

# Leeds Pituitary Centre Patient Handbook

Information for patients



Leeds Centre for  
Neurosciences

You have been referred for an operation for an abnormality within or near the pituitary gland.

We find that most patients have similar concerns and this patient information handbook is intended to explain some of the surgical aspects of your treatment and hopefully to put your mind at ease.

### Leeds Pituitary Centre Team Introduction



Or [https://www.youtube.com/watch?v=YRzKlb\\_Kt1k](https://www.youtube.com/watch?v=YRzKlb_Kt1k)

### Leeds Pituitary Team

You have been referred for an operation for an abnormality within or near the pituitary gland. We find that most patients have similar concerns and this patient information handbook is intended to explain some of the surgical aspects of your treatment and hopefully to put your mind at ease.

There are also some useful contact details for further information and advice in this leaflet. Your surgical and endocrine team will be happy to explain any further queries and unfamiliar terminology.

The Leeds Pituitary surgical service serves a population of about 2.5 million people centred on West Yorkshire and beyond. Pituitary surgery is undertaken in adults and children at the Leeds General Infirmary.

We also accept and treat patients referred from outside the region, including overseas patients. New patient referrals from within the UK require a referral letter from a patient’s General Practitioner.

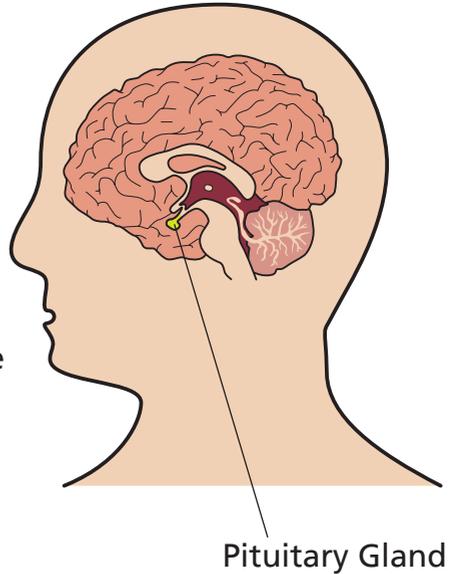
Pituitary surgery in Leeds is mainly done through the nose, with the expertise of neurosurgeons and ear, nose & throat (ENT) surgeons.

<b>Neurosurgery Consultants</b>	<b>Pituitary Endocrinologists</b>
- Mr Nick Phillips - Mr Atul Tyagi - Mr Asim Sheikh	- Dr Robert Murray - Dr Nikolaos Kyriakakis - Dr Khyatisha Seejore
<b>ENT Consultants</b>	<b>Oncologist</b>
- Mr Paul Nix - Mr Tom Wilson - Mr Panas Symeonides	- Dr Michael Flatley
<b>CNS team</b>	
<b>Pituitary Surgery</b> - Roisin Darley	<b>Leeds Endocrine</b> - Mel Gerrard

As part of a multi-disciplinary team (MDT), the pituitary surgeons work closely with Endocrinologists across the Yorkshire region, Neuroradiologists, Oncologists, Pathologists, Neuro-Ophthalmologists and Specialist Nurses.

## Pituitary Gland

The pituitary gland is a small gland that sits inside a bony cavity in the midline, between and behind both eyes. The normal gland is about the size of pea and secretes hormones directly into the blood stream. The pituitary gland is responsible for producing hormones that regulate various organs and glands in the body, including the thyroid gland, the adrenal glands, the ovaries and the testicles.



The pituitary gland regulates a number of the body's hormones and which in turn play a role in maintenance of multiple bodily systems. These include growth during childhood, fertility, weight, salt and water balance, the menstrual cycle, sexual function, energy levels and well-being.

