this clinic, we will ask for details of your medical history and carry out any necessary clinical examinations and investigations. Please ask us any questions about the procedure, and feel free to discuss any concerns you might have at any time.

We will ask if you take any tablets or use any other types of medication either prescribed by a doctor or bought over the counter in a pharmacy. Please bring all your medications and any packaging (if available) with you. Please tell the ward staff about all of the medicines you use. If you wish to take your medication yourself (self-medicate), please ask your nurse. Pharmacists visit the wards regularly and can help with any medicine queries.

We also need to know if you are on any of the following medicines as these can cause increased risk of bleeding at the time of surgery.
  - Aspirin
  - Warfarin
  - Clopidogrel
  - Or any medications that may thin your blood.
If to your knowledge the answer to any of the following is **YES**, it is important that you tell us:

- Have you ever received Human Growth Hormone;
- Have you had brain surgery prior to 1992 or;
- Has anyone in your family been diagnosed with Creutzfeldt- Jakob Disease (CJD)?

A positive answer will not prevent any treatment, it will however allow us to take the infection control advice and plan your procedure so as to minimise any risks to the patient.

This procedure involves the use of general anaesthesia. We explain about the different types of anaesthesia or sedation we may use at the end of this leaflet. You will see an anaesthetist before your procedure.

Most people who have this type of procedure will need to stay in hospital for three to four days. Your doctor will discuss the length of stay with you.

Before the procedure you will have been seen by the endocrinologist who will have taken extensive specific blood tests. You may also be seen by an eye doctor either here at Addenbrookes or at your local hospital.

**During the procedure**

The surgeon gains access to the small bony dish where the pituitary gland and tumour arise by making a small cut on the inside of the roof of the nose (passing through the nose) by either using a microscope or endoscope. The operation is performed under a general anaesthetic. At the end of the operation small absorbable pads are placed in the nose to reduce bleeding. However, some bleeding and oozing from the nose for one or two days after the operation is common.

**After the procedure**

Once your surgery is completed you will usually be transferred to the recovery ward where you will be looked after by specially trained nurses, under the direction of your anaesthetist. The nurses will monitor you closely until the effects of any general anaesthetic have adequately worn off and you are conscious. They will monitor your heart rate, blood pressure and oxygen levels too. You may be given oxygen via a facemask, fluids via your drip and appropriate pain relief until you are comfortable enough to return to your ward.

**If there is not a bed in the necessary unit on the day of your operation, your operation may be postponed as it is important that you have the correct level of care after major surgery.**

**Eating and drinking.** After this procedure, you should be able to eat and drink. The nurses will measure your fluid intake and your urine output. This is to assess if the hormone controlling your fluid balance (vasopressin) has been disturbed.
**Getting about after the procedure.** After this procedure, you will be able to sit out of bed either that day or the following day. We will try to get you mobile (up and about) as soon as we can to help prevent complications from lying in bed. Typically, you will be able to get up between four to six hours after the procedure depending on how you feel. If you have any mobility problems, we can arrange nursing or physiotherapy help.

**Leaving hospital.** Generally most people who have had this operation will be able to leave hospital after three to four days. However, the actual time that you stay in hospital will depend on your general health, how quickly you are recovering from the procedure and your doctor's opinion. Your nose will feel blocked and uncomfortable for a small period of time. On the first morning after your surgery, a blood test will be taken to measure your body’s natural steroid (cortisol) level. If either of these hormones are low, they may need to be replaced. If you were already taking steroids before the operation these will be continued. Your hormone levels will be re-assessed by an endocrinologist.

**Resuming normal activities including work.** Usually you can resume normal activities after three days. You might need to wait a little longer before resuming more vigorous activity. When you will be ready to return to work will depend on your usual health, how fast you recover and what type of work you do. Please ask your doctor for his/her opinion.

**Special measures after the procedure:** The clinical nurse practitioner will give you further information about any special measures you need to take after the procedure. We will also give you information about things to watch out for that might be early signs of problems (eg infection).

**Check-ups and results:** Before you leave hospital, both the neurosurgery and endocrine nurse practitioner will give you details of when you need to return to see us, for example outpatient clinics or for the results of your surgery. At this time, we can check your progress and discuss with you any further treatment we recommend.

