

Endoscopic pituitary operation

Information for patients



We know that patients and their relatives often share concerns and ask similar questions about their endoscopic pituitary operation so we've created this booklet to cover key information that you may need and want to know.

If you still have some unanswered questions or you'd like a little more information or clarification on the topics we've mentioned, then get in contact with us. Our details are at the back of this booklet.

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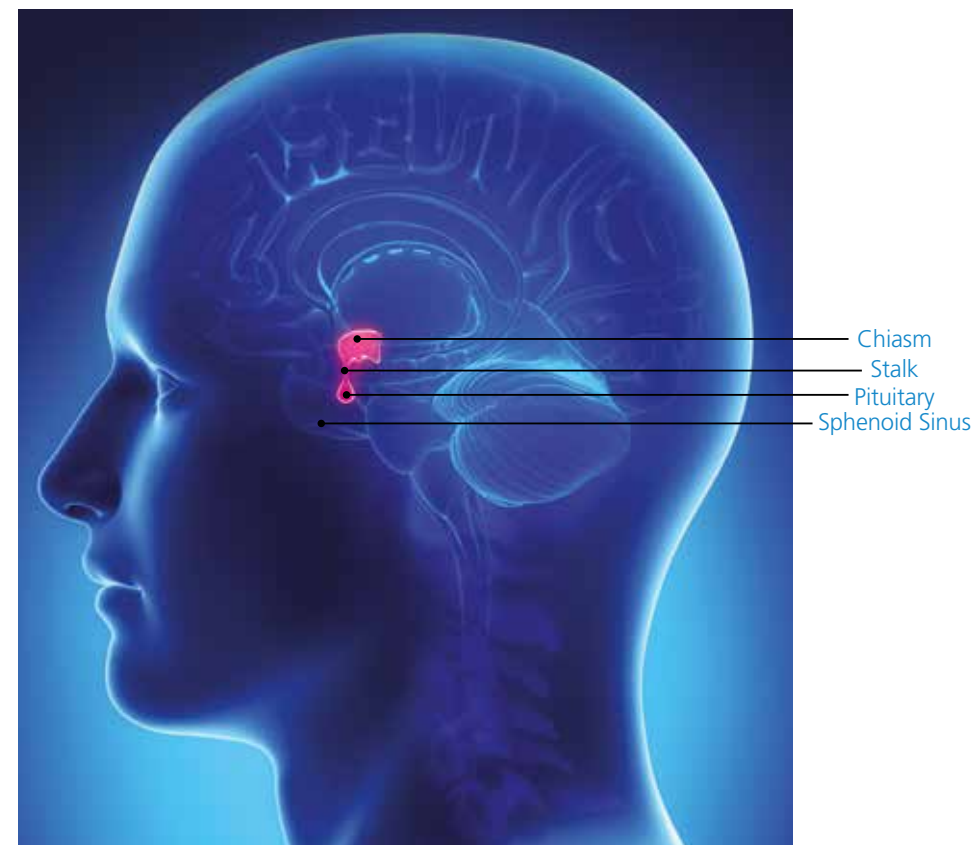
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About your condition

Where is the pituitary gland?



How big is the pituitary gland?

It's usually around the size of a broad bean (approx 1.5cm x 1.0cm) and weighs less than 0.75g (or 0.026oz). A macro-adenoma is a tumour 1cm or above, while a micro-adenoma is a tumour 1cm or below. (See The Pituitary Gland booklet by the Pituitary Foundation).

What is the name of the operation and what does it do?

It's most commonly referred to as an endoscopic pituitary operation and it's designed to remove a tumour from the pituitary gland using a small camera attached to a tube – an endoscope.

The full name of the operation is endoscopic endonasal transsphenoidal decompression.

Endoscopic – using an endoscope as a visualising tool

Endonasal – making use of nostrils for access

Transsphenoidal – across the cavity at the back of nose

Decompression (or removal)

What is a benign tumour?

The majority of pituitary tumours (also known as pituitary adenomas) are benign, which means they're non-cancerous and won't spread to other parts of the body. They only become troublesome if they grow large enough to press on the surrounding areas such as the optic nerves, or if they start to affect your hormone levels. We do occasionally see other types of tumours in the pituitary gland but as these are so rare, they will be discussed (when appropriate) on an individual basis.

