

# Surgery and Radiotherapy

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*As part of your treatment for your pituitary condition you may need to have surgery or radiotherapy. The booklet explains how surgery and radiotherapy works.*

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# Where is my pituitary gland and what does it do?

## What is the pituitary gland?

The pituitary gland is a small gland located just below the brain that secretes hormones. Hormones are chemicals that carry messages from one cell to another through the bloodstream. The pituitary gland controls several other hormone glands in the body, including the thyroid, adrenals, ovaries and testes. It also secretes several hormones which have direct effects on other tissues (growth hormone, prolactin, vasopressin and oxytocin). The pituitary gland is therefore often described as the master gland.

If the pituitary gland is not producing sufficient amounts of hormones this is called hypopituitarism. If hormones are being over-produced, this can cause specific problems related to hormone excess (known as hypersecretion).



# What is a pituitary tumour?

Pituitary tumours are also referred to 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 the gland, and slowly increase in number. More than 95% of all pituitary tumours are adenomas.

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. It will help you understand this booklet better if you know what sort of tumour you have. If you do not know, ask your endocrinologist or surgeon to explain the type of tumour that you have.

If you have already had an operation, you will have a very detailed diagnosis from the analysis of your surgical specimen. If you have not had an operation, your team will still be able to tell you what kind of pituitary tumour they think you have based on your scan and your hormone tests. Tumours of the pituitary gland might affect your vision or change your hormone levels.

You may see the terms 'macro' and 'micro' adenomas. Macroadenomas are defined as tumours over 1cm and microadenomas are those that are smaller than 1cm. If your tumour affects your vision, then it is called a macroadenoma. Tumours that secrete hormones are often discovered when they are smaller than 1cm because of the symptoms they produce.

Pituitary tumours can also stop the pituitary gland from producing its normal hormone secretion. This can cause symptoms of hormone deficiency (hypopituitarism). Pituitary tumours are therefore managed jointly by endocrine specialists and surgeons who specialise in pituitary tumours.

# Surgery



## Why might I need an operation?

*There are many reasons why you may need to undergo surgery. This may be because your pituitary tumour is affecting your vision or may grow to impact your vision, or because you have too much of a certain type of hormone (hormone excess or hypersecretion). Surgery also has the advantage of giving you and your team a more accurate diagnosis and can therefore guide your further management.*

### Vision

If your pituitary tumour has grown upwards, it may be pressing on the nerves that allow you to see properly which lie just above the pituitary gland. These are called the optic nerves and where they join is called the optic chiasm. If these structures are compressed by the tumour it can affect your eyesight in a variety of ways:

- It may affect your peripheral vision (to the sides) and makes it seem as if you are looking down a tunnel. This may be more noticeable in one eye than the other. This is known as a bitemporal hemianopia and is measured with a visual field test.
- It can reduce your ability to see clearly. This is called reduction in visual acuity.
- Sometimes tumours can cause double vision, but very rarely. It is important to let your team know if you have any double vision as this can mean there has been a bleed into the tumour, and this is an emergency. A bleed into the pituitary gland is called pituitary apoplexy and you can find out more at: [www.pituitary.org.uk/pituitary-apoplexy](http://www.pituitary.org.uk/pituitary-apoplexy)

Your vision will be assessed by an expert (an ophthalmologist). They will assess the clarity of your vision and your peripheral vision and they may also do a scan of your retina called an OCT. Sometimes this can detect early damage to the eye nerves before you have noticed any problems with your vision.

### **Hormone disturbances**

Many pituitary adenomas are discovered because they cause the over-production of a particular hormone (hormone excess or hypersecretion) or because the normal pituitary gland has stopped working (hypopituitarism).

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

- **Prolactinomas:** Prolactin-secreting tumours, which produce the hormone prolactin.
- **Corticotroph adenomas:** These tumours produce the hormone ACTH (adrenocorticotrophic hormone) which in turn stimulates the release of cortisol (the body's natural glucocorticoid steroid hormone). This causes a condition called Cushing's disease.
- **Somatotroph adenomas:** These are growth hormone-secreting adenomas. The excess secretion of growth hormone causes a condition called acromegaly.

If a tumour does not produce any hormones it is called a non-functioning pituitary adenoma.