**Significant, unavoidable or frequently occurring risks of this procedure**

- The most common problem is leakage of brain fluid. When this occurs during the operation, the surgeon will use a variety of material like artificial fat or muscle from the thigh sealed with glue. In addition, a lumbar drain will be inserted to lower the pressure in the brain. If you find a clear salty fluid leaking from your nose or down the back of your throat after discharge please contact us. This occurs in 1% of cases.
- We advise you to collect any drips in a clean small container to bring to us for testing. Your GP can provide you with a specimen bottle.
- If there is a leak of brain fluid after surgery (see above) this can cause infection leading to meningitis. This will be treated by antibiotics and vaccination against the infection.
- Your tumour may have already damaged the pituitary and caused hormone imbalance. However, sometimes surgery can also damage the normal pituitary gland, leading to hormone deficiency. The hormone imbalance will be treated with medication.
- Vision after surgery can deteriorate but this is very rare. This is because the optic chiasm (nerve) can be damaged during surgery. If vision problems were present before surgery, removing the tumour may not restore normal vision function. This is because the nerve may have been permanently damaged by the tumour.
- After operation, small adhesions can stick together and form scars that block air flow through the nose. This can cause sinus congestion or cause sinus infection. The infection can be treated with antibiotics.
- Like any other major surgery, the procedure carries a small risk of approximately 2% including stroke, bleeding, blood clot and very rarely death.

General risks associated with all major operations and from being hospitalised: e.g. bleeding, infection, blood clots.

**Alternative procedures that are available**

The alternative to this surgery is decide not to have surgery and the implications of deciding not to have surgery will be discussed with you.

**Information and support**

- You will be given some additional patient information after the procedure, for example leaflets that explain what to do after the procedure and what problems to look out for. If you have any questions or anxieties, please feel free to ask a member of staff.
- The Pituitary Foundation is a charity in the United Kingdom and Republic of Ireland supporting patients with pituitary conditions. They can be contacted on 0845 450 0375 for support and help, available Monday to Friday from 09:00 to 17:00. Their website address is [www.pituitary.org.uk](http://www.pituitary.org.uk)

**Anaesthesia**

Anaesthesia means ‘loss of sensation’. There are three types of anaesthesia: general, regional and local. **The type of anaesthesia chosen by your anaesthetist depends on the nature of your surgery as well as your health and fitness.** Sometimes different types of anaesthesia are used together.
**Before your operation**

Before your operation you will meet an anaesthetist who will discuss with you the most appropriate type of anaesthetic for your operation, and pain relief after your surgery. To inform this decision, he/she will need to know about:

- your general health, including previous and current health problems
- whether you or anyone in your family has had problems with anaesthetics
- any medicines or drugs you use
- whether you smoke
- whether you have had any abnormal reactions to any drugs or have any other allergies
- your teeth, whether you wear dentures, or have caps or crowns.

Your anaesthetist may need to listen to your heart and lungs, ask you to open your mouth and move your neck and will review your test results.

**Pre-medication**

You may be prescribed a ‘premed’ prior to your operation. This is a drug or combination of drugs which may be used to make you sleepy and relaxed before surgery, provide pain relief, reduce the risk of you being sick, or have effects specific for the procedure that you are going to have or for any medical conditions that you may have. *Not all patients will be given a premed or will require one and the anaesthetist will often use drugs in the operating theatre to produce the same effects.*

**Moving to the operating room or theatre**

You will usually change into a gown before your operation and we will take you to the operating suite. When you arrive in the theatre or anaesthetic room and before starting your anaesthesia, the medical team will perform a check of your name, personal details and confirm the operation you are expecting.

Once that is complete, monitoring devices may be attached to you, such as a blood pressure cuff, heart monitor (ECG) and a monitor to check your oxygen levels (a pulse oximeter). An intravenous line (drip) may be inserted. If a regional anaesthetic is going to be performed, this may be performed at this stage. If you are to have a general anaesthetic, you may be asked to breathe oxygen through a face mask.

**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.

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 at the correct level of unconsciousness for the period of the surgery.

Endoscopic hypophysectomy/Transphenoidal hypophysectomy, CF466, V2, February 2017
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.

**What will I feel like afterwards?**

How you will feel will depend on the type of anaesthetic and operation you have had, how much pain relieving medicine you need and your general health.

Most people will feel fine after their operation. Some people may feel dizzy, sick or have general aches and pains. Others may experience some blurred vision, drowsiness, a sore throat, headache or breathing difficulties.