What types of pituitary tumours are there and how are they treated?

Pituitary tumours fall into two categories:

1. **Non-secreting pituitary tumours** tend to press on the pituitary gland, preventing it from working effectively. If they grow large enough to press on the optic nerves (just above the pituitary gland) then they can also affect your eyesight. They do not release any hormones into the blood. An operation is usually required to relieve this pressure and we may do it urgently if your vision is badly affected.
2. **Secreting pituitary tumours** cause high hormone levels in the blood. They can also grow large enough to press on the optic nerves, but they are usually diagnosed before they get to that point.

The most common types are:

- **Prolactin secreting tumour** - this causes a condition called prolactinoma. (See the Prolactinomas booklet by the Pituitary Foundation). This can usually be treated effectively with medications instead of an operation. A simple blood test can identify its presence.
- **Growth hormone secreting tumour** - this causes a condition called acromegaly. (See the Acromegaly booklet by the Pituitary Foundation). An operation is usually required to correct this.
- **ACTH secreting tumour** - this causes a condition called Cushing's disease. (See the Cushing's Syndrome booklet by the Pituitary Foundation). An operation is usually required to correct this.

Pituitary tumours may secrete many of the other hormones produced by the pituitary gland but the three listed above are the most common.

The type of tumour you have will be identified by the laboratory after your operation and also by the blood test that your endocrinologist (specialist doctor) will have done.

Before your operation

Multidisciplinary meeting (MDT)

Specialist healthcare professionals including surgeons, endocrinologists, neuropathologists, oncologists and neuroradiologists get together monthly in what's known as a multidisciplinary meeting (MDT) to agree the best course of treatment for you. If your case is clinically urgent then this discussion will take place after any necessary surgery. (MDT meetings are recommended by the National Institute of Clinical Excellence).

The aim of surgery

In addition to trying to remove as much of the tumour as is possible and safe, surgery also aims to leave some of the normal pituitary gland behind (unless discussed before the operation). However, normal pituitary function may be affected by surgery.

Will my eyesight improve?

In patients where the tumour is already affecting their eyesight, the best results are often seen in those whose eye problems were either mild or have only recently developed, with less improvement shown in those who have had the condition for longer, or have a greater degree of deterioration. There are, however, some patients with very poor vision who have experienced significant improvement.

If your eyesight has not been affected by the tumour, but the doctor can see from the scan that the pituitary tumour is growing close to your optic nerves, then the operation is designed to prevent problems from developing.

Your surgeon should already have talked to you about how close your tumour is to your optic nerves, but if you do have any questions, please ask.

MRI scans

An MRI (magnetic resonance imaging) scan shows the size and shape of a pituitary tumour in great detail. It also shows the position of the surrounding structures such as arteries and nerves, including the optic nerves. You'll usually have an MRI scan before you're seen in the neurosurgery clinic and again after your operation. We know that some people get quite anxious about having an MRI scan so, if it helps, you can ask a member of your family, a friend or the pituitary nurse to go into the scan room with you. CT scans are occasionally used when we cannot perform an MRI scan, for example, if you have a pacemaker.

Pre-assessment

About one to two weeks before your scheduled operation, you will be asked to attend a pre-assessment clinic. This is where we'll assess your fitness for anaesthetic and surgery and undertake any preparations for your operation, if required.

Research

As a university hospital we have a number of ongoing research projects, all of which have received ethical approval. This research gives us vital information that may benefit future patients. We may mention some of these projects to you while you're with us, but your treatment will not be affected in any way if you would prefer not to take part. We won't involve you in any of these studies without discussing them with you first (including giving you an information sheet) and receiving your signed, research-specific consent form. Please ask if you would like to know more.

The team involved in your care

In addition to your neurosurgeon and pituitary nurse, there are a number of other people involved in your care:

The anaesthetist: It's the anaesthetist who will ensure you enjoy a deep sleep and will continually monitor you throughout the operation. You will meet the anaesthetist on the morning of your operation so that you can discuss any concerns you may have.

The ward nurse: The nurse will make a record of your personal details and take your blood pressure, temperature and pulse. They will also look after your day-to-day needs and give you and your family support during your hospital stay.