If you have Cushing's disease or acromegaly you are likely to be offered surgery to try and make your hormone levels normal. If you have a prolactinoma you are likely to be offered a medication to try and shrink the tumour first but you may wish to have a conversation about surgery too if you are getting side effects from the medication, or in the rare cases where the medication does not work.

We have more information about these conditions on our website, or in our booklet library.



### *Other reasons for surgery*

A pituitary tumour may be discovered by chance when you have a scan for a different condition. If your tumour has been discovered this way and you have no symptoms, it is called an incidental finding. This is likely to lead to you having your hormones and your vision checked (endocrine and ophthalmology reviews). You may be advised to have surgery if you are found to have excess hormones or there is a threat to your vision.

If you do not require surgery for these reasons it is common to monitor the tumour with annual eye checks and MRI scans every year. You may then require surgery if the tumour is growing or has reached a certain size and there is deemed to be a threat to your vision. Sometimes the diagnosis of a pituitary adenoma cannot be made confidently on an MRI scan and it may be necessary to have an operation to confirm the diagnosis.

## **What is the aim of surgery?**

The aim of surgery is to remove as much of the tumour as can be safely removed, without damage to the delicate nerves and blood vessels in the area. The aim of surgery depends on the type of tumour you have i.e. if you have a hormone-secreting tumour (a 'functioning' adenoma) the surgeon will try and remove all of it to cure you or at least give you long-term remission from your disease.

If the tumour is compressing your eye nerves but not functioning, the aim of surgery is to prevent further deterioration in vision and if possible, to regain lost vision. The extent of recovery of vision will depend on how bad the vision is prior to the operation. Although some people report an immediate improvement in their vision on the day of surgery, improvement can continue over the 3-6 months after surgery.

Although all the tumour will be removed where safely possible, it is not necessary (and in some cases not possible) to remove the entire tumour, so some may be left behind. This is called residual tumour. If there is residual tumour further treatment, such as radiotherapy or drug therapy, may be required. The decision to recommend surgery should be made in the context of a pituitary multidisciplinary team.

## **What sort of surgery is undertaken?**

It is important that the surgical team and team looking after you post-surgery are experienced in pituitary surgery.

Most operations on the pituitary gland are 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. Trans-sphenoidal surgery was traditionally performed using an operating microscope. However, technological advances have led to the use of fibre optic endoscopes in pituitary surgery. This newer technique is called endoscopic pituitary surgery and has now been widely adopted.

Operations through the skull (craniotomy) are far less common these days than they used to be.

The length of time of the operation can vary. The anaesthetic will take 20 to 40 minutes, depending on a number of different factors. Endoscopic pituitary surgery usually takes one to three hours and a craniotomy usually takes two to four hours. These are guidelines only and everyone is different, in some cases the surgery may take longer.

You will normally remain in hospital for around 2-3 days, depending on the type of surgery you had. For a craniotomy, this can be around 3-7 days. Any complications can lead to a longer stay.

### **Endoscopic trans-sphenoidal surgery**

This operation is carried out under general anaesthetic. There are no incisions on the outside i.e. on the face. An endoscope (a small fibre-optic tube) and some instruments i.e. a small suction tube and some surgical tools are inserted through one or both of the nostrils. These instruments are specifically designed to be used with the endoscope via the nasal route. Some bone and soft tissue are removed from the back of the nose to join the two nasal passages and allow the surgeons to remove the tumour.

This does not need a formal repair necessarily and therefore some surgeons allow this to heal naturally. 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 (called fascia lata), sometimes with a bit of muscle as well. Your surgeon should tell you if they use this sort of repair.

## Craniotomy

A craniotomy may be required if parts of the tumour are more safely or effectively reached this way. This is performed through an opening in the skull, and as with a transnasal operation, you will be put under a general anaesthetic.

Increasingly, this operation is performed through a small incision within the eyebrow which usually heals with a good cosmetic result. A larger skin incision may be required either just behind the hairline at the area of the temple or across the top of the head. 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 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 can sometimes be under the skin of the forehead to collect blood and reduce swelling 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. Many neurosurgeons use metal clips rather than stitches as these heal with a very neat scar and are quick to put in and easy to take out. Stitches if used may need to be removed or may dissolve. Clips or stitches that are not absorbable (dissolvable) are removed between seven and ten days following the operation.

