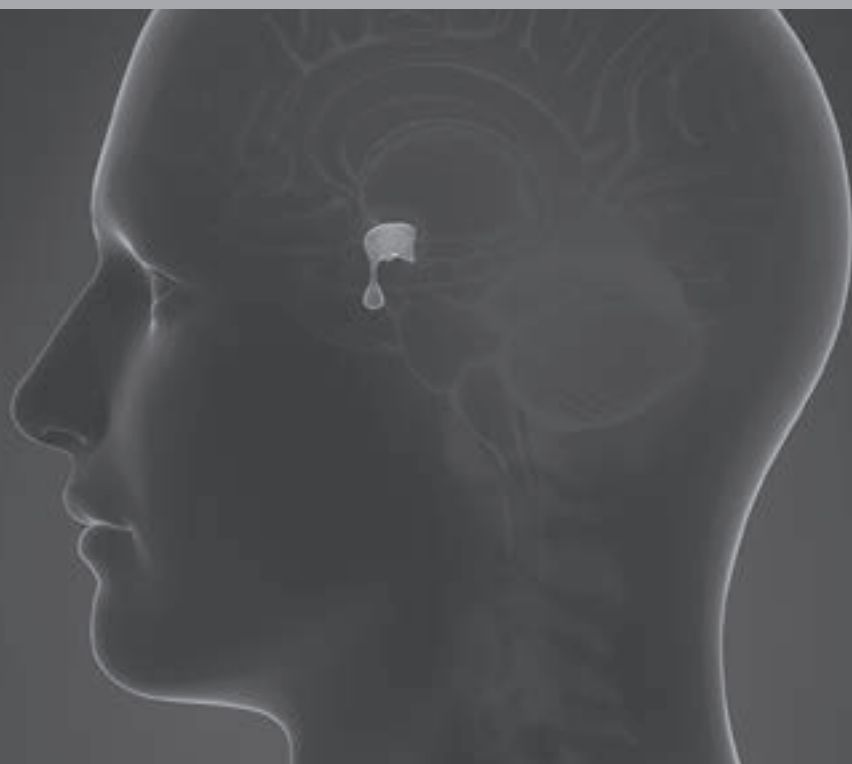


Pituitary Surgery & Radiotherapy



The Pituitary Foundation Information Booklets

The
Pituitary
FOUNDATION

Working to support pituitary patients, their carers & families

The Pituitary Foundation is a charity working in the United Kingdom and Republic of Ireland supporting patients with pituitary conditions, their carers, family and friends.

Our aims are to offer support through the pituitary journey, provide information to the community, and act as the patient voice to raise awareness and improve services.

About this booklet

The aim of this booklet is to provide general information about pituitary surgery and radiotherapy. You may not find that all of the information applies to you in particular but we hope it helps you to understand your condition better and offers you a basis for discussion with your GP, endocrinologist and neurosurgeon.

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Where is my **pituitary gland**, & what does it do?

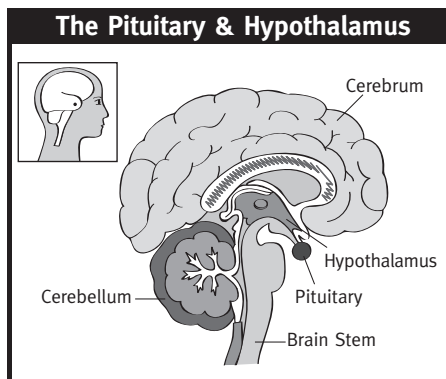
Your **pituitary gland** is about the size of a pea and is situated in a bony hollow just behind the bridge of your nose. It is not part of the brain but is connected to it by a stalk with a tuft of special blood vessels through which the brain sends the hormonal messages that control the functions of the gland. Across the space between the gland and the brain lie the optic nerves - the nerves that connect the brain to the eyes.

The pituitary gland produces hormones, which are distributed in the body by the blood stream to control various important body functions. The pituitary is the controlling gland through which the brain instructs all the other major endocrine glands. Special cell groups within the pituitary gland control different functions:

- the stress response
- metabolic rate (which is the speed at which the body uses food as fuel, i.e. calories/food)
- growth
- milk production
- sexual function (in particular, the menstrual cycle in women) and fertility.

What is a **pituitary tumour**?

Pituitary tumours are often known as 'adenomas'; this means a benign (non-cancerous) tumour involving glandular material. With an adenoma, cells of the pituitary gland begin to function independently of the normal control by the brain, and slowly increase in number. Adenomas account for more than 95% of all pituitary tumours. We do not know what causes the majority of pituitary



adenomas, but they are not caused by stress. Only in very exceptional cases, less than 1%, are they hereditary.

The other 5% of pituitary tumours have many causes. The most common in a very long list are meningiomas and craniopharyngiomas. All of these tend to cause similar symptoms to pituitary adenomas, although there are some subtle differences.

The word 'tumour' covers a lot of different conditions and may often have frightening connotations. The vast majority of pituitary tumours are benign: only very rarely (less than 1%) the tumour will be malignant (cancerous).

There are several different types of pituitary tumours. You will probably understand this booklet better if you know what sort of tumour you have. If you do not know, ask your endocrinologist to explain the different types of tumour to you and tell you which one you have.

Why do I need an Operation?

A pituitary tumour may affect your vision, your hormonal balance or other functions. These symptoms commonly lead to the diagnosis.

Vision

If your pituitary tumour has enlarged considerably, it may be pressing on the optic nerves (to the eyes) which lie just above the pituitary gland. This can affect your eyesight, and may cause any of the following symptoms:

- It may reduce the amount that you can see overall so that particular areas in your field of vision are reduced. This usually affects the periphery (to the side) and makes it seem as if you are looking down a tunnel. It often affects one eye more than the other. This is technically known as a bitemporal hemianopia
- It can affect vision by reducing your ability to see detail. This is called reduction in visual acuity. This will be discovered when you look at the reading chart that you will undoubtedly have seen in almost every doctor's surgery and perhaps, too, in one of the endocrine clinics you have attended
- Large tumours can cause double vision, but very rarely

Hormone disturbances

A significant number of pituitary adenomas are discovered because they cause the over-production of one particular hormone. In contrast, another group of pituitary adenomas fail to produce one or more hormones.



