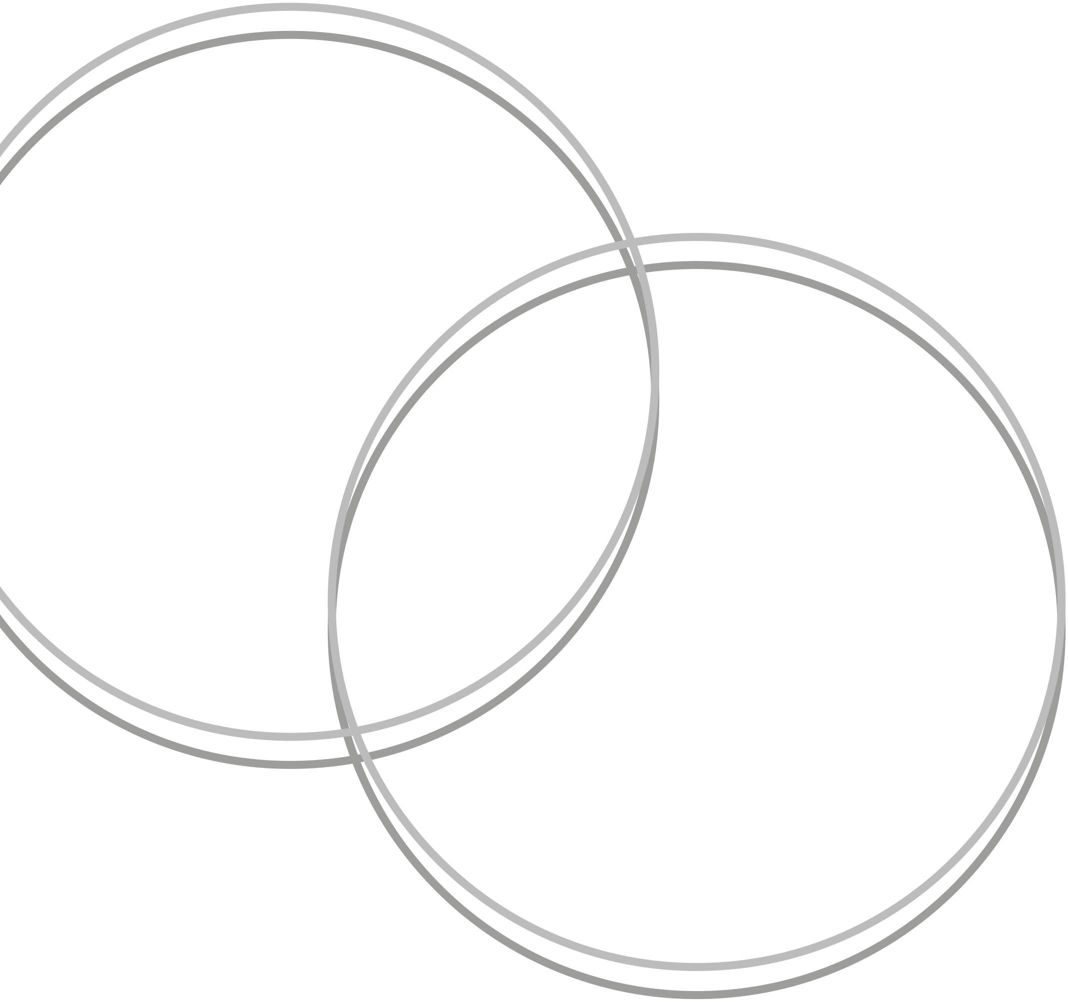
NHS
Oxford University Hospitals
NHS Foundation Trust

Surgery for Pituitary Tumours

Information for patients



You have been diagnosed with an abnormality on or near your pituitary gland. We have designed this booklet to help cover key information that you may need and want to know. If you have any questions or concerns that have not been covered please do contact us. Our details are at the end of this booklet.

Contents:

About us

The Oxford pituitary service is one of the busiest in the country. Pituitary clinics and multidisciplinary team meetings are based at the Churchill Hospital in Oxford. Pituitary surgery is undertaken at the John Radcliffe Hospital in Oxford, in the West Wing. We work as a multi-disciplinary team of endocrinologists, surgeons, specialist nurses, neuroradiologists, oncologists, pathologists and opthalmologists. We all work closely together to ensure patients are comprehensively managed and supported.