A pituitary tumour, is an abnormal growth in the pituitary gland. Up to 20% of people have small pituitary tumours or cysts, most of which remain undiagnosed as they rarely cause any problems. Most pituitary tumours are non-cancerous (benign). "Functioning" tumours produce hormones. They cause symptoms accordingly, depending on the hormone being produced. Those that do not produce hormones are called "Non-Functioning" tumours.

## Signs and Symptoms of a Pituitary Tumour

Pituitary tumours can cause symptoms due to the tumour pressing on surrounding structures, failure of the normal pituitary hormones (Hypopituitarism), or the pituitary tumour producing an excess of a hormone (Functional pituitary tumours). For example,

### 1) *Pressure Symptoms*

Loss of peripheral vision, headaches, watery discharge from the nose (cerebrospinal fluid leak)

### 2) *Hypopituitarism*

Weight gain or loss, lethargy, dizziness, nausea, vomiting, loose stools, dry skin and hair, thin bones, infrequent or absent menstrual cycle, loss of libido, erectile dysfunction, hot flushes, mood changes.

### 3) *Functional Tumours*

- Growth hormone secreting tumours (Acromegaly) can lead to large hands and feet, a change in facial features, excessive sweating, headaches
- Prolactin secreting tumours (Prolactinoma) often lead to breast milk discharge (galactorrhoea), infrequent or absent menstrual cycle, loss of libido, erectile dysfunction, hot flushes, mood changes
- ACTH secreting tumours (Cushing's syndrome) lead to an excess of the natural steroid, cortisol. This often presents with flushing and roundness of the face, purple stretch marks, easy bruising, weight gain, muscle weakness, thin bones and menstrual irregularity

- TSH-secreting tumours lead to an overactive thyroid gland with weight loss, palpitations, shakiness, heat intolerance and sweating

Rarely pituitary tumours present with pituitary apoplexy. This is a syndrome resulting from a spontaneous stroke or bleed in a pituitary tumour and causes some combination of: acute severe headache, visual impairment, double vision, drowsiness, confusion or low blood pressure. This is a medical emergency and warrants immediate presentation to your nearest emergency department.

## Diagnosing Pituitary Tumours

The suspicion of a pituitary tumour is raised either by presenting symptoms (as above), abnormal hormone levels, or not infrequently is discovered when head imaging is performed for an unrelated reason. Further investigation usually includes:

- Blood tests to check hormone levels released from the pituitary gland
- Goldmann visual fields
- Dedicated MRI scan of the pituitary
- Further specific tests are required where a functioning tumour is suspected

## Treatment of Pituitary Tumours

Treatment of pituitary tumours may involve surgery, radiotherapy, medical therapy (some functioning tumours), or a combination of these treatments.

Most large tumours of pituitary gland will require removal via surgery. Tumours that produce Prolactin can generally be treated with medicines. Sometimes, if there is tumour residuum or recurrence, other medication, further surgery or radiotherapy may be advised.

Prior to and after surgery we may ask you to fill out a questionnaire or two on your symptoms. This helps us to understand the impact of the diagnosis and treatment on you and allows us to improve our services. We would be grateful for your participation.

We sometimes use radiological images and operative videos for teaching purposes and publication on social media and medical journals. These are used as anonymous pictures with no identifiable data. This will usually be discussed with you at the time of consultation in clinic. If you do not wish the images to be used for teaching purpose, please indicate this at the time of consultation.

## Decision to perform surgery



Or [https://youtu.be/liJ4MupZ\\_qw](https://youtu.be/liJ4MupZ_qw)

## Surgery

Surgery to remove a pituitary tumour is needed if the tumour is pressing on the nerves to the eyes, and as the first treatment for some functional tumours, this is called endoscopic trans-sphenoidal surgery.

Most of the time, pituitary tumours can be removed using an endoscope (camera) via the nasal passages. If the tumour cannot be removed this way, it is removed via an operation through the skull (Craniotomy). The surgery is performed under general anaesthesia. The surgery itself is performed jointly by an ENT (Ear, Nose and Throat) surgeon and neurosurgeon. The role of the ENT surgeon is to gain access through the nose into pituitary gland. The lining from inside the nose is prepared to cover the defect in bone at the end of operation.