The three most common types of over-producing adenomas are:

- Prolactin-secreting tumours (prolactinomas), which produce the hormone prolactin. Please see our *Prolactinoma Booklet*
- Cushing's disease: this is caused by over-production of the hormone ACTH (adrenocorticotrophic hormone) which in turn releases cortisol (the body's natural glucocorticoid steroid hormone). Please see our *Cushing's Booklet*
- Growth hormone-secreting adenomas: the excess secretion of growth hormone causes a condition called acromegaly. Please see our *Acromegaly Booklet*

There are a couple of other hormone-producing tumours, but these are very much rarer.

The groups of pituitary adenomas which fail

Why do I need an Operation?

to produce one or more hormones are called non-functioning pituitary adenomas. This condition results in symptoms of hormone deficiency. They are often diagnosed late because they don't produce specific symptoms of hormone excess. Please see our booklet entitled *The Pituitary Gland: Its Conditions and Hormones Explained*.

Other functions

A tumour can also be discovered when its increase in size has effects on functions other than vision. For example, occasionally (and again very rarely) tumours can be so large that they can cause blockage of the circulation of the fluid inside the brain, leading to a condition called hydrocephalus (water on the brain).

Size

When pituitary tumours are very small, (less than 1cm) they are called microadenomas. Large tumours (over 1 cm) are called macroadenomas. Large tumours can also prevent normal hormone secretion by other parts of the pituitary gland causing symptoms of hormone deficiency. Sometimes they are more difficult to control.



Incidental discovery

Pituitary tumours are sometimes discovered when a patient has a scan for some other reason. This is happening more and more commonly as patients receive scans for other conditions. For example a CT scan or an MRI scan may be performed to investigate headaches, dizziness, hearing loss or other symptoms and this may lead to discovery of a pituitary tumour which is completely unrelated to these symptoms. Patients with incidentally discovered tumours require surgery only if the tumour has reached a certain size or if it is found to increase in size over time.

Surgical treatment

Operations on pituitary tumours are generally quite safe, although as with all surgical procedures there are some associated risks and potential complications. The choice of surgeon is crucial to the likelihood of successful removal of the tumour, with experienced pituitary surgeons having the best results. The duration of hospital stay depends on the type of surgery (see below).

Some units like to transfer their patients back to the referring endocrinologist fairly soon after the operation for more detailed tests. Other units discharge the patient home and refer the patient to the endocrinologist as an outpatient.

What will surgery achieve?

The aim of surgery is to remove as much of the tumour as safely as possible, without damage to the delicate nerves and blood vessels in the area. Surgery can, in some cases, remove all of very small tumours but complete removal of large tumours can be difficult and inaccessible areas of the tumour will be left in place. For many patients it is an essential part of their treatment to achieving restoration of hormone balance - there is more information on this subject later in this booklet.

What sort of surgery is undertaken?

Most operations on the pituitary gland are now carried out through the nose. This is called trans-sphenoidal surgery. 'Trans' means across and 'sphenoid' is the air cavity in which the pituitary gland sits, as you will see from our diagram on page 7. Trans-sphenoidal surgery is traditionally performed using an operating



image: Zdenko Zirkonic

microscope. More recently, technological advances have led to the use of fibre optic endoscopes in pituitary surgery. This is a newer technique and is called endoscopic pituitary surgery.

Operations through the skull (craniotomy) are far less common these days than they used to be. However, there are still situations where a craniotomy is required, for example, if parts of the tumour cannot be reached through the nose.

Preparations for pituitary surgery

Patients having pituitary surgery are usually under the care of an endocrinologist who will have carried out extensive blood tests and special scans (MRI scans) before referring them to a neurosurgeon who specialises in pituitary surgery. Many of these tests will have been done on an outpatient basis, and you will probably only need to be admitted to hospital for the operation itself.

You would usually be admitted to the ward the day before your operation. Pituitary operations are performed under a general

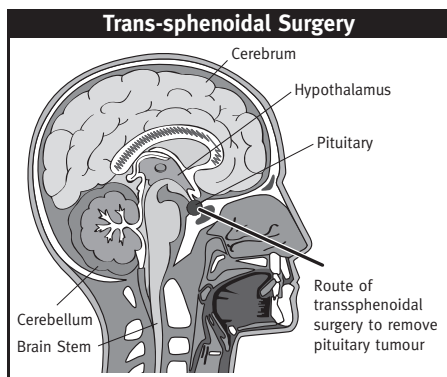
Surgical treatment

anaesthetic. The anaesthetist will see you before the operation and will give you details of what will be happening. If you have any concerns about general anaesthetic you should discuss them with the anaesthetist at this stage. If you require further information with regards to anaesthesia you can obtain this from the website of the Royal College of Anaesthetists where there is a section for patient information (<http://www.rcoa.ac.uk/>).

Following trans-sphenoidal surgery you would usually stay in hospital for 3 to 5 days. Recovery is generally quite straightforward and depending on the individual, you could expect to pick up the threads of your life again after a few weeks, although some require longer. You may require a further few weeks away from work if necessary. We advise that you listen to what your body is telling you and don't try to do too much, too soon. If the operation has to be performed through a craniotomy, the hospital stay is usually 7 to 10 days. Recovery following craniotomy is slower and you may need to stay off work for approximately 2 months. Following craniotomy you cannot drive for 6 months (see section on driving).