You may have fewer of these effects if local anaesthesia has been injected close to your wound whilst you are unconscious. When the effects of the local anaesthesia wear off you may need pain relieving medicines.

**What are the risks of 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 performed in an emergency.

**Very common (1 in 10 people) and common side effects (1 in 100 people)**

- Feeling sick and vomiting after surgery
- Sore throat
- Dizziness, blurred vision
- Headache
- Bladder problems
- Damage to lips or tongue (usually minor)
- 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
- Muscle pains
- Slow breathing (depressed respiration)
- Damage to teeth
- An existing medical condition getting worse
- Awareness (becoming conscious during your operation)
Rare (1 in 10,000 people) and very rare (1 in 100,000 people) complications
Damage to the eyes
Heart attack or stroke
Serious allergy to drugs
Nerve damage
Death
Equipment failure

Deaths caused by anaesthesia are very rare. There are probably about five deaths for every million anaesthetics in the UK.

For more information about anaesthesia, please visit the Royal College of Anaesthetists’ website: www.rcoa.ac.uk
Information about important questions on the consent form

1 Creutzfeldt Jakob Disease (‘CJD’)
We must take special measures with hospital instruments if there is a possibility you have been at risk of CJD or variant CJD disease. We therefore ask all patients undergoing any surgical procedure if they have been told that they are at increased risk of either of these forms of CJD. This helps prevent the spread of CJD to the wider public. A positive answer will not stop your procedure taking place, but enables us to plan your operation to minimise any risk of transmission to other patients.

2 Photography, Audio or Visual Recordings
As a leading teaching hospital we take great pride in our research and staff training. We ask for your permission to use images and recordings for your diagnosis and treatment, they will form part of your medical record. We also ask for your permission to use these images for audit and in training medical and other healthcare staff and UK medical students; you do not have to agree and if you prefer not to, this will not affect the care and treatment we provide. We will ask for your separate written permission to use any images or recordings in publications or research.

3 Students in training
Training doctors and other health professionals is essential to the NHS. Your treatment may provide an important opportunity for such training, where necessary under the careful supervision of a registered professional. You may, however, prefer not to take part in the formal training of medical and other students without this affecting your care and treatment.

4 Use of Tissue
As a leading bio-medical research centre and teaching hospital, we may be able to use tissue not needed for your treatment or diagnosis to carry out research, for quality control or to train medical staff for the future. Any such research, or storage or disposal of tissue, will be carried out in accordance with ethical, legal and professional standards. In order to carry out such research we need your consent. Any research will only be carried out if it has received ethical approval from a Research Ethics Committee. You do not have to agree and if you prefer not to, this will not in any way affect the care and treatment we provide. The leaflet ‘Donating tissue or cells for research’ gives more detailed information. Please ask for a copy.

If you wish to withdraw your consent on the use of tissue (including blood) for research, please contact our Patient Advice and Liaison Service (PALS), on 01223 216756.
Privacy & dignity

Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and/or specialist one to one care is required.

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.info@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

Document history

Authors Neurosurgical team
Pharmacist n/a
Department Cambridge University Hospitals NHS Foundation Trust, Hills Road, Cambridge, CB2 0QQ www.cuh.org.uk
Contact number 01223 245151
Publish/Review date February 2017/February 2020
File name Endoscopic_hypophysectomy.doc
Version number/Ref 2/CF466/Document ID 29854
Consent Form

Patient agreement to investigation or treatment for neurosurgery, spinal surgery or vitreoretinal surgery

Please use ‘Procedure completed’ stamp below on completion:

Interpreter’s statement (if appropriate)

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

Signed (Interpreter): ................................................................. Date: D D / M M / Y Y Y Y

Name (PRINT): ................................................................................

Or, please note the language line reference ID number: ..............................................................
Endoscopic hypophysectomy / transphenoidal hypophysectomy

The aim of the surgery is to remove the abnormal tumour tissue, leaving as much normal pituitary tissue as possible.

Leakage of brain fluid which can cause infection leading to meningitis. Damage to the pituitary which can caused hormone imbalance. Sinus congestion or sinus infection. Small risk of stroke, bleeding, blood clot and very rarely death.