## Preparations for pituitary surgery

Before the surgery, you need to pack a bag to bring to the hospital. Your hospital should tell you what to bring. Here are some of our suggestions:

- Multiple pairs of pajamas and comfy clothes
- Zipped jumpers or cardigans as it may be tricky to put tops over your head
- A dressing gown
- Slippers
- Toiletries
- Something to do, such as a book or gaming device
- Don't take jewellery as it may get lost

Before the operation you will need to be 'nil by mouth' which means you can't drink or eat. Your hospital should give you guidance on that, and you should let them know at your pre-op appointment if you are on any medication.

Prior to surgery you will go through the 'pre-assessment' process which involves checking you are fit for surgery and gives you information on how to prepare on for your operation. Usually you will be admitted to hospital on the morning of the operation.

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: [rcoa.ac.uk/patients](http://rcoa.ac.uk/patients).

If you have medical problems like high blood pressure, diabetes, or you are overweight you may be advised to work with your GP to improve these conditions in order to make sure the risks of surgery are kept to a minimum.



## What complications may occur?

Like all operations, there are some risks associated with surgery for pituitary tumours. Your surgeon will explain to you the particular risks relevant to your case and how they will try and keep them to a minimum.

You will be asked if you find these risks are acceptable and you can balance this against the risks from your tumour e.g. losing your vision or ongoing acromegaly or Cushing's disease. Usually you will have time to make this decision and discussing this with friends and family can be useful.

Risks include temporary or permanent loss of sense of smell, although this is very rare. There are also risks of general anesthetic including clots in the veins of the legs or the lungs.

## CSF Leak

There is a thin layer separating the brain from the pituitary gland, and sometimes this can be breached by the tumour or during surgery. This causes a leak of cerebrospinal fluid (CSF) from the nose.

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. Sometimes, however, the fluid is simply watery mucous, which is completely safe.

Each hospital has its own way of managing this problem. A small fine tube (a spinal drain) may be placed in your back for a few days to control the leak. In some cases it is preferable to perform a second operation.

## Meningitis

If the CSF continues to leak, bacteria can creep up via the route that the CSF is escaping from. This can 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

Although in all operations there is some bleeding, bleeding during a pituitary operation can cause a serious problem such as a stroke, blindness or a risk to your life. This is very rare but is serious.

Heavy nose bleeding can occur after surgery. This is rare, but if this does happen you should contact your neurosurgery team or seek urgent medical attention if the bleeding does not stop.

## Vision

Occasionally there is a deterioration in vision following surgery. This risk is higher when the vision is very poor prior to surgery as the nerves have already been damaged. Sometimes the deterioration can be due to some bleeding in the surgical area or overpacking of the site. If this is the case it may be advisable to do a second operation to remove the blood or packing. This is rare.

## Hormone problems

Your tumour may have already damaged the pituitary gland and caused hormone deficiencies. However, surgery can also affect any remaining normal pituitary gland and lead to further hormone deficiencies. Pituitary hormones can be replaced by medication. Taking these medications may be a temporary or a life-long requirement.

You should receive hydrocortisone around the time of surgery and then a complete assessment of the pituitary function will be made a few weeks after surgery once everything has settled down. The timing of this testing is dependent on the diagnosis and outcome of the surgery.

The most common hormone problem during the first few days after surgery is called AVP Deficiency (previously diabetes insipidus). If this happens you will pass large volumes of very dilute urine and feel very thirsty. The pituitary gland controls your ability to concentrate your urine.

This condition, apart from being inconvenient, can be dangerous so the amount of urine you produce will be closely monitored in those first few days and regular blood tests are usually required. If this occurs you may need an injection or tablets of DDAVP (desmopressin).

This mimics the natural anti-diuretic hormone to help control the excess urine. It may be necessary to continue this for a few weeks or even months. Occasionally, AVP Deficiency can be permanent. We have more information on this condition on our website: [www.pituitary.org.uk](http://www.pituitary.org.uk). The most common reason for feeling thirsty is because you are breathing through your mouth.

Some people can develop problems with low sodium (called SIADH) 1-2 weeks after surgery. This occurs when the pituitary releases its stores of the hormone AVP. This causes water retention and low sodium. Symptoms include headaches, nausea, vomiting, drowsiness, confusion and feeling generally unwell.