Trans-sphenoidal surgery

Trans-sphenoidal surgery is performed through the nose. Traditionally, the operation has been performed using an operating microscope (standard trans-sphenoidal surgery). More recently, fibre optic endoscopes have been used in some centres (endoscopic trans-sphenoidal surgery).



Microscopic trans-sphenoidal surgery:

The procedure is performed using an operating microscope. There are a number of different ways in which the surgeon can reach the pituitary area:

- Through one nostril. This can be done without any external (outside) incision but in some people (particularly those with small nostrils) it may be necessary to make an external incision in the crease on the side of one nostril.
- An alternative approach is through an incision under the lip, just above the front teeth, which then allows access to the nasal cavity.

In the next step, the nasal septum is moved to the opposite side. Metal retractors are placed inside the nasal cavity. Some bone is removed from the roof of the nose. This allows access to the pituitary tumour. The tumour (or as much of it as possible) is removed. At the end of the procedure, the nose is packed to decrease the amount of bleeding from the nose. The packs are removed after 48 hours.

Surgical treatment

Endoscopic trans-sphenoidal surgery:

This is a newer technique and is a modification of the standard technique.

There is no need for an external incision. There is no need for insertion of metal retractors into the nose. An endoscope (a fine fibre-optic tube) is inserted through one of the nostrils. Similar to the standard technique, some bone is removed from the roof of the nose. The rest of the procedure is the same as the standard approach although slightly different instruments are used. The main difference in using an endoscope is to provide light and vision for the surgeon, instead of an operating microscope. In addition, it is less common to use nasal packing at the end of the operation which makes the first few days after surgery more comfortable for the patient.

For both types of surgery, once the tumour is removed, some repair work will be needed at the site through which the tumour has been removed. Some surgeons allow this to heal naturally, which it usually does. Others use body tissue to make a repair. Usually this tissue is either fat from the abdomen or a postage stamp-sized piece of a membrane from the thigh, sometimes with a bit of muscle as well. Your surgeon should tell you if he or she uses this sort of repair.

Each of these routes has theoretical and practical advantages and disadvantages, and ultimately will be the choice of the surgeon.

How long will the operation take?

The anaesthetic will take 20 to 40 minutes, depending on a number of different factors. Trans-sphenoidal surgery usually takes approximately 1 to 2 hours. These are guidelines only and in some cases the surgery may take longer depending on a number of factors.

Craniotomy

Craniotomy is an operation performed through an opening in the skull. This is also performed under a general anaesthetic

Surgeons differ in the amount of hair they remove for surgery. Usually only a small amount of hair is shaved. This is often a thin strip along the line of the skin incision and thus isn't very noticeable. A window is made in the skull by taking a flap of bone off, which is put back at the end of the operation and fixed in place with small titanium plates. Through the opening in the skull the surgeon performs the surgery under an operating microscope and removes as much of the tumour as possible. When you wake up, a small drain is usually under the skin of the forehead and you may have a headache. The incision is usually just behind the hairline, so that when everything settles down your hair will regrow and the incision is invisible. You may find that there is some swelling in the forehead and you may even have a black eye for a while caused by blood in the wound. Most neurosurgeons use metal clips rather than stitches as these heal with a very neat scar and

Surgical treatment

are quick to put in. These clips or stitches are removed between four and seven days following the operation.

How long will the operation take?

The anaesthetic will take 20 to 40 minutes, depending on a number of different factors. Craniotomy usually takes 2 to 4 hours. These are guidelines only and in some cases the surgery may take longer depending on a number of factors.

What is the aim of surgery & how likely is a cure?

The aim of surgery depends on the type of tumour and the presenting symptoms.

For hormone producing tumours (Prolactinoma, Cushing's and Acromegaly)

the aim of treatment - a cure* - is a normalisation of hormone balance. In many cases, surgery is one stage of treatment to bring about a cure; radiotherapy and medication may also be required. It may take some time before hormones reach a 'normal' level. For small hormone-producing tumours, most surgeons would expect over half of their patients to be cured by the operation, but larger tumours may not be completely removed even by an experienced surgeon.

**The use of the word 'cure' in the section above is often used by surgeons as stated: the complete normalisation of hormonal balance. This use of 'cure' can be confusing to some patients. Some*

patients find significant reduction in symptoms, other patients have complete reduction. However, most patients experience life changes which can include taking medications long-term or adapting to physical changes that don't go back to 'normal'.

For non-functioning pituitary adenomas, which usually present with visual symptoms, the aim of surgery is to prevent further deterioration in vision and if possible to regain lost vision. It is not essential (and in many cases not possible) to remove the entire tumour. The aim is to remove the pressure from the optic nerves. Therefore the word "cure" which would imply removal of the entire tumour is probably not appropriate. Most surgeons would expect at least three quarters of patients overall to show improvement in vision, with about a third returning back to normal. The extent of recovery will depend on how bad the vision is prior to the operation. The improvement, when it occurs, continues over 6 months after the operation.

What can go **wrong** during & after the operation?

Potential complications

CSF Leak The most common problem, in 5-15% (as per recent literature) of patients, is a leak of brain fluid. This fluid is known as CSF (cerebrospinal fluid). If it occurs, a clear salty fluid will drip down through the nose or down the back of the throat. If you find clear fluid leaking from your nose after being discharged from the hospital, phone your surgical ward to arrange to go back as soon as possible. It will be important for them to see the fluid, so collect any drips in a small clean jar. The fluid will be tested to see if it is CSF. Sometimes, however, the fluid is simply watery mucous, which is completely safe.

Each unit has its own way of managing this problem, but it is vitally important to control it. Many units use a small fine tube (a spinal drain) in the back for a few days to control the leak. A second operation may be needed to take a patch of fat from the abdomen or a bit of a membrane from the thigh, to seal the leak. Please note, this second operation is only required in about 1% of all patients undergoing surgery.