Endocrinologists

- Dr Aparna Pal
- Mr Bahram Jafar-Mohammadi
- Dr Christine May

Neurosurgeons

- Mr Simon Cudlip
- Ms Jane Halliday

Specialist Nurses

Oncologists

- Dr Claire Hobbs
- Dr Meera Nandhabalan

Radiologist

- Dr Robin Joseph

Pathologist

- Dr Olaf Ansorge

Opthalmologists

We work closely with a number of opthalmologists in Oxford and the wider region.

About your condition

What is the pituitary gland?

The pituitary gland is an important hormone producing gland, which is typically pea sized, sitting at the base of the brain approximately 5cm behind the tip of your nose. It produces eight different hormones that are important for a number of functions in the body. The hormones are important for, among other things, your general wellbeing, ability to manage infection and stress, appetite, energy levels, body growth, thirst and sexual function.

What is a pituitary tumour?

Pituitary tumours are common, affecting up to 20% of the general population. The majority of pituitary tumours (99% or more) are benign, called adenomas, and are often detected incidentally. They are typically slow growing and respond well to treatment if required, which can include surgery, medication and radiation. They can require treatment when they grow large enough to cause compression to surrounding structures, such as the optic nerves, or if they start to affect hormone levels (figure 1).

Tumours of the pituitary gland are often divided into micro and macroadenomas

- Microadenoma: Less than 1 cm in size, and not invading nearby structures (often the cavernous sinus, a spongey vein either side of the space where the pituitary gland sits)
- Macroadenoma: More than 1 cm in size and / or invading nearby structures

Pituitary tumours fall into two categories:

1. **Non-secreting pituitary tumours** do not produce extra hormones but can affect the normal functioning of your pituitary gland by compression, this may stop your pituitary gland working properly and thus you may require hormone replacement. They can grow large enough to compress the optic nerves which lie just above the pituitary gland. If this is the case an operation is usually required to relieve this compression, and this may be urgent if your vision is already affected. If your tumour is not compressing the optic nerves the tumour may be monitored with MRI scans.
2. **Secreting pituitary tumours** produce extra hormones, which can cause high hormone levels which require treatment. Usually these tumours are smaller when they are diagnosed due to their extra hormone secretion. The treatment of these types of tumours can be medical or surgical depending on the type of hormone they produce.

The most common types of secreting tumours are:

- **Prolactin secreting tumours** (prolactinoma). These can often (85% of the time) be treated effectively with medication rather than an operation and are diagnosed through blood tests and MRI scans.
- **Growth hormone secreting tumours**. These cause a condition called acromegaly in adults and operations are often recommended for this type of tumour. Again they are diagnosed through clinical history and examination, more detailed blood tests and MRI scans.
- **ACTH secreting tumours**. These cause a condition called Cushing’s disease in adults. They can be treated medically but often an operation will be recommended.

Pituitary tumours can produce any of the other hormones that the pituitary gland produces but these are less common than those listed above.

There are also other lesions that can be encountered around the pituitary gland which can require surgical intervention. For example:

- Craniopharyngiomas (another type of benign tumour)
- Pituitary apoplexy (bleed into a pituitary adenoma)
- Cystic lesions (for example Rathke's cyst)
- Inflammatory disease (for example lymphocytic hypophysitis)
- Meningomas of the anterior skull base and bony tumours.

The type of tumour you have will be discussed in detail with you in clinic.

Figure 1: MRI scan of a Pituitary macroadenoma

What symptoms do pituitary tumours cause?

Symptoms are variable, depending on the type of tumour and its size. Generally non-secreting tumours do not cause symptoms until they are greater than 1cm, at which point they may start to compress the nerves that control vision. If the optic nerves are affected people can suffer with:

- Blurring of vision
- Loss of peripheral vision
- Double vision

All of these symptoms are usually gradual.