ENT surgeon: ENT surgeons specialise in diagnosis and treatment of disorders of the head and neck, including particularly the ears, nose, and throat. An ENT surgeon will only be involved if yours is a complicated case. If they have been involved in your operation then you may also see them after the operation to ensure the wound inside your nose is healing well.

Endocrinologist: You'll see an endocrinologist immediately after your operation and will then be referred to an endocrinologist at your local hospital (if it's not Southampton General) so they can monitor your hormone levels.

Ophthalmologist: They will assess your eyesight after the operation and periodically thereafter.

On the day of your operation

Arriving and getting booked in

On the day of your surgery you will need to go to level C – Wessex Neurological Centre. The nurse will guide you to your bed and complete all the necessary checks, including any blood tests.

Allergies

If you are allergic to any medications (such as penicillin or iodine) or to any materials or substances (like latex or metal), you must tell the surgeon before the operation so we can take adequate precautions.

Medications

It's important you let the surgeon know if you are taking any regular medications so that they can make adequate preparations for your operation. Some medications (including aspirin, warfarin or clopidogrel) may make your blood thin and result in you experiencing excessive bleeding during the operation. We may ask you to stop taking these medications a few days prior to your operation to allow their effects to wear off. You will be able to take your blood pressure tablets on the day of surgery, but please discuss it with your surgeon or any member of staff first.

Consent

Your surgeon or a member of their team will discuss your operation with you including all the potential risks involved (see next page). Any alternatives to surgical treatment and expected benefits of the operation will also be discussed. It's important that you understand the benefits and risks involved in the operation before you sign your consent, which is often obtained in the clinic during your consultation. If you have any questions or concerns, please ask the surgeon or pituitary nurse before your operation.

How long will the operation take?

The operation usually takes about two hours from when you're anaesthetised to when you wake up. You will usually be in recovery for about an hour while you wake up and will stay with us for around three to four days.

Potential risks

As with any other operation there are potential risks. For this surgery the most significant risks are:

- **Infection:** Your sinuses will be opened during an endoscopic surgery and so sinus infection is a possibility. For this reason antibiotics are given at the beginning of the operation and continued for a week after.
- **Bleeding:** The amount of blood loss expected during surgery is minimal and is often not an issue for adults. It is essential you let us know if you're taking any other medications as these may affect the blood. (See the Medications section earlier in this booklet).
- **Panhypopituitarism:** The pituitary gland is usually compressed by the adenoma and there is a risk that gland may get damaged during surgery resulting in pituitary failure. In that case, an endocrinologist will replace all the required hormones.
- **Diabetes insipidus** (which is different from sugar diabetes): If there is any disturbance to the back section of the pituitary gland or the connecting 'stalk' between the pituitary gland and the brain, diabetes insipidus can occur. This will make you feel very thirsty so you'll drink excessive amounts of water and pass excessive amounts of urine, but this can be controlled with medication called desmopressin. The condition may only be temporary and will be carefully monitored by your doctors. (See the Diabetes Insipidus booklet by the Pituitary Foundation). However, it is important to note that you may just be feeling thirsty as a result of needing to breathe through your mouth for a short time after the operation, while your nose is packed.
- **Cerebrospinal fluid (CSF) leak:** There is a very thin layer of the brain's 'cling film' which lies over the pituitary gland. If a tear occurs in this membrane during surgery then CSF can leak into the nose. If this happens,

the surgeon can usually identify the break and repair it with fat and or tissue taken from your stomach or thigh.

If you notice that your nose is constantly leaking clear fluid (which is perhaps worse when you lean forward) after your operation, it is vital you report this to your doctor or nurse so that the appropriate treatment can be given immediately.

In very unusual circumstances we may need to place a small drain in your back using a lumbar puncture needle. This lumbar drain channels your brain fluid into a collection bag, giving the main wound a chance to heal. This collection bag will be placed at shoulder height and you will be able to walk around with it (the height we place the bag regulates the amount of fluid drained). You may get a headache, which is best relieved by bed rest, fluids and painkillers. This drain is usually removed 48 to 72 hours after the operation but you will need to stay in hospital during this time, and possibly for a further couple of days.