Meningitis If the CSF continues to leak, bacteria can creep up via the route that the CSF is escaping from and lead to inflammation of the brain, a form of meningitis. If you did suffer from this, you would feel unwell, develop a fever, a stiff neck and find bright lights bothered you. You should seek medical advice immediately and if meningitis is confirmed you will be treated with antibiotics.

Bleeding Very rarely, bleeding during the operation can cause a problem and an operation may be abandoned and a repeat operation

offered at some later stage. Bleeding into the brain or damage to/from the carotid artery (main blood vessel/artery to the brain) can cause a stroke but fortunately this is very rare as explained in the above complication.

Vision Deterioration in vision following surgery can occur after surgery but is rare.

Hormone problems Your tumour may have already damaged the pituitary gland and caused hormone deficiencies. However, surgery can also damage any remaining normal pituitary gland and lead to further hormone deficiencies. Fortunately, all pituitary hormones can be replaced by medication. Taking these medications may be a temporary or a life-long requirement. The most common hormone problem during the early postoperative period is called diabetes insipidus (see page 11 for more details).

Repeat surgery In case of hormone producing tumours, sometimes the surgeon will offer a second operation if the hormone condition has not been corrected. This decision should always be reached in conjunction with your endocrinologist. In case of non-functioning pituitary adenomas, further surgery may be required if the tumour recurs at a later date.

Seizures (craniotomy only) Epileptic fits (seizures) can occur in patients who have had craniotomy although this is fortunately not common. Because of risk of seizures, patients who have undergone craniotomy should not drive for 6 months after surgery and should inform the DVLA about their operation. If a seizure occurs, then treatment with anti-epileptic medications may be necessary and additional rules for driving apply (see under driving).

What happens **after** the operation?

Immediate

If you have had standard trans-sphenoidal surgery, you will wake up from the operation with padding inside your nose. Some units use special sponges and some units prefer to use long ribbons. How long these are left in place varies. Usually they are removed 1 or 2 days after surgery, but this may differ between different centres. The doctors and ward nurses will tell you, but be sure to ask. You may experience some discomfort whilst the packs are in and removal can be painful for some, but it is a short procedure. Usually, packs are not used following endoscopic surgery.

When you wake up from the operation, you are likely to have a painful nose, perhaps a headache or bruising of your face. You will be asked routine questions by the nurse, many of which will seem a little strange, such as what day it is and where you are. They will also test your eyesight, and check movement of your arms and legs. You will have a drip in your arm and you will not be allowed to drink for a while. Because you have to breathe through your mouth you may feel rather dry and thirsty. When you go back to the ward you usually feel very much more comfortable and you should be on your feet the following day.

The next few days

If you have excess production of a hormone, you may not notice very much difference in symptoms at all, at first.

If your vision was affected before the operation, you may notice your vision improving while you are still in the hospital

although this is not always the case. Most units will check this before you are discharged to make sure that the operation has had its desired effect. Note, that even if your vision does not improve the operation may be considered successful if it prevents further deterioration.



The doctors and nurses will want to know how much fluid you are taking in, and passing out in your urine, and therefore you will be on a strict fluid balance chart.

Very occasionally, the part of the pituitary gland which helps control the volume of urine can be disturbed and you may start to produce a lot of urine and be very thirsty. This is called diabetes insipidus (DI) and is not connected with the much more common diabetes mellitus where you have too much sugar in the blood. If this occurs you may need an injection, tablets or a nasal spray of DDAVP (desmopressin) which mimics the natural anti-diuretic

What happens **after** the operation?

hormone to help control this excess urine. It may be necessary to continue this for a few weeks or even months. Occasionally, it can be permanent. If you do feel thirsty, however, the most common reason is because you are breathing through your mouth. Please see our *Diabetes Insipidus Booklet*.

About ten days following surgery, usually when you have returned home, a problem can occur with fluid balance, the ratio of fluid input to urine output (this is very rare, although more common in the over 65s). The pituitary becomes 'confused' and releases too much of the natural 'DDAVP'. This interferes with the control of urine production and the body is unable to pass sufficient urine to balance the amount you drink. This results in very dilute blood and causes the sufferer to feel washed out, tired and headachy. If you feel like this after you have been discharged, tell your GP or the neurosurgery/endocrine unit as soon as possible. They should do a simple blood test to measure your blood electrolytes to see if your sodium level is low. If it is, you will be told to restrict your fluid intake to about half a litre a day and the problem will usually right itself. They may want to re-admit you for a short while.

You may discover some stitches in your nostril or under your upper lip used to close the incision. These stitches are usually soluble. The wound will be completely healed in two to three weeks.



Going home

If you are given any medication to take home, you will usually be given enough for the following seven days. You will also be given a letter to give to your GP, which includes information about your medication. This may be faxed to your GP.

If you need to keep taking your medication, make sure you arrange to get a repeat prescription from your GP before your hospital supply runs out. Some surgeries require up to 48 hours notice for repeat prescriptions. Have someone collect you to drive you home, but let the staff know if this isn't possible, so they can arrange transport.

You may need a sick note for your employer. Speak to the nurse in charge of your ward if you need a form to be completed.

Once you are home, you may feel a bit anxious after such surgery and the level of care you've had. This is normal and you'll gain confidence each day. Rest when you can, even if

What happens **after** the operation?

it's just putting your feet up in the afternoon for the first days or weeks home. If you have any concerns during this time, contact your GP or the ward you stayed on for advice.

Hormone replacement

Most patients will be given cortisol replacement as a drug called hydrocortisone. In some hospitals, all pituitary patients are given these hormones; other hospitals restrict it to those patients with large tumours and those who have had surgery for Cushing's.

Hormone replacement is often given as a precaution. The pituitary gland stimulates the adrenal glands to make up the necessary anti-stress hormone (cortisol), without which you would rapidly become very ill. At first, hormone replacement will be administered in higher doses than needed and then reduced to normal levels.