The pituitary tumour is then removed by a Neurosurgeon. The tumours are dissected off of the carotid arteries to the side, and from the nerves to the eyes above. However, in some cases it is not possible to remove all the tumour if it cannot be dissected from the carotid arteries or sensitive tissue around the tumour. In that case, the aim is to remove as much as it is possible safely, whilst trying to preserve function of the gland. The final step is to reconstruct the defect in the skull base. This is done by using a flap of nasal lining to cover the bony defect. If the fluid surrounding the brain (cerebrospinal fluid) leaks out during the operation, the repair is done by using a graft of fat and fibrous tissue (fascia lata) graft from the thigh.

Sometimes it is necessary to repeat the surgery for recurrent tumours or to repair a persistent leak of cerebrospinal fluid. A lumbar drain may be inserted for such a repair.

## On the day of surgery



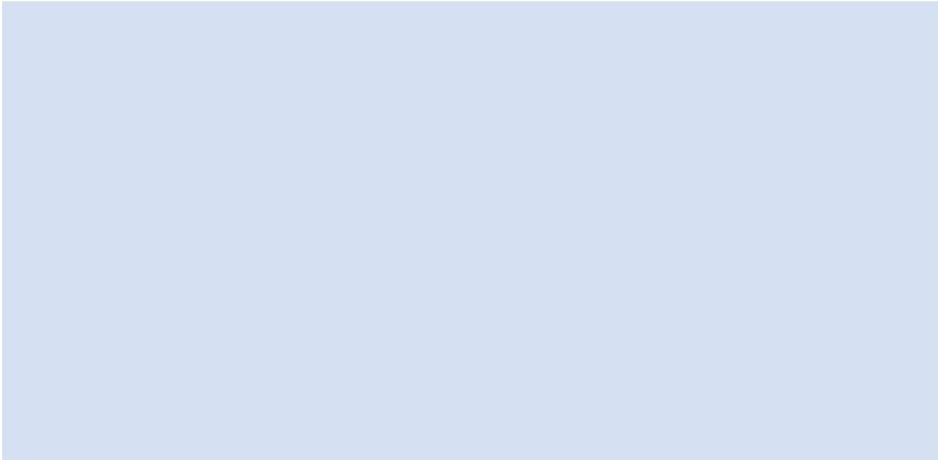
Or [https://youtu.be/E\\_MUa8kuvPk](https://youtu.be/E_MUa8kuvPk)

## Check list for Next Day Discharge

	Yes	No
Age above 65		
Coronary stents		
History of being on Antiplatelet, Anticoagulant		
Intradural extension of lesion		
Sleep apnoea		
COPD		
Known diabetes insipidus		
Other significant co-morbidities		
Uncontrolled hypertension		
Renal impairment		
TIA / CVA within last six months		
No accompanying adult carer 48 hours after discharge		
No access to emergency service		

If all of the above is checked, then you are suitable to be discharged home the next day after surgery. Discharge will also be guided by events during the operation.

If it is not suitable to discharge you the next day after surgery, the reason is:



### After your surgery



Or <https://youtu.be/IB0M7loXHDM>

### After discharge home



Or <https://youtu.be/AJzVI-rKzY>

## Post Operative Instructions

### What to Expect after Surgery:

#### *Headaches & Pain*

You will be given a prescription for pain medication. Directions will be on the package. Pain following pituitary surgery is usually readily controlled by medication. Do not be afraid to take a pain pill if you are uncomfortable, especially when going to bed at night or awakening in the morning. Sleeping with your head elevated (on at least two pillows) helps decrease pain and swelling. Do not operate machinery or drive when taking strong pain medication (narcotics).

If your headaches worsen or are unrelieved by pain medication or your neck feels stiff and painful please call the contact numbers given below.