If you experience these symptoms you should contact your neurosurgery team or endocrine team as soon as possible, or if very unwell attend accident and emergency. The treatment for SIADH is usually restriction of how much fluid you drink and consume in your food. This will be managed by your neurosurgery or endocrine team. Some people may need to be admitted to hospital if their sodium is very low.

### **Repeat surgery**

In cases of hormone producing tumours, sometimes the surgeon will offer a second operation if the hormone condition has not been corrected. You should always discuss this with your endocrinologist. In case of non-functioning pituitary adenomas, further surgery may be required if the tumour grows back.

### **Seizures (craniotomy only)**

Epileptic fits (seizures) can occur in people who have had craniotomy, although this is uncommon. Seizures can be treated by anti-epileptic medications. If you undergo a craniotomy, you should not drive for 6 months after surgery, and should inform DVLA about the operation.

# What happens after the operation?

## Immediate

When you wake up from the operation, you are likely to have nasal congestion, perhaps a headache. 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 much more comfortable and you should be on your feet the following day.

Sometimes some nasal packing is left in the nostrils after surgery which either dissolves by itself or needs removing 1-2 days after surgery. The decision to leave packing is usually made during the operation. You may experience some discomfort whilst the packs are in and removal can be uncomfortable for some, but it is a short procedure. You will be provided with a salt water nasal spray, which will help to clear the nasal passages and prevent excessive crusting in your nose.

## The next few days

If you have excess production of a hormone, you may notice an immediate difference in symptoms but sometimes it will take longer.

If your vision was affected before the operation, you may notice your vision improving while you are still in the hospital. Most units will check your vision at the bedside before you are discharged to make sure that the operation has had its desired effect. Even if your vision does not improve, the operation may be considered successful if it prevents further deterioration.

You may have some stitches or clips in your abdomen or your thigh if a fat or fascia has been used for the repair. These stitches are usually soluble. The wound will be completely healed in two to three weeks.

## Going home

Following trans-sphenoidal surgery, you would usually stay in hospital for 1-3 days. Recovery is generally quite straightforward and depending on the individual, you can return to your normal levels of activity over a 6-12-week period. Some people may require longer, especially if there are problems with AVP Deficiency (diabetes insipidus) or CSF leak. If the operation has to be performed through a craniotomy, the hospital stay is usually 7-10 days, but through an eyebrow incision is usually 2-3 days.

You need someone to collect you once you have been discharged, although some people may be eligible for non-emergency patient transport services.

If you are given any medication to take home, you will usually be given enough for the next seven days. You will also be given a letter to give to your GP, which includes information about your medication. A copy should be sent to your GP surgery. 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.

You may require a few weeks away from work. We advise that you listen to what your body is telling you and don't try to do too much, too soon. Recovery following craniotomy is slower and you may need to stay off work for approximately 2 months. You can ask the nurse in charge of your ward for a fit note, if your employer requires one.

Once you are home, you may feel a bit anxious. This is normal and you'll gain confidence each day. Rest when you can, even if 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

If you have had surgery for a large tumour or for Cushing's then you will be given the drug hydrocortisone which will replace the hormone cortisol. In some hospitals everyone who has had pituitary surgery is given this medication. This is because you may have a condition called adrenal insufficiency.

This replacement is often given as a precaution. The pituitary gland stimulates the adrenal glands to make the stress hormone cortisol. At first, hormone replacement will be administered in higher doses than needed and then reduced to normal levels. You may be tested in the hospital and taken off hormone replacement before going home.

If you are sent home with hydrocortisone or prednisolone, you should ensure that you can continue the prescription until you are reviewed again by an endocrinologist. You should also carry a steroid emergency card. It is crucial to educate yourself about emergency cortisol replacement in case of a serious injury or infection (such as flu), this is called the sick day rules. We have more information available for those who have to take hydrocortisone or prednisolone long term ([www.pituitary.org.uk/adrenal-insufficiency](http://www.pituitary.org.uk/adrenal-insufficiency)).



*I remember, being wheeled into theatre after changing into the hospital gown sobbing and crying my eyes out. I took in the gas and air, and I was knocked out and did not remember a thing. I was told the surgery took about 3-4 hours. When I had regained some sort of consciousness after the surgery, I had woken up and, there was a crowd of people around me and a nurse called my name and said: 'Serena, your surgery was very successful.' I am so thankful.*

Serena, who had surgery for a prolactinoma.