Often, patients will be tested in the hospital and taken off hormone replacement before going home. Some patients will be sent home on hydrocortisone or prednisolone. If so, make certain you contact your GP so that you can continue the prescription until reviewed in clinic.

Those still on hormone replacement should carry a steroid card. It is crucial to educate yourself about emergency cortisol replacement in case of a serious injury or bad infection (such as flu). In cases such as these, you will need to double up on your dose in response to the extra stress. Please see our *Hydrocortisone Advice Booklet*. If the hydrocortisone needed is long-term, patients should wear a medical talisman (necklace or bracelet).

Aftercare

You will need to return to the hospital both shortly after the surgery and on a regular basis. After surgery, some hospitals follow you up in specialist pituitary clinics where you see the surgeon and an endocrinologist, and possibly even a radiotherapist (if you need or have had radiotherapy - your endocrinologist will usually explain this) at the same time. Others prefer individual follow-up, in which case you may need to go to more than one clinic.

It is usually possible to get your condition stabilised and, possibly with the help of additional medication and radiotherapy, to balance your hormones to the ideal state. This may take a couple of years. Most endocrinologists prefer long-term follow-up, maybe a visit initially every four to six months then every year or two. These visits give you an opportunity to ask the specialists about your particular case, and what the outlook is. You may find it useful to take a list of questions with you and again ask someone to come with you to help write down or remember the answers.

In many cases your long-term monitoring will be shared by your endocrinologist and GP. Because pituitary conditions are relatively rare, you might find that you will be the only patient with pituitary disease that your GP is treating and they may find it helpful to have a copy of our *Pituitary Disease Fact File for General Practitioners*.

The Foundation has a list compiled by patients with practical advice and suggestions on how to prepare and what to bring during hospital stays. This can be viewed on our website or requested from The Foundation.

What happens **after** the operation?

Surgery - one patient's story

The following story is of a man who had all the symptoms of a large non-functioning pituitary adenoma: vision loss, hormonal problems (particularly loss of sex hormones and cortisol) and severe headaches.

Everything moved quickly from the point of diagnosis. I saw a number of specialists for tests and a scan revealed a large tumour of my pituitary gland. My neurosurgeon proposed to remove it through the nose. I started taking replacement hormones and these made me feel much better. The headaches and vision problems in my left eye were still bad however.

The tumour was one of the largest the surgeon had seen. It had partially severed my left optic nerve. The operation was for me the easy part. Everyone was wonderful and very supportive.

When I woke up I was in intensive care. There were tubes and needles everywhere and a wonderful nurse seemed to be looking after me on a full-time basis. I was alive and it was over! My nose seemed as big as 'Mount Everest'. I had to acknowledge every touch as the nurse gently prodded my toes, etc. to see if everything was working. Could I see this, could I see that? Could I feel this, could I feel that? After a few hours of intensive care I was

dispatched back to my ward. My other overwhelming recollection of intensive care is of feeling very, very tired. I had my operation in the evening so I guess I was up all night! Anyway, I slept soundly once I was back on the ward.

For a few days I felt OK lying down but very odd when I sat up. I began to wonder if I would ever sit up and walk about again. Also my eyesight was all over the place. I had my nose filled with nasal packs and this was uncomfortable but not a real problem. Quite soon however, I returned to normal and within 5 days I was going for walks around the hospital and even outside. I was home within a week of the operation. My vision settled down within a month and the headaches also went at about the same time and never came back.

I now rub on the (testosterone) gel once a day and take pills every day but in truth this has no negative impact on my life whatsoever. I have regular check ups and my endocrinologist recently said that I need only return to clinic every two years.

Radiotherapy



Radiotherapy is sometimes used as part of the overall treatment for pituitary tumours (also called pituitary adenomas).

The aim of radiotherapy treatment for patients with pituitary tumours is to control the growth of the tumour (or any remaining tumour after surgery) and prevent it enlarging. In some cases, radiotherapy also results in shrinkage of the tumour, but this can take many months or years to happen.

Although radiotherapy treatment is most often used for patients with cancer, patients with pituitary tumours do not have cancer; their tumours are benign.

Pituitary tumours grow very slowly and tend to respond to radiotherapy slowly as well. Because of this, if radiotherapy treatment is required, it does not need to be given urgently within days or weeks of surgery and can safely be given months after the operation.

What exactly is radiotherapy?

Radiotherapy uses X-rays to treat disease and it works by damaging the DNA in the nucleus of any cells that it passes through.

Although cells can continue to live for some time with damaged DNA, eventually cells either repair the damage and survive, or, if the damage is too great, the cell dies. This cell death happens some time after the radiation is delivered, often after the cell has divided a few times, many weeks, months or years after the treatment.

Normal body cells are better able to repair radiation damage than tumour cells and by delivering the radiotherapy using repeated small dose treatments, the chance of permanent damage to your own normal body cells is reduced. In addition, by giving many small treatments, the total dose that can safely be delivered to the tumour is higher, thus increasing the chances of success.

Radiotherapy is delivered using high-energy X-ray machines, called linear accelerators (Linacs) which are similar to CT scanners. They focus an X-ray beam onto the pituitary tumour and surrounding area, from several different angles, one at a time.

Because the radiotherapy source is external, it does not make you radioactive. It is perfectly safe for you to be with other people, including children, throughout your weeks of treatment (although not during the radiotherapy itself). External radiotherapy is usually given as an outpatient. It is planned and supervised by a Clinical Oncologist (a cancer specialist with training in radiotherapy treatment).

Radiotherapy

Why do I need to have it?

It is not always possible to remove the whole of the pituitary tumour during surgery without running the risk of damaging surrounding structures, such as the optic nerves (the nerves that come from the eye and enable us to see) or major blood vessels. This is particularly true of larger tumours. Although pituitary tumours are almost invariably benign, they do have a tendency to grow and if even a few cells remain after surgery, they can be the seed for a recurrence of the tumour in the same area.

