



## Post Pituitary Surgery Fact Sheet

This information has been provided for patients who have recently had pituitary surgery and to inform patients of what they could expect post-operatively.

Please refer to our ***Pituitary Surgery & Radiotherapy*** and ***Pituitary Gland*** booklets where you can read a full explanation of the pituitary gland, its hormones and their function.

The reason you have been referred for pituitary surgery is due to findings of an abnormality in or near to the pituitary gland; these can be called growths/tumours or adenomas. Please remember that the vast majority (over 99%), are benign, non-cancerous tumours. An explanation of your individual condition should have been explained to you by your endocrinologist and/or neurosurgeon.

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

Most operations on the pituitary gland are performed through your nasal cavity (nostril); this is called trans-sphenoidal surgery. 'Trans' means across and 'sphenoid' is the air cavity leading to the pituitary gland. Trans-sphenoidal surgery is traditionally performed using an operating microscope. More recently, technological advances have led to the use of rigid endoscopes in pituitary surgery. This is a newer technique and is called endoscopic pituitary surgery. Often Neurosurgeons and ENT (Ear Nose and Throat) surgeons work together for this type of 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.

Every individual responds differently, but it is important to remember that just because you do not have a visible scar, you have still had major surgery and a general anaesthetic.

### **How will I feel after my pituitary surgery?**

This is one of the many questions asked frequently by pituitary patients, who are about to have their operation, as well as "How long will it be before I'm feeling OK, up and about, and ready to take up the daily threads of living"?

This fact sheet will explain in sections the important post-operative stages:

1. Immediately after your operation
2. On discharge
3. Two – six weeks, post operatively

Like most surgical procedures involving a general anaesthetic, this can have an overall effect on your body; of course, this is different for each individual. The body takes some time to recuperate and repair and it is easy to expect this to happen more quickly than it actually happens in reality. How well you are prior to surgery can also affect your post-operative recovery.

Replacement hormone therapies may have been initiated prior to surgery and are still given as routine in some units and you may be feeling an overall improvement in your health. Others may still be waiting to see if their hormones will recover naturally following surgery. It is not always appropriate to replace hormones prior to surgery.

One statement to remember and which hopefully is reassuring for the pituitary patient facing surgery, is that if one or more hormone production is lost, then we can replace these hormones artificially in tablet or injection form.

Another frequent question is "How long will I stay in hospital following surgery"? Generally, it is a minimum of between two to five days, although this can vary from both individual to individual and surgical units

### **Immediately after the operation**

When you wake up from the operation, you will initially be in the recovery area of theatre and once your overall condition is stable, and you are relatively awake and responsive, you will be transferred to your neurosurgical ward or high dependency unit. (This depends on your hospital setting). It is very unlikely you will need to go to intensive care.

Please remember, these wards and units have a variety of surgical patients - not only pituitary patients, so try not to be too alarmed by all the different sounds and discussions that you may hear.

You will probably need to breathe through your mouth; this can be quite frightening initially but you will soon relax and find that you will manage this well. You will probably have a sore, painful nose. It can depend on how the operation goes, as to whether any packing in your nose is necessary. The length of time this remains in place depends on the individual's surgery and is dictated by the surgeon, but in general, this will be removed within the first couple of days. This can be uncomfortable, but is performed quickly and you can have painkillers if required.

Initially, you will have your vital signs monitored frequently i.e. blood pressure, pulse and temperature. You will be attached to a cardiac monitor and have an intravenous infusion of clear fluids and oxygen therapy. Initially, you will be questioned frequently to ensure you are alert mentally. These are all standard procedures and observations following surgery and a general anaesthetic.