## Aftercare

You will be referred back to the endocrinologist after your surgery. 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 at the same time. Others prefer individual follow-up, in which case you may need to go to more than one clinic with different medical professionals.

It is usually possible to get your condition stabilised and, possibly with the help of additional medication and radiotherapy, to balance your hormones. 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.

# Radiotherapy

***Radiotherapy is sometimes used as part of the overall treatment for pituitary tumours.***

The aim of radiotherapy treatment 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. Radiotherapy can also be used to reduce excess hormone levels if you have a functioning pituitary tumour.

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. If part of the tumour remains then this can cause it to grow again.

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 or even years after the operation.

## What is radiotherapy?

Radiotherapy may be given as a single treatment in some cases in which case it is called radiosurgery. In other cases, it is “fractionated” meaning you have a number of treatments over several weeks.

Radiotherapy uses X-rays to treat disease and it works by damaging the DNA in the cells that it passes through. Cells can live for some time with damaged DNA. But eventually the damage is either repaired and the cells survive or if the damage is too great, the cell dies. This cell death happens sometime after the radiation is delivered, often after the cell has divided a few times, many weeks, months or years after the treatment.

Normal cells are better able to repair radiation damage than tumour cells. By delivering the radiotherapy using repeated small dose treatments, the chance of permanent damage to your own normal body cells is reduced by giving time for the repair in healthy cells to take place. 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 often delivered using high-energy X-ray machines, called linear accelerators (Linacs). They focus an X-ray beam onto the pituitary tumour and surrounding area, from several different angles, allowing the radiation to focus onto the target.

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. 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).

In addition to Linac radiotherapy, there are alternative radiotherapy machines including radiosurgery with Linac based systems or Gamma Knife and Proton Beam Therapy which is another fractionated treatment that is useful for some young people. These can have technical advantages under certain circumstances and your Clinical Oncologist can talk with you about these and whether they may be appropriate in your individual case.

## Will I need radiotherapy?

Following surgery, you will undergo further scanning (MRI or CT) and blood tests. Your case will then be reviewed and discussed by the multi-disciplinary team (including an endocrinologist, neurosurgeon and radiotherapist).

In general, radiotherapy is recommended if:

- the tumour is high risk
- the tumour is secreting a hormone even after surgery despite treatment with drugs
- the pituitary tumour re-grows (this could be some time after surgery, perhaps following a second operation)

If there is a small amount of tumour remaining after surgery, this will often be kept under surveillance with scans, blood tests and visual field checks prior to a decision to go ahead with radiotherapy. Your team will explain their recommendation to you based on your own circumstances.



*The surgeons entered the brain through the nose and removed as much of the tumour as they could, however I had a bleed during surgery and they had to stop with some tumour remaining. At first my surgeon was not too concerned but when the biopsy results returned it showed I had acromegaly. 12 months later I return to the Walton Centre for another MRI and they have now decided I will face Radiotherapy as the residual tumour has grown back.*

**Amy**, who was diagnosed who had surgery to remove a pituitary tumour, and will now undergo radiotherapy.



## How effective is radiotherapy?

When we look back on the outcomes for people treated 20 years ago, radiotherapy is very effective.

- Re-growth of the tumour is prevented in nine out of ten people (for similar types of patients who were not given radiotherapy following surgery, the tumour re-grew in over half of all cases)
- Half of people whose eyesight has been affected by the tumour notice an improvement following surgery and radiotherapy
- For those who are receiving radiotherapy in order to reduce hormone secretion, it can take longer for the full effect to become noticeable. About half of people will have normal hormone levels two years after treatment, with more showing improvement at five years plus.

## What should I expect?

A clinical oncologist will see you in the oncology clinic. This may not be available in your local hospital as this is specialist treatment. The radiotherapy treatment will be explained to you and side effects outlined.

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

Radiotherapy affects different people in different ways. You may find that you are able to continue working, or you may get very tired. 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.

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 radiotherapy department 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.

Tell the oncologist and radiotherapy staff if you are concerned about feeling claustrophobic in the mask. 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.

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 the ears) and the hairline of the forehead. They meet at the point within the pituitary gland where treatment is needed.