Following surgery, patients undergo further scanning (MRI or CT) and blood tests. Their cases are then reviewed and discussed by the multi-disciplinary team (including an endocrinologist, neurosurgeon and radiotherapist) looking after them. A consensus decision on each case is then made by the team and recommended to the patient.

In general, radiotherapy is considered for patients:

- Who have evidence of persisting tumour outside the pituitary fossa (the space where the pituitary gland sits) following surgery
- Whose tumour is secreting a hormone that continues to be raised in blood tests following surgery despite treatment with drugs
- Whose pituitary tumour re-grows (this would be some time after surgery, perhaps following a second operation)

Some patients, whose post-operative scan shows minimal persistent tissues within the pituitary fossa only, are not given radiotherapy after surgery. They are followed up with annual scans, blood tests and visual field checks.

How effective is radiotherapy?

When we look back on patients treated 20 years ago, radiotherapy is very effective.

- Re-growth of the tumour is prevented in nine out of ten patients (for similar types of patients who were not given radiotherapy following surgery, the tumour re-grew in over half of all cases)
- Half the patients whose eyesight has been affected by the tumour notice an improvement following surgery and radiotherapy
- For those patients who are receiving radiotherapy, in order to reduce hormone secretion, it is effective in nine out of ten patients, starting about two years after radiotherapy and continuously improving for ten to fifteen years



What should I expect?

The Clinical Oncologist will see you in the oncology clinic. The radiotherapy treatment will be explained to you and side effects outlined (see page 18). You will be

asked to sign a consent form in order to receive the treatment. Your treatment will be carefully planned by a Clinical Oncologist, who will be assisted by a physicist and radiographers (who operate the machines that give you your treatment). The actual radiation is delivered in

Radiotherapy

small daily doses (called fractions) over a period of five to six weeks (usually Monday to Friday only, with a rest at the weekend).

Because radiotherapy has to be very precise to treat exactly the right area of your body, it is essential your head and neck are kept as still as possible during treatment. Before your treatment begins, you will attend the clinic on two or three occasions to have a special mask or fixation device made, with generous holes for your eyes, nose and mouth to allow you unrestricted breathing. You will need to have scans or X-rays taken whilst wearing the mask or fixation device so that the treatment can be planned and the accuracy of the planned treatment confirmed. Some centres show you pictures to explain this.

A linear accelerator, a machine which generates high voltage X-ray beams, is used to deliver the treatment. You will lie on a treatment couch for approximately 15 minutes each day for the positioning and delivery of the therapy. The therapy itself takes about two minutes.

Radiation beams are shone from the linear accelerator from multiple directions, usually entering the head at the hairline of each temple (above or in front of the ears) and the hairline of the forehead. They meet at the point within the pituitary gland where treatment is needed.

How is the fixation device or mask used?

There are a number of ways of ensuring that your head remains immobile during the treatment.

A clear plastic mask is often used. You visit the mould room where a cast of your head is

made. Once this is done, and after you have left, clear plastic is moulded into the cast to form the mask, which fits your head and neck snugly. You attend again to have the mask fitted and then to have the scans and X-rays needed to plan the radiotherapy.

During treatment, the mask is placed over your face and then attached to the treatment couch. You need the fixation device to immobilise your head during treatment, enabling very accurate treatment. This enables the dose of radiation to be concentrated in the exact area, reducing the risk of damaging the tissues the radiation passes through on its way to the pituitary gland.

More recently, some departments are using thermoplastic masks. This uses a special sheet of plastic with holes in it. Once warmed it becomes very flexible and can be pulled down over your face and fixed to the baseboard that you are lying on. Scans for planning the radiotherapy can be carried out on the same day using this system.

Finally, some departments use a stereotactic system. This involves having a special impression made of the upper teeth and back of head. These are attached to a ring, which fits on to the head and is pulled tight using velcro straps over the top of the head. The ring is then clipped to the treatment couch.

Whichever system is used, the staff in the mould room will explain it fully to you before you start. However, if you have questions or concerns, you should feel free to ask any member of the team before treatment. In general, with the mask system, it is best for men to shave off beards and moustaches to ensure the snuggest fit throughout treatment.

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Will I have any side effects?

Radiotherapy is painless and you will not feel anything. You will leave the treatment room having sensed nothing of the X-ray beam therapy. However, some patients find that they have an altered sense of taste and smell but these should return to normal within about two months. During the course of the treatment, patients do feel increasingly tired and may need to sleep longer at night or in the afternoon. This usually wears off after a month or two. Some patients feel queasy during the radiotherapy and occasionally patients are sick. Eating small meals frequently usually helps this. Your oncologist will give you medication to reduce nausea if necessary.

After three weeks of treatment, the skin at the point where the beam passes into and out of the head in the temples, the high forehead and the nape of the neck will become pink, perhaps sore and itchy. Hair at these places will start to fall out. But, in most cases, this will re-grow within three to six months. Your oncologist will give you medication to reduce soreness if necessary.

What is Stereotactic radiosurgery?

Some patients with pituitary tumours are offered treatment using stereotactic radiosurgery. This may be delivered in two different ways - gamma knife treatment or stereotactic radiosurgery using a linear accelerator. These use a machine that can deliver a single high dose radiation treatment with more precision than standard radiotherapy. The gamma knife uses multiple gamma rays focused on the tumour. Gamma rays are lower

energy X-rays than those used in conventional radiotherapy machines (linear accelerators). It is now possible to deliver stereotactic radiosurgery using special attachments to standard linear accelerators used for conventional radiotherapy. The effect of these two different ways of delivering stereotactic radiosurgery is identical.