1-2% of pituitary tumours can expand rapidly due to a bleed within them, causing sudden headaches and visual deterioration. This is called pituitary apoplexy and is a medical emergency. If the pituitary gland is compressed and not functioning normally people can also suffer from generalised tiredness, weakness and loss of energy. Secreting tumours typically cause symptoms related to excessive circulating hormone levels. For example tumours that cause an excess of growth hormone (acromegaly) or cortisol (Cushing’s disease) can cause changes to your body and appearance.

What are the treatment options?

Observation with monitoring blood tests and scans, surgery, medications and/or radiotherapy are all treatment options. Which is chosen will depend on many factors including the type of tumour, its size, your age, general health and patient preferences. As most tumours are benign and slow growing many patients are managed on a ‘wait-and watch’ policy which involves regular clinical review and MRI scans.

Treatment options will be discussed in detail with you in clinic, outlining the advantages and disadvantages of each approach to help decide what will be the best treatment option for you.

The following information aims to cover surgery in more detail.

Surgery

What are the benefits?

Surgery aims to remove as much tumour as safely possible. Most tumours are removed endoscopically through the nose, called an endoscopic endonasal transphenoidal decompression. The key terms are described below:

Endoscopic – using a small telescope attached to a high definition camera as a tool for visualisation

Endonasal – through the nose

Transphenoidal – the pituitary gland is accessed through an air sinus (sphenoid sinus) at the back of the nose

Surgery for **non-secreting tumours** is typically recommended to preserve eye -sight, and is effective at improving vision in approximately 90% of patients in whom it is affected pre-operatively. Usually this improvement in vision is seen within days or weeks of the operation, but can continue for several years after your operation. If vision is severely affected before the operation it may well not recover completely. If your pituitary gland function is affected before your operation it may improve afterwards. Equally some patients have long term hormone deficits before and after surgery that require hormone replacement.

Surgery for secreting tumours is aimed at removing, fully or partially, the tumour that is producing the excess hormones. This is to prevent the long term health problems that can occur from having an excess of certain hormones, and may avoid long term medical management to control hormone levels. The likelihood of successfully controlling excess hormone levels from surgery varies between tumours depending on their size and if they have invaded nearby structures, and will be discussed in depth with you beforehand.

What are the risks?

Pituitary surgery is safe, and the majority of patients recover quickly and well from surgery.

The risks of major complications from endoscopic transphenoidal surgery, the most common approach to pituitary tumours, are explained overleaf:

- There is less than 1 in 1000 risk of serious complications such as injury to major blood vessels, blindness and death.
- There is a 5-10% of less severe complications occurring such as infection, meningitis, bleeding from the nose, leak of cerebrospinal fluid requiring further repair and of stroke.
- Following surgery the normal pituitary gland may not function normally, requiring replacement of hormones. This is often temporary, but in some patients can be long term. There is a small risk of infertility. This will be discussed carefully with you before your operation if that is a consideration.
- There is a risk, as outlined above, that if your vision is affected before your operation it may not recover completely.
- There is the risk that some tumour may be left behind, and that further treatment such as further surgery, medications and/or radiotherapy.
- There are also risks of a general anaesthetic, which includes chest infections, clots to the legs or lungs, and heart problems. The anaesthetist will be able to advise further on these risks if required.

Before surgery

Before surgery you will have met with our surgical and endocrine team in clinic, and will have had a number of blood tests, visual tests and scans (usually magnetic resonance imaging scans). Once the decision to proceed to surgery has been made you will undergo a pre-operative assessment and be given a date for your operation. It is important that we are informed of your allergies, past medical problems, and of all medications that you take. Some medications, such as aspirin and warfarin, thin the blood and need to be stopped in advance of your operation so that their effects wear off making surgery safer. We will advise you on how long to stop those medications for before your operation. You will also be given guidance on when to stop eating and drinking prior to surgery.

Your operation will be performed in the Department of Neurosurgery in the West Wing of the John Radcliffe.

You will come in to the Neuroscience ward on level 2 of the West Wing either the night before, or the morning of your operation. You will be provided with a contact number to confirm that the day before your operation. When you arrive you may have a further set of blood tests taken, and a scan if navigation is required for your operation. You will meet the surgical team again, as well as your anaesthetic team and the nursing team will perform a number of checks to ensure that you are ready for your operation. Your surgical team will re-discuss your operation with you and ensure you have the relevant information to be able to give your consent for the surgical procedure to take place.