#### *Fatigue*

It is normal to feel fatigued after surgery for three to four weeks. Pace yourself. Slowly increase your activity and remember to rest when you are tired.

#### *Sinus Congestion*

Don't be discouraged if you can't breathe through your nose at first. It typically takes two to three weeks before the inflammation and swelling inside the nose have subsided enough to provide a good nasal airway. If you think you have a sinus infection, please call the contact numbers provided. Initial nasal congestion may cause a temporary loss of taste.

#### *Nasal Drainage*

You can expect some bloody mucus drainage from your nose. This drainage will be greatest the first three days after surgery.

It is best not to blow your nose immediately after surgery, as this may cause bleeding. After three days, you may blow your nose gently. Clear fluid, like water dripping from a tap, or a lot of bright red blood like a nosebleed is not normal. Please contact us immediately, in that case.

### ***What happens if my nose bleeds?***

Spotting of red blood, or bloody mucous, is normal. Brisk bleeding, dripping from the nose that doesn't stop after a few minutes of sitting up and squeezing your nostrils together is not. This happens rarely, and when it does, it is almost always a small vessel in the nose (not the tumour or brain). Control it with pressure and go to your local A&E. They may have to pack your nose to stop it. Notify us if this occurs.

### ***Cleaning Your Nose***

The best way to clear your nose of mucus and dried blood is with Sinurinse irrigation, starting on Day two after surgery. This should be done up to four times every day for up to six weeks. If done correctly, mucus will be flushed out of the front of the nose. Some mucus may even be rinsed to the back of the nose and flow out of the other nostril or the mouth.

### ***Demonstration on using the nasal rinse and DIY recipe***



Or <https://m.youtube.com/watch?v=DYZDeiOV>

**DIY recipe for sinurinse: one pint of cooled down boiled water with one teaspoon of salt and 1/2 teaspoon of bicarbonate of soda.**

## ***Sneezing & Coughing***

If you need to sneeze or cough during the two weeks after surgery, stay relaxed and let it happen! Don't hold your breath or pinch your nose!

Avoid things that make you sneeze. Sneezing through an open mouth may be helpful.

## ***Medication and Laboratory Testing***

After surgery, you will likely be placed on a low dose of steroid medication (Hydrocortisone). It is important to continue to take this medication daily until you are instructed to stop.

Your endocrinologist will monitor your salt (sodium) and hormone levels in the weeks after surgery. They will instruct you on when and where to obtain the blood tests.

**Please refer to Steroid Replacement Therapy Booklet for more information.**

## ***Fever***

If your fever is higher than 38°C, double your steroid dose until the fever subsides. If during the first two weeks after surgery your fever goes above 38°C, please contact us. Please refer to Steroid Replacement Therapy Booklet for more information.

## ***High Blood Sodium - Hypernatremia***

If you begin to pass excessive amounts of urine and become extremely thirsty (awakening multiple times at night, for example), this may be a temporary condition called Diabetes Insipidus.

The pituitary gland may not be releasing enough of the hormone that regulates sodium levels in the blood. Your blood sodium level may be too high - hypernatremia.

You may need regular blood tests after surgery because of this reason. You may need medications until the condition subsides. Please contact the Endocrine nurse specialist to arrange blood tests.

### ***Low Blood Sodium - Hyponatremia***

If you are nauseous and have been vomiting, but don't have a fever, you may have a temporary condition called the Syndrome of Inappropriate Antidiuretic Hormone or SIADH for short. The pituitary gland may be releasing too much of the hormone that regulates sodium levels in the blood. Your blood sodium level may be too low - hyponatremia.

You may need regular blood tests after surgery because of this reason. You may need medications until the condition subsides. Please contact Endocrine nurse specialist to arrange blood tests.