The advantage of stereotactic radiosurgery is that this is a single treatment, which can be delivered with a high degree of accuracy (within 1mm of the desired target area) and a rapid fall-off in dose around the target area. The disadvantage is that because it is a single treatment, the potential for damaging normal tissues is much higher than for standard radiotherapy and so it is only used for selected cases where the tumour is small and some way distant from the brain and optic nerves, minimising the dose to these important structures. It is sometimes used when standard radiotherapy has been used previously and the tumour has recurred in a position where it can be safely treated by stereotactic radiosurgery. Stereotactic radiosurgery using linear accelerators or a gamma knife is only available in a limited number of specialist centres within the UK.

Are there any permanent side effects?

There are some side effects; however the majority are easily helped. It is important for you to weigh up the chances of the treatment helping you against the risk and seriousness of possible side effects.

- There is an increased chance of requiring pituitary hormone replacement therapy in the years following radiotherapy. About

Radiotherapy

half of patients who are not already taking hormone replacement tablets when the radiotherapy starts will eventually need to take them. This need can take five to 20 or more years to appear. Patients are usually given male or female hormones using a gel, injections, tablets, and steroid and thyroid hormones via tablets. Please see our booklet *The Pituitary Gland: Its Conditions and Hormones Explained*

- Patients with pituitary tumours have a slightly higher risk than the general population of having a stroke. This may be partly to do with radiotherapy and partly to do with the pituitary tumour and effect of raised pituitary hormones
- There are some very rare side effects. In less than one in 100 patients, the eyesight may become worse following radiotherapy. By 20 years following radiotherapy, two in 100 patients will have developed a further brain tumour. This is not the case for radiosurgery; there is no evidence for second tumours.

After-care

Your after care will continue to be monitored on a regular basis and this will be shared between your endocrinologist and GP. Because pituitary conditions are relatively rare, you might find that you will be the only patient with a pituitary condition that your GP is treating and they may find it helpful to have a copy of our *Pituitary Disease Fact File for General Practitioners*.

Radiotherapy questions

Q: *Will I be able to attend my local hospital for treatment?*

A: Linear accelerators, the machines needed to deliver a course of radiotherapy, are usually situated in large cancer centres. These machines are sophisticated and expensive and require specially trained staff. So you will probably have to travel to your nearest specialist cancer (oncology) centre.

Q: *Will I be able to drive myself to and from the hospital?*

A: This will depend a little on how tired you become. If at all possible, try and have someone with you who can share the driving or take over if you are very tired. If you have to travel to and from the hospital on public transport, talk to the hospital staff as they might be able to time your treatment each day to fit in with bus and train timetables. You should inform the DVLA of your diagnosis and the treatment you are receiving.

Q: *Will I be able to work? To look after my children?*

A: Radiotherapy affects different people in different ways. Many patients are able to continue working throughout their course of treatment while others do find they get very tired, especially towards the end of the course. If you do experience tiredness, listen to your body and allow yourself extra time to rest. Try and maintain a healthy diet and drink plenty of fluids.

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Q: *I'm claustrophobic - will I be able to cope?*

A: Tell the oncologist and radiotherapy staff of your concerns. It is quite normal to feel anxious about having your treatment but as you get to know the staff (who will probably be the same every day) and the procedure, it should become easier. Do try and relax and don't be afraid to express your fears to the staff as they are there to help you. Don't be afraid to ask questions if there is anything you do not understand. This is especially important when you start your treatment.

Q: *How long is it before the treatment is fully effective?*

A: The effects of radiotherapy are gradual and cumulative over a period of several years.

Radiotherapy - One patient's story

I had been warned of the possibility that I might need radiotherapy (RT) after my surgery, as my tumour was very large, but, even so, was somewhat dismayed when the need was confirmed. After a short wait I headed off to the local cancer centre to see what was in store. More unknowns!

The specialist was really interested in pituitary tumours and took great care in explaining what was going to happen, in particular all the preparation that would be needed. I was concerned about my eyesight but was reassured that the beams would not affect that area. Soon I was having my mask made. The technician was brilliant. He explained

exactly what was happening, and at the times when I needed to lie still and close my eyes kept talking to me. He put pink gunge over my face, allowing space for my eyes, nose and mouth and I had to lie very still while this set, making a mould of my face. I found it quite pleasant: as the gunge warmed up, I tried to imagine I was having a very expensive beauty treatment; but I'm sure many others would find it claustrophobic.

When the transparent plastic mask was made (did I really look like that?) I had several more visits for fittings. At these my post-surgery MRI scans were used to identify exactly where the beams needed to hit the mask which became marked with an assortment of lines and crosses until it was ready.

My five and a half weeks of treatment went very quickly. It took much longer to get everything set up than it did to receive the treatment. I hated the sound of the screws fixing me down - the metal screeching against the plastic! The radiographers were careful to explain everything and I had a chance to talk to the consultant at various times. I became quite sore above my ears and at the top of my forehead and some hair fell out - about the size of a 2p piece - where I was sore. It grew back quite quickly. I did get tired, perhaps the RT or perhaps the daily journey. For several years after I still needed to take medication to keep my growth hormone levels under control, but now I don't need it.

How will **surgery** &/or radiotherapy affect my life?



Prescriptions

If you will have to take hydrocortisone, thyroxine or desmopressin permanently you will get free prescriptions for all medicines. Ask at your GP's surgery, hospital or pharmacist for form FP92 (EC92A in Scotland).

The form (which will need to be signed by your doctor) tells you what to do. You will then receive an exemption certificate. These certificates only last for a finite period after which they must be renewed. Your health authority may automatically send out an application for renewal.

Information about free prescriptions and the full list of medical conditions which qualify for exemption from prescription charges can be found in leaflet HC11, available from pharmacies and main Post Offices or on www.dh.gov.uk.

If you are not sure whether you are entitled to free prescriptions, you must pay for your prescription and ask for a NHS receipt (form FP57 in England, EC57 in Scotland)

when you pay; you can't get one at a later date. This form tells you how to get your money back. You must claim within three months.