### **Important: Post-operative observations following pituitary surgery**

You may have had a urinary catheter inserted into your bladder whilst under anaesthetic; this is to monitor fluid balance (intake and output), which is extremely important following pituitary surgery. We are anxious to know that we have not upset the mechanism that helps to control the volume of urine you make. To do this we will be measuring the amount of urine you make

and what strength it is. Once the catheter has been removed (usually a day or two post-op), your urinary output will be continually monitored and to do this you will have to use urinals/bedpans. Also, we measure your fluid intake. Sometimes pituitary surgery affects your ability to retain water; this condition is called diabetes insipidus (please see our booklet called ***Diabetes Insipidus***). If this occurs, it usually settles down after a few days. However, it may last longer and need hormone medication treatment.

Following the operation, most patients experience headaches or discomfort after surgery for a few days. You will be prescribed pain relief, so please ensure you inform the nursing staff if you have pain or discomfort. Your nose may feel blocked and you may experience some discharge of mucous, blood clots and crusting; this is to be expected (*read more about this later on page 5*).

It is important to report if there is any leakage of clear fluid from your nose or you are frequently swallowing liquid from the back of your throat, which may have a salty taste. This is known as a CSF leak and can be a complication following pituitary surgery. Sometimes it is necessary to use packing in the area where they have removed the growth and this can be done using a special surgical sponge or they may take a piece of fat (fat graft) from your thigh or abdomen. If this is the case you will have a small wound. This heals well and you should not experience any complications from it. Ask for pain relief if this area is tender/sore. You may be prescribed prophylactic antibiotics to prevent any infection and you will be monitored for signs and symptoms of meningitis.

You should be up and out of bed sitting in a chair and possibly walking to the toilet/shower etc. on your first post-op day.

Each day following surgery, brings an improvement in how you feel. Most people feel fine but some people feel extremely tired, wiped out and scared of what may lie ahead of them; others feel instant relief, especially if there has been improvement of previous headache or loss of vision.

If there was previous visual impairment prior to surgery it is important to remember that although the majority improve, this may not be significant initially but can improve over time. Your surgeon will almost certainly check your vision as soon as you wake up, but if you feel your vision is worse, which is fortunately very rare, you should let your doctors know, as this should lead to an early repeat scan

There will be numerous blood tests taken on the days you are in hospital and this is to assess your hormone production and to ascertain whether you need treatment with medication prior to discharge.

If you are given steroid replacement therapy you should be instructed on how to take these tablets, and importantly, what to do in the event of illness/stress situations.

**NB: If you are sent home taking hydrocortisone it is very important that you continue to take it. Your GP will continue to prescribe this until you are seen in clinic for your first post-op assessment**

**Do not run out of this medication and do not stop taking it without instruction from your endocrinologist**

For more information about hydrocortisone treatment and 'sick day rules' (what to do if you are ill), please see our leaflet ***Hydrocortisone Advice for Patients***

On your discharge home, it is understandable that you will feel anxious and concerned that all will be well and what to expect in regards to your recovery, but you will feel more confident as the days pass.

### **Please seek medical advice if you notice:**

- Leakage of clear fluid from your nose or are frequently swallowing liquid from the back of your throat, which may have a salty taste
- Excessive bleeding from your nose that does not stop spontaneously as this symptom could indicate an impending emergency
- Onset of a headache with a temperature and neck stiffness. Severe pain or change in your headache
- Difficulty with vision or deterioration in your vision
- You are passing large amounts of urine with excessive thirst and/or you start to feel generally unwell and excessively tired, a week or two after your surgery. This may be due to a disturbance of the body's salt and water levels

You are advised to go to your GP to have a blood test within five to seven days of discharge. This is to check salt and other electrolyte levels in the blood.

It is advisable that you do not arrange a holiday until after you have discussed this with your doctors

### **General advice on what to expect when you are discharged home**

You must avoid blowing your nose for two weeks after surgery. This is to avoid putting pressure directly on the healing operation site. Avoid sneezing if possible, but if in the event you have to sneeze, try and do this through your open mouth with your nose uncovered.

It is normal for your nose to feel stuffy and blocked; this can take some weeks to improve.