**Note that severe hyponatremia is dangerous and can cause seizures. Signs of severe hyponatremia include headaches, dizziness, confusion, lethargy, and an inability to stay awake. Seek immediate medical attention - go to your local emergency department - if this occurs.**

### ***Thigh Incision Care***

If a graft was used from the thigh, the wound will need the same care as any surgical wound. You may have had some clips on the skin, which would need to be removed in one week's time at the GP surgery.

If absorbable sutures are used, you will be notified before discharge. If a large swelling or bruise appears on the wound or if you develop a fever and discharge from wound, please contact us.

### ***Showering***

You may shower anytime. Cover the thigh incision with plastic when you shower during the first week after surgery. You can get the incision wet after seven days.

### ***Constipation***

Pain medication may cause constipation. If you become constipated increase your fiber intake and you may need to take a stool softener or laxative (ducolax, senna, etc).

### ***Bending & Lifting***

Heavy lifting, straining, and exercise that might cause bleeding should be avoided during the first two weeks. Don't be surprised if you tire more easily than usual. Wait for about four weeks before resuming a strenuous exercise program.

### ***Other Activities***

- Generally you can return to work in four - six weeks depending on the work you do
- You can jog after two weeks and exercise regularly after four weeks
- You can eat whatever you like and drink to thirst
- You can fly in four - six weeks' time
- You can drive once recovered from surgery as long as you are not taking narcotic pain medications and depending on your pre-existing visual loss

- You can swim after two weeks and can play golf any time
- There are no restrictions on being sexually intimate with your partner

### **When to call after surgery:**

- Fever after the day of surgery higher than 38°C
- Constant clear watery discharge after the first week of surgery - **please ring the ward for advice**
- Sudden visual changes/loss or eye swelling
- Severe headache or neck stiffness
- Severe diarrhea
- Steady, brisk nose bleeding that doesn't get better after elevating head / nose pinch

### **Who to call after surgery:**

- **Within the first two weeks of your surgery:**  
(Monday to Friday between 09:00 - 17:00)

**Pituitary Surgery Nurse Specialist,**

**Roisin Darley**

**0113 206 7571**

- **After hours you should call:**

**Male Neurosurgical Ward L25**

**0113 392 7425**

**Female Neurosurgical Ward L24**

**0113 392 7424**

- **For endocrine related concerns, please contact your local endocrine nurse specialist. For patients under care of Leeds Endocrinology service:**

**Leeds Endocrine Nurse specialist,**

**Mel Gerrard**

**0113 206 6418**

- Secretary of Dr Murray **0113 206 4937**
- Theatre scheduler for Mr Phillips and Mr Sheikh **0113 392 5606**
- Theatre scheduler for Mr Tyagi **0113 392 8102**
- After two weeks of your surgery, please contact your local GP for advice
- In case of an emergency, please contact your nearest Emergency Department

### Follow up (as a guide):

- You will be seen in ENT Clinic in six weeks
- You will be seen in Neurosurgery Clinic in three months
- You will have repeat Goldmann's Visual Field testing in three months
- You will have a repeat MRI scan in six months
- You will undergo endocrine assessment in two - six weeks, with out-patient review shortly thereafter
- For further information:  
The Pituitary Foundation - [www.pituitary.org.uk](http://www.pituitary.org.uk)  
Macmillan - [www.macmillan.org.uk](http://www.macmillan.org.uk)

### Follow up after the surgery



Or <https://youtu.be/4pgE7Ele8UE>

## My information

Name	
Date of Birth	
Hospital Number	
Consultant Neurosurgeon	
Consultant ENT	
Endocrinologist	
Diagnosis	
Checklist	

## My contacts

Next of Kin	
Phone Number	
GP Name	
GP Address	
Past Medical History	
Allergies	

## My treatment

Date of Operation	
Operation one	
Date of Operation	
Operation two	
Medication	
Radiation Treatment	
Other	



**What did you think of your care?**

Scan the QR code or visit [bit.ly/nhsleedsfft](https://bit.ly/nhsleedsfft)

***Your views matter***



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