What the treatment or procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient:

Any extra procedures that might become necessary during the procedure such as:
- Blood transfusion
- Other procedure (please state)

Was the patient born after 1 January 1997?
- Yes
- No

The following information leaflet has been provided:
CF466 Endoscopic hypophysectomy / transphenoidal hypophysectomy; version 2; February 2017

I have offered the patient information about the procedure but this has been declined.

This procedure will involve:
- General and/or regional anaesthesia
- Local anaesthesia
- Sedation
- None

Signed (Health professional):
Name (PRINT):
Designation:

Contact/bleep no:
Consent of patient/person with parental responsibility

I confirm that the risks, benefits and alternatives of this procedure have been discussed with me and that my questions have been answered to my satisfaction and understanding.

Important: please read the patient information on ‘Consent’ and then put a tick in the relevant boxes for the following questions:

1 Creutzfeldt Jakob disease (CJD)
   a) Have you ever been notified that you are at risk of CJD or variant CJD for public health purposes? If yes, please inform your health professional. □ Yes □ No

   b) Have you had a history of CJD or other prion disease in your family? □ Yes □ No

   c) Have you ever received growth hormone or gonadotrophin treatment? □ Yes □ No

      If yes, please give details below:

      Please specify:
      (i) whether the hormone was derived from human pituitary glands □ Yes □ No

      (ii) the year of treatment

      (iii) whether the treatment was received in the UK or another country □ UK □ Other

   d) Have you ever had surgery on your brain, eye or spinal cord? □ Yes □ No

      If yes, please give details below:

   e) Since 1980, have you had any transfusions of blood or blood components (red cells, plasma, cryoprecipitate or platelets)? □ Yes □ No

      If yes, please answer questions below:

      Have you either:
      (i) received more than 50 units of blood or blood components, □ Yes □ No

      or

      (ii) received blood or blood components on more than 20 occasions □ Yes □ No

      Where possible, please provide the names of all the hospitals where you received blood or blood components:

In the case of a positive reply to any CJD question, staff should immediately inform Infection Control on ext 3497 (bleep numbers 152-198 or 151-803) and the theatre co-ordinator (24 hour bleep number 152-585); out of hours contact the on call medical microbiologist via the hospital contact centre.

2 Photography, Audio or Visual Recording
   a) I agree to the use of any of the above type of recordings for the purpose of diagnosis and treatment. □ Yes □ No

   b) I agree to unidentified versions of any of the above recordings being used for audit and medical teaching in a healthcare setting. □ Yes □ No

3 Medical Training
   I agree to the involvement of medical and other students as part of their formal training. □ Yes □ No
4 Use of Tissue

a) I agree that tissue (including blood) not needed for my own diagnosis or treatment can be used and stored for ethically approved research which may include ethically approved genetic research.

☐ Yes  ☐ No

b) Where additional clinical information is needed for the purposes of ethically approved research, I agree that relevant sections of my medical record may be looked at by researchers or by relevant regulatory authorities. I give permission for these individuals to have access to my records.

☐ Yes  ☐ No

I have listed below any procedures that I do not wish to be carried out without further discussion.

I have read and understood the Patient Information entitled Consent and the above additional information. I agree to the procedure or treatment.

Signed (Patient): ___________________________ Date: __D.D./M.M./Y.Y.Y.Y__

Name of patient (PRINT): ___________________________

If signing for a child or young person; delete if not applicable.

I confirm I am a person with parental responsibility for the patient named on this form.

Signed: ___________________________ Date: __D.D./M.M./Y.Y.Y.Y__

Relationship to patient: ___________________________

If the patient is unable to sign but has indicated his/her consent, a witness should sign below.

Signed (Witness): ___________________________ Date: __D.D./M.M./Y.Y.Y.Y__

Name of witness (PRINT): ___________________________

Address: ___________________________

D Confirmation of consent

Confirmation of consent (where the treatment/procedure has been discussed in advance)

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

Signed (Health professional): ___________________________ Date: __D.D./M.M./Y.Y.Y.Y__

Name (PRINT): ___________________________ Job title: ___________________________

Please initial to confirm all sections have been completed:

E Withdrawal of patient consent

☐ The patient has withdrawn consent (ask patient to sign and date here)

Signed (Patient): ___________________________ Date: __D.D./M.M./Y.Y.Y.Y__

Signed (Health professional): ___________________________ Date: __D.D./M.M./Y.Y.Y.Y__

Name (PRINT): ___________________________ Job title: ___________________________