- **Meningitis:** Occasionally a CSF leak (see above) can result in meningitis. If you develop some or all of the symptoms described below contact your GP or the hospital immediately:
 - Violent or severe headaches
 - High temperature
 - Stiff neck
 - Vomiting
 - A dislike of bright lights
 - Painful joints
 - Drowsiness and lack of energy

When diagnosed early, meningitis can usually be treated effectively with antibiotics for four to six weeks. It is extremely rare to develop meningitis after you leave the hospital.

- **Vascular injury and stroke:** There is a less than 1% risk that the carotid artery (the major blood vessel on either side of the pituitary gland) may get damaged. This will result in severe bleeding and the carotid artery may need to be blocked to control the bleeding. In severe cases this could result in a stroke which may carry a risk of death.

Your surgeon and anaesthetist will discuss specific risks that apply to you. Please remember you may ask any questions and voice any concerns you or your family may have with the doctors and nurses looking after you.

CJD questionnaire

Everyone having an operation on the brain, spine and pituitary gland will be asked a series of questions to assess the risk factors of Creutzfeldt–Jakob disease (CJD). It's completely normal so please don't be alarmed by the questions we ask. If you have had previous operations on your brain, spinal cord or pituitary, or you've previously been treated with human growth hormone, then please tell the surgeon as soon as possible before your operation as they may need more time to clarify the facts before your surgery.

Anaesthetic room

Once you have consented, all checks have been completed, and theatre is ready for you; the porter and nurse will escort you to the anaesthetic room adjacent to the theatre, where your anaesthetist will put you into a deep sleep. Once you are anaesthetised you will be monitored before you are moved into the operating room.

After your operation

Biopsy

A biopsy (or sample) of the tumour will be taken at the time of the operation to assess what type of tumour you have. Ask the surgeon if you would like more information about this.

Waking up after the operation

Immediately after the operation you will be taken to the recovery room where you will be monitored carefully as you wake up. You will be made comfortable, given painkillers if required, and allowed a little time to wake up from the anaesthetic. Expect to be asked to move your arms and legs and answer questions such as "what day is it?" or "where are you?". The nurse will also do some simple eyesight tests. This may all seem strange or frustrating but it's an important part of assessing how well you are recovering from your operation. You will usually stay in recovery for about an hour, until you are awake.

Nasal packs

We use packs in your nose and a nasal dressing to reduce bleeding after the operation so you may feel as if your ears and nose are blocked, and your mouth may feel a little dry whilst you're breathing through it. It won't be for long though as we remove the packs the day after the operation.

Intravenous infusion

You will have an intravenous infusion, commonly known as a drip, to replace the fluids you are unable to drink whilst you're nil by mouth. Once you are drinking normally, this will be removed.

Fluid restriction

Occasionally, after your operation, the pituitary gland may fail to control how much urine you pass and you may develop a condition called diabetes insipidus (not to be confused with sugar diabetes). So that we can keep an eye on this we need to keep a strict record of how much fluid you're drinking and passing for the first few days after your operation. We do this by restricting

the amount you drink to 2.4 litres of fluid (approximately five pints) over a 24-hour period and asking you to use a bottle or bedpan (which will be placed over the toilet) so that we can accurately measure your output. Catheters and commodes are not routinely used.

Up and about

Gone are the days of complete bed rest for weeks after an operation. The day after the operation you will be encouraged to get up and about as much as you feel able, as we know early mobilisation helps to prevent many postoperative complications such as pneumonia and blood clots.

Stitches

One of the benefits of endoscopic surgery is that we shouldn't have to place stitches in and around the nose. If we have to obtain fat and or tissue from the thigh or stomach to repair a CSF leak, you will have stitches or skin clips placed in these areas and these can be removed after a week by a nurse at your local GP practice.

Eyesight test

We may check your eyesight before you are discharged, to enable your doctors to compare your eyesight before and after the operation. It may be wise to keep your current prescription for a few weeks after the operation, as you may find your eyesight continues to improve over the next few weeks which will therefore change your prescription. Your optician will be able to give you advice on this.

Smell and taste

You may experience a dulling of your sense of smell and taste, but this will usually return to normal over time.

Hormones

Immediately after surgery we might give you a hormone to stop you passing too much water.