Surgery

Surgery is performed under a general anaesthetic and can take between 1 and 4 hours. Your surgeon will be able to advise further on the likely duration of surgery if you wish to know.

A small camera, called an endoscope, will be used to look through to the back of your nose. Therefore no skin cuts are required. Sometimes navigation will be used in theatre, for which a scan will have been obtained beforehand. Your surgeon opens into air sinuses at the back of your nose to give access to the pituitary tumour, which is then removed with specially designed surgical tools. At the end of the operation absorbable materials are used in the space left by the tumour and nasal packs typically are not used.

Sometimes, particularly for larger tumours, there is a small leak of fluid from the brain (Cerebrospinal Fluid - CSF). Sometimes when this occurs a small piece of fat is taken from your abdomen, or fascia from your thigh, to help repair that leak and reduce the chance of its recurrence. This, along with other materials used in the repair, are naturally broken down and absorbed. If a leak of CSF is predicted before your operation your surgeons may also place a temporary tube in your spine, called a lumbar drain. Lumbar drains can be very helpful when operating on large tumours, and to also help repair defects at the back of the nose to prevent recurrent CSF leaks. Your surgeon may also plan an internal flap of mucosa to be used as part of the repair (called a nasoseptal flap), if there is a high risk of a CSF leak.

After surgery

Immediately Post-Op

After your operation you will be transferred to recovery and then to the Neuroscience ward on level 2 in the West Wing. When you are on the ward you can be visited by friends and family. You will experience some headaches, a blocked nose and a transient discharge of blood stained fluid from your nose immediately after surgery. You will be given medications to help with headache, and any nausea if required. You will be able to eat and drink after your operation. We ask you to avoid hot fluids and food on the night after your surgery. Most patients will have an altered or no sense of taste or smell initially that will improve over time. You will be encouraged to mobilise as soon as possible. Many patients find sleeping with their head elevated by two to three pillows helpful in the immediate post-operative period.

Blood Tests

Blood tests are taken on the day after your operation. If your fluid balance is in the normal range, your bloods in the normal range and you feel ready to manage at home you will likely be discharged home the following day after your operation (for example if you were operated on a Monday you would be discharged home on the Tuesday late afternoon). Sometimes you may need to stay in hospital slightly longer if there an imbalance of your blood electrolytes and fluid balance so that this can be treated.

Fluid Restriction

You will be placed on a 2 litre fluid intake restriction immediately after your operation, and have the volume of fluids you drink and urine you pass measured by the nursing staff. Sometimes surgery to pituitary tumours can affect that part of the pituitary gland that regulates your thirst and fluid balance. Usually this imbalance is short-lived, but can require hormone replacement to control it.

We advise you to continue to measure your own fluid balance at home for the week following your operation, until you are seen for your follow-up one week from your operation, and will be given advice on how to do this and what to look out for.

Nasal Symptoms

The nasal discharge is greatest in the first 48hrs then settles over a two week period from your operation. You should avoid sneezing, coughing or excessively straining for the first two weeks after your operation to minimise disruption to the surgical sealant at the back of your nose. If you need to sneeze we would advise doing so with your mouth open and both uncovered. If you are constipated we would advise taking laxatives.

If you have a persistent leak of clear fluid from your nose you should inform your medical team. This may occasionally indicate a CSF leak. It is important that this is detected and treated early, as there is a risk of meningitis occurring with ongoing CSF leaks. If confirmed you many require a further operation to re-pack at the back of the nose and/or insert a temporary fine tube in your lower back (lumbar drain) for a few days to help repair the leak. Thankfully the risk of this is low and most patients with a nasal discharge do not have a CSF leak. Please let one of the team know if you are concerned about this. All patients are screened for a CSF leak prior to discharge from hospital.

Medications after surgery

You will be started on hydrocortisone medication after your operation, typically given three times a day. This is a precaution in case you are missing this important hormone after your operation. You will be given this medication for you to take home as well as an injection in case you need to use this in an emergency. This will all be explained to you by a nurse or pharmacist before you leave hospital. The hormones in your blood will be checked to see if you require hydrocortisone in the long term, at your first follow-up appointment one week after your operation.