## **Will I have any side effects?**

Radiotherapy is painless and you will not feel anything as the treatment is being delivered, just like with a routine scan or X-ray. You will leave the treatment room having sensed nothing of the X-ray beam therapy. However, some people have an altered sense of taste and smell. This should return to normal within about two months.

During the course of the treatment, you may feel increasingly tired and need to sleep longer at night or in the afternoon. This usually wears off after a month or two. Some people feel sick during the radiotherapy and occasionally people are sick. Eating small meals frequently usually helps this. Your oncologist will give you medication to reduce nausea if necessary.

After about three weeks of treatment, the skin where the beam passes in and out of the head can start to feel a little sore and itchy and you may notice some patchy hair loss.

## **What is stereotactic radiosurgery?**

You may be offered treatment using stereotactic radiosurgery. This may be delivered in two different ways - Gamma Knife treatment or stereotactic radiosurgery using a linear accelerator (including a Cyberknife machine). These use a machine that can deliver a single or a small number of high dose radiation treatments with more precision than standard radiotherapy. The gamma knife uses multiple gamma rays focused on the tumour.

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). The disadvantage is that because it is a single treatment, the potential for damaging normal tissues is much higher than for standard radiotherapy.

It is only used for selected cases where the tumour is small and far away from the brain and optic nerves to minimise 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 hospitals within the UK.



## What is proton beam therapy?

There are two proton beam therapy centres in the UK, one in Manchester and one in London. These deliver a different type of radiotherapy treatment that causes fewer late side effects from treatment, particularly to the young and developing brain. For that reason, it is the recommended way to deliver fractionated radiotherapy to pituitary tumours in children, teenagers and young adults.

If you are eligible for NHS proton beam therapy treatment, your Clinical Oncologist will discuss this with you. Proton beam therapy can be considered in other patients occasionally too and you can discuss this with your oncologist. In most older adults there will not be any significant advantage.

## 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.
- There is a slightly higher risk for those with pituitary tumours having a stroke. This may be to do with radiotherapy and/or with the pituitary tumour and effect of raised pituitary hormones.
- Radiotherapy can have a subtle effect on memory and brain function over time.
- There are some very rare side effects. In less than one in 100 people, the eyesight may become worse following radiotherapy.
- Even more rarely, radiotherapy can trigger the growth of a different type of tumour in or near the treated area.

## Aftercare

Your aftercare will continue to be monitored on a regular basis and this will be shared between your endocrinologist and GP.

## Notes



# More information

We have a full range of booklets to support people with their pituitary conditions, as well as information across our website. You can find this at [www.pituitary.org.uk](http://www.pituitary.org.uk).

*If you would like more support then we have a range of services that may be suitable:*

## Endocrine Nurse Helpline

Our specialist endocrine nurses can provide medical guidance.



## Information and Support Helpline

Our volunteer and staff run helpline allows you to speak to others with pituitary conditions, and ask practical questions about living with a pituitary condition.



## Telephone Buddy

This service provides one to one support with someone with a similar pituitary journey as you. For example someone with the same condition, or a parent of someone with a condition.



## Support Groups

We have a number of volunteer-led support groups across the UK, which host meetings with endocrinologists and peer support for patients.



## Events

We host online and in-person events with endocrinologists on specific conditions/topics. These give people the opportunity to hear from professionals and ask questions.



# About The Pituitary Foundation

We're a dedicated team offering practical, emotional and peer support to everyone living with or impacted by a pituitary condition, to feel empowered and live with a greater sense of wellbeing.

For over 30 years, we've been amplifying voices and striving towards positive developments for the pituitary community. We work alongside healthcare professionals, clinical research teams and specialist organisations to raise the profile of pituitary conditions, finding better solutions for everyone affected by these life changing illnesses now and in the future.

## Become a member and support our work

Becoming a member is an excellent way to show your commitment to our work at The Pituitary Foundation.

As members you'll enjoy a range of benefits including free copies of Pituitary Life magazine – full of great articles from endocrinologists and inspiring stories from people living with pituitary conditions. You'll also be able to have a say on how the charity is run, and get early access to our fantastic events.

**A yearly donation of £25 allows us to continue our work now and in the future.**

You can become a member at: [www.pituitary.org.uk/membership](http://www.pituitary.org.uk/membership)

All information in this guide is general. If you 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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