All other hormones are assessed about 6-12 weeks after your operation by a hormone specialist (endocrinologist). We can replace any hormones you're not producing but it can take time to get the levels right. (See The Pituitary Gland and Hormone Replacement booklets by the Pituitary Foundation).

Headaches and sinusitis

You may suffer from mild headaches for a few weeks after the operation. Take some painkillers and allow yourself plenty of rest. Severe headaches or worsening headaches rarely occur but should be reported to your GP straight away. It's also not unusual for your sinuses to feel blocked after the operation. Sinusitis can also cause headaches and pain around the forehead and eyes, which is often worst first thing in the morning. You may also get a nasal discharge.

Healing

To promote healing inside the nose, we prescribe a saline washout called Sinus Rinse. It's a plastic bottle you fill with mildly warm water and then add salt, which comes in a sachet. Bend forward over the sink and keep the bottle to one nostril and gently squeeze. The wash will go up that nostril and come out through the other nostril. Repeat the process from the other nostril. You may have to do this about three to four times a day for six to eight weeks. Sinus Rinse is freely available in pharmacies with or without a prescription. You can find a video about this on www.youtube.com – just search 'SinusRinse'.

Prescriptions

You will be given one months' supply of hydrocortisone (see next page) when you are discharged from hospital, plus a supply of any other medications you are prescribed. After this you will need to arrange a repeat prescription through your GP.

If you have diabetes insipidus or are on steroid replacement therapy (for example, hydrocortisone tablets or Levothyroxine tablets) you are entitled to free prescriptions. You will have to claim an exemption certificate from your local health authority. These can be claimed using the FP92A form which is available from pharmacies or main post offices. For further information telephone **0300 330 1341**.

You should be given a blue steroid treatment card with your prescription; please contact the pituitary nurse if this doesn't happen.

Hydrocortisone

You must continue to take your hydrocortisone tablets as prescribed until you see your endocrinologist.

Take your morning dose first thing and your last dose around 5pm – taking it later may disrupt your sleep. When you see the endocrinologist they may change either the dose or the time you take your hydrocortisone to suit your individual needs. They'll also advise you whether to continue to take hydrocortisone or not.

- Do not stop taking hydrocortisone without discussing it with your endocrinologist first because you may become very unwell.
- Make sure you don't run out of your medication.
- If you can't take the tablets (if you have a bout of diarrhoea and vomiting for example), you should inform your GP immediately as you may need to be given hydrocortisone by injection.
- If you develop a serious illness such as a fever, pneumonia, or an injury such as a broken bone, you will need to take extra hydrocortisone. This should be brought to the attention of your doctor immediately.
- If you're planning to travel abroad, you will need to consider taking your own injection kit, a letter from your GP for Customs, medic alert bracelet and extra tablets in case of illness. Advice can be sought from your endocrinologist.
- Always carry your steroid card with you.
- Do not pack your medication in checked-in baggage.

Post-surgery complications

It is important that you read the potential risks section of this booklet to familiarise yourself with the symptoms to look out for while you're recovering from your operation. This is because these may indicate serious post-operative complications such as diabetes insipidus, cerebrospinal fluid leak and meningitis.

You should:

- sleep with your head elevated by two to three pillows
- take a mild laxative or stool softener if you are constipated
- sneeze with your mouth open

Avoid:

- drinking hot liquids or eating spicy food for several days after your operation
- any activities that will raise your blood pressure, such as running, exercising, heavy lifting or similar activities
- drinking through a straw
- swimming or air travel for two weeks after surgery
- blowing your nose
- prodding or poking the nasal area for three to four weeks

Emotions

Patients often experience emotional highs and lows after having a big operation – from feeling happy and relieved one minute to tearful and tired the next. This is not unusual but should your low mood continue for any length of time, you should contact your GP or endocrinologist, or discuss it with your pituitary nurse.

Care of the abdominal/thigh wound

If you have suffered a tear in the membrane surrounding your brain during your operation (see cerebrospinal fluid (CSF) leak in the potential risks section), then it will need to be repaired using fat and/or tissue taken from your stomach or thigh. To help this area heal:

- you can remove the dressing on the second day after surgery
- you can shower, but do not soak in a hot bath for two weeks
- keep the wound dry
- clips or stitches need to come out three to ten days after your operation
Please make an appointment with your GP practice nurse. The ward nurse will give you necessary papers for you to take with you to your GP

Follow-up appointments

Your case will be reviewed in a MDT meeting following your biopsy report and postoperative MRI scan (see Before your operation section earlier in this booklet for an explanation of MDT). Further follow-ups and treatment are planned at this meeting.