If you don't qualify for free prescriptions and need more than five prescription items in four months, or more than 14 in a year, ask your pharmacist about pre-payment certificates. This will be more economical way of paying for a large number of prescription items. NB: This information does not affect those living in Wales who do not have to pay prescription charges.

Driving

You have a legal obligation to advise the Driver and Vehicle Licensing Agency (DVLA) if there is any reason why you should not drive. Many patients with pituitary conditions will find there are no restrictions, but you should check with your GP. The only condition likely to affect patients is having a problem with your eyesight. Trans-sphenoidal surgery does not in itself limit your entitlement to drive and your doctor or specialist will give you full advice.

DVLA say that patients with a pituitary tumour should tick the 'brain tumour' box and put a note at the side of the form, stating 'pituitary tumour'. DVLA will accept any extra brief notes with the form (or at side of form) regarding the patient's condition, such as stating 'pituitary tumour' etc. and that DVLA should contact their specialist endocrinologist for further information if required.

You may also seek further advice from the DVLA by consulting the **For England, Scotland and Wales: The Medical Adviser,**

How will **surgery** &/or radiotherapy affect my life?

Drivers Medical Group, DVLA, Longview Road, Morriston, Swansea SA99 1TU.
Tel: 01792 782337 (medical professionals only) or **mailto:medadviser@dvla.gsi.gov.uk** (medical professionals only) **For Northern Ireland: Driver and Vehicle Licensing Northern Ireland, Castlerock Road, Coleraine, BT51 3TB. Tel: 028 4703 41369**

Alcohol & replacement hormones

There is no interaction between alcohol and these drugs, and you are allowed to drink in moderation. You should restrict yourself, such as the national guidelines - currently 2 units for women and 3 units for men per day.

Insurance & pensions

Each case will need to be assessed individually. As a guide, if a pituitary tumour has been completely removed, you will probably be accepted at normal rates. Of course, each insurance company will have its own practices. You need to persevere and be specific about your condition, as the people you speak to initially may not have any medical knowledge themselves. It is not unheard of, for instance, for diabetes insipidus to be confused with diabetes mellitus (sugar diabetes).

If you would like further information please call The Pituitary Foundation or see our website for up to date insurers contact details which other patients have used, with success, and have informed us about these companies.

Employment

If your pituitary condition is causing you difficulties in retaining, seeking, or returning to employment, contact the Helpline or your local Citizens Advice for the most up to date information about employment rights and where to get advice about benefits.

Please also contact the Foundation for our *Employment booklet*.

Loss of libido, infertility & relationships

You may suffer from a low sex drive, impotence or lack of self-esteem due to the imbalance of hormones and, in some cases, physical changes. This, in turn, may cause a strain on your relationship. There is also a possibility that you may have problems conceiving. It may help to talk to your partner about how you are both feeling and to consult your GP/endocrinologist.

The Pituitary Foundation has a Well-being series including focussing on quality-of-life issues during diagnosis and treatment and another booklet addressing concerns you may face along your pituitary journey. Please contact us to request a copy of these booklets.

Personal medical identification

If you are taking hormone replacement medication, it is a good idea to wear a medical information bracelet or equivalent as the information will help doctors if you have an accident and are unconscious.

There are various medical emblems available; our website includes contact details for several organisations.

Please support The Pituitary Foundation

Join the The Pituitary Foundation today and enjoy the benefits of membership!

- ✓ Receive our members' magazine, *Pituitary Life*, three times a year full of the latest information, updates and patient stories, to help you better understand, or manage your pituitary condition.
- ✓ Our monthly e-bulletin, which includes the latest pituitary news, information and ways to get involved.
- ✓ Become an important part of the only charity in the UK providing support to pituitary patients.
- ✓ Receive a welcome pack and a membership card and enjoy discounts to Pituitary Foundation events, such as our conferences.
- ✓ Give us a stronger voice to raise awareness, and understanding, of pituitary disorders.

Individual membership costs **£25.00** for a full year, which is only **£2.08** a month!

(Family, concessionary and life membership rates are also available). To become a member, please complete the form below and return to us with your payment (cheques made payable to **The Pituitary Foundation**) to:

The Pituitary Foundation,
86 Colston Street,
Bristol, BS1 5BB

If you would like to pay for your membership by standing order, please contact **0117 370 1333** or to join online visit **www.pituitary.org.uk**

I wish to become a Member of THE PITUITARY FOUNDATION			
Title:	First Name:	Surname:	
Home Address:			
Postcode:			
Telephone No:	Email:		
Please tick (✓) the type of Membership you require:			
Individual	<input type="checkbox"/> £25.00 (annual)	Joint	<input type="checkbox"/> £35.00 (annual)
Life Membership	<input type="checkbox"/> £350.00	Concessionary*	<input type="checkbox"/> £15.00 (annual)
Additional donation (optional) £			
*(Concessionary rate for people on a state pension, in receipt of state benefits, on low income, students, and under 18s only).			
<input type="checkbox"/> Yes! I want to Gift Aid any donations I have made in the past, present and future to The Pituitary Foundation. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. Please notify The Foundation if you want to cancel this declaration, change your name or full address, or no longer pay sufficient tax on your Income or Capital Gains.			
Signature:	Date:		

Helpline

Monday - Friday 10:00am-4:00pm
0117 370 1320

Endocrine Nurse Helpline

available scheduled hours
0117 370 1317

Website: www.pituitary.org.uk

Email: helpline@pituitary.org.uk

Text: 07786 202 249

More Information

The Pituitary Foundation publishes a library of booklets on pituitary conditions, treatments and well-being issues. For more information please visit our website, or call our Helpline.

The Pituitary Foundation

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www.pituitary.org.uk

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Disclaimer: All information is general. If you or your carer, have any concern about your treatment or any side effects please read the Patient Information booklet enclosed with your medication or consult your GP or endocrinologist



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The
Pituitary
FOUNDATION

Working to support pituitary patients, their carers & families