***NB: Please contact your neuro surgeon, about the following information and product use, to ask if it applies in your individual case:***

Nasal crusting can be minimised by the regular use of nasal douches (rinsing) to wash out the nose four times daily. Start douching one week after surgery (***or as advised by your medical staff***) and continue for at least six weeks. You may then reduce the frequency of douches to twice daily, but it is advisable to continue doing this for three months. Nasal douches are effectively delivered using the NeilMed Sinus Rinse system, which can be purchased from your local chemist. (Please ask your GP as you may be entitled to have these on prescription). If dryness and crustiness persists, despite nasal douches, then use NeilMed NasoGel for dry noses, which can be used to soothe and rehydrate the nasal passages.

Your sense of smell, and thus taste, may be altered but hopefully over time this will improve. However, for a few patients this doesn't return to what it was before. Curiously, this is more likely with endoscopic procedures.

Avoid heavy lifting, heavy housework, and bending or straining on the toilet. If you are constipated please ask your GP to prescribe laxatives. It is generally recommend that you avoid swimming with the head below the water for three months, due to risk of infection. Although this is generally sensible, it is extremely unlikely that swimming will cause you any danger.

If you are having difficulty sleeping, try sitting up in a chair/recliner or use several pillows to raise your head and shoulders. We recommend you space out your activities at first and give yourself plenty of rest periods. You may increase your activities as you are able to tolerate them and as your endurance increases.

**Returning to work:** can really depend on your type of job, but we would strongly recommend that you take at least two to six weeks off. Although you may be able to work at home, this should be discussed with your surgeon.

**Driving:** this depends very much on whether you have had any visual disturbance. If your vision has been impaired, you are duty bound to advise the DVLA of this fact and post-surgery you will need to be re assessed formally by the eye department prior to resuming driving.

**Travel/flying:** Avoid long distance travel in the initial weeks post operatively and we advise you not to fly for six weeks. If this is unavoidable then please discuss with your surgeon.

### **Review/follow up**

You should have been given contact numbers for your neurosurgical / ENT / and endocrinology departments. If not, please do ASK! Find out if your hospital has an Endocrine Specialist Nurse (if you have not already met her/him) and ensure you have their contact details.

The Pituitary Foundation's Specialist Endocrine Nurse can be contacted on 0845 450 0377, Mondays 10:00am to 1:00pm and 6:00pm to 9:00pm, plus Thursdays 9:00am to 1:00pm

Review and follow-up plans may vary at your individual hospital, but remember, **you should always be reviewed following pituitary surgery.**

### **One month post-operatively**

ENT may request an appointment for you within the first month to check your nasal passages. This is done using a special "scope and camera" that may be 'flexible' or 'rigid' which is inserted into your nostril. This enables them to view this area on a screen. This may feel uncomfortable, but is generally well tolerated and is usually a quick process.

### **Six to eight weeks post-operatively**

A review with your endocrinologist should be carried out to assess your pituitary function and the ability of hormone production. If you have not heard by six weeks post-op about your appointment, PLEASE contact the unit and ensure you are on the waiting list. Neurosurgical review is usually within the first couple of months.

A follow up MRI or CT scan will be booked following surgery, although the exact timing varies between units. Some neurosurgeons request an early MRI following surgery whilst others wait at least three months post operatively. This allows for swelling and inflammation from the surgery to subside. If you have had a hormone condition completely resolved following surgery, there is no need to check with a scan at all, although it will probably still be requested as part of a routine.

Further and subsequent follow up will be decided on an individual basis and also dependant on the medication you require (if any).

Following diagnosis with a pituitary tumour you should always be kept under some sort of specialist review, usually by an endocrinologist/endocrine department, especially if you are on

replacement hormone medication. This is because these extremely benign tumours can, on some occasions, very slowly return over a decade or two.

### ***A Patient's Perspective/Experience***

“The thought of your forthcoming ‘brain surgery’ might make you feel anxious, or quite terrified. It is quite normal to feel like this but, in reassurance, many other patients who’ve had their surgery do say that it was not nearly as frightening as they had imagined it to be. A patient suggests that she