You will need to attend a couple of follow-up appointments after surgery:

Endocrinologist – four to six weeks after the operation. The endocrinologist will carry out a postoperative assessment of your pituitary hormones. Only they can tell you whether you need to adjust or stop taking your hydrocortisone. If your pituitary gland does not wake up after the operation the endocrinologist will replace all necessary hormones.

Pituitary surgeon – usually three to six months after surgery. The surgeon will follow up with a postoperative MRI scan. At this consultation, the biopsy report, your scan findings and the MDT recommendations will be discussed with you.

ENT surgeon – if your nasal symptoms do not settle down in six to eight weeks, or if you needed extensive repair during your operation, you will be required to see the ENT surgeon (usually the one who works within the pituitary surgery team). They will inspect and then clean inside your nose (if required), taking care not to disturb the repair undertaken during your operation.

Eye surgeon – if you have any ongoing visual problems after the operation, a consultation with an eye surgeon may be required.

Oncologist – almost all pituitary tumours are benign but if your tumour is aggressive, or you are left with residual tumour in an area where we can't operate, the MDT might recommend additional treatment for you such as radiotherapy and or chemotherapy. Your doctor will explain all of this to you in the follow-up clinic.

MRI scans – if some of the tumour is left behind during your operation, it tends to grow back with time so you will be given periodic MRI scans for a period of time after your initial operation.

Other useful information

Alcohol

Alcohol is not harmful to people taking hydrocortisone however other medications including some painkillers do not mix well with alcohol, so it's wise to check with your GP or pharmacist if you are unsure.

Driving

If you drive you have a statutory obligation to inform the DVLA of any illness which may affect your ability to drive, within three months. If you fail to do this you may be breaking the law. Also if you have an accident, then your insurance may be invalid. After the operation the DVLA will want to know that your eyesight is safe to drive. A further eyesight test may be required. You must inform the DVLA and your insurance company about your surgery, unless you were told before leaving the ward that you are permitted to drive once you have recovered. You can contact the DVLA by telephone: **0843 658 0785** or visit **www.dvla/medical.co.uk**

Travel expenses

Anyone in receipt of income support, job seekers' allowance, family credit or disability living allowance is entitled to help with travel expenses to and from hospital. Public transport costs or mileage can be claimed. However, taxi fares and costs incurred by your escort can only be claimed if your GP or consultant has written a letter stating that it is medically necessary. You will require proof of your entitlement such as a benefit award notice and your hospital appointment letter and receipts. Information about this can be found at the hospital's finance office - the ward nurses or the ward clerk will be able to direct you.

Accommodation for relatives

Accommodation on the premises is severely restricted and priority goes to the relatives of those most seriously ill. Your pituitary specialist nurse or any of the ward clerks will be able to provide you with a list of local bed and breakfast and hotel accommodation.

Contact details

Mr Mathad and Mr Hempenstall

Mrs Rebecca Hooper, secretary: **023 8120 6694**

Dr Al-Mrayat, consultant endocrinologist

Mrs Joy Trevena, secretary: **023 8120 6177**

Alicja Knysak, pituitary specialist nurse

Email: Alicja.Knysak@uhs.nhs.uk

Mobile: **07824 600 449** (Monday, Thursday, 8am to 4pm)

Useful numbers

The Pituitary Foundation: **0117 370 1320**

The Cushing Society: **01628 670389**

Medic Alert Bracelet: **0207 833 3034**

Carers UK: **0808 808 7777**

RNIB: **0303 123 9999**

Useful links

www.pituitary.org.uk

www.nhs.uk

Neurosurgery

Southampton General Hospital

Tremona Road

Southampton

SO16 6YD

Main switchboard: **023 8077 7222**

For a translation of this document, or a version in another format such as easy read, large print, Braille or audio, please telephone 023 8120 4688.

For help preparing for your visit, arranging an interpreter or accessing the hospital please visit www.uhs.nhs.uk/additionalneeds

www.uhs.nhs.uk