Recovery after surgery and return to work

At home we usually advise that you have support in the first one to two weeks from your operation, as you are likely to feel more tired than normal and benefit from some help. It is usual to require 6-8 weeks of recuperation from surgery, although this does vary from person to person. We advise that you do not fly for at least

6 weeks from your operation. We would recommend not driving until you have had your post-operative check one week after your operation.

If you develop worsening headaches, nose bleeds, vomiting, worsened vision or clear nasal discharge when you are at home it is important that you contact us as you may require assessment. If you feel you are passing excessive volumes of urine in relation to what you are drinking, feel excessively thirsty and notice on your fluid balance charts that your urine output is >200mls/hr for three consecutive hours or excessive to your input contact Bagot and Drake (01865 857334) in hours (08.00-16.00). If it is out of these hours, or you don’t receive a response from Bagot and Drake after one hour please contact the Endocrine Registrar on call via switchboard (01865 741841).

Things NOT to do after discharge from hospital:

- No driving until instructed to do so by the DVLA or your doctors (dependent on your vision)
- No strenuous exercise including swimming for 4-6 weeks
- No flying for at least 6 weeks
- Avoid strenuous household activities for 4-6 weeks, for example gardening
- Do not stop hydrocortisone until instructed to do so

Symptoms to alert us to:

- Worsening headaches
- Persistent clear fluid dripping from the nose
- Feeling generally unwell and nauseous
- Passing excessive volumes of urine
- High temperature, neck stiffness, intolerance of bright light
- Deterioration in vision

Post-surgery appointments

One week after your operation you will be asked to come for a follow-up appointment at the Bagot and Drake ward, in the Oxford Centre of Diabetes, Endocrinology and Metabolism (OCDEM) at the Churchill.

It is important not to take hydrocortisone on the evening before and morning of that appointment unless your Doctor has told you otherwise. Please bring your hydrocortisone medication with you to this appointment as you will need to take it once the blood tests have been taken.

The endocrine nurses will take blood tests to check your hormone levels, check your visual fields and see a Doctor from the endocrine team. The appointment usually lasts most of the morning.

Six weeks after your operation you will have a further appointment at the Bagot and Drake Ward for a second post-operative assessment.

Three months after surgery you will have an MRI scan to assess the extent of the surgery and whether all of it has been removed. This may take place at the Neurosciences Department, West Wing, John Radcliffe or at the X-ray department at the Churchill Hospital. Your appointment letter will let you know where to go.

Following that MRI scan you will have an outpatient appointment to discuss your results and plan further follow-up.

Other useful information

Getting here:

For the John Radcliffe Hospital please see:
https://www.ouh.nhs.uk/hospitals/jr/find-us/default.aspx

For the Churchill Hospital please see:
https://www.rdm.ox.ac.uk/about/our-divisions/oxford-centre-for-diabetes-endocrinology-and-metabolism/how-to-find-ocdem

Who to contact?

Many questions can and do arise and we are here to help you. We advise that if you have any questions, however small, or you are concerned about a change in symptoms to contact our specialist nurses in the first instance who will be able to help.

Endocrine advice:

Oxford Centre of Diabetes, Endocrinology and Metabolism (OCDEM)
Churchill Hospital
Old Road, Oxford OX3 7LE

Telephone: **01865 857334** (08.00-16.00 Monday to Friday)

If urgent endocrine advice is required out of these hours please contact the Endocrine Registrar on call via switchboard (**01865 741841**).

Neurosurgery:

West Wing, John Radcliffe
Headley Way, Oxford OX3 9DU

Telephone: **01865 231 599**

Visiting hours: **no restriction**

If you have to cancel or delay any of your appointments please contact the endocrine nurses on:

Telephone: **01865 857334**

Other web links

Pituitary Foundation www.pituitary.org.uk

Tel: **0845 450 0375**

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Author: Miss Jane Halliday, Consultant Neurosurgeon
November 2022
Review: November 2025
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

Leaflet reference number: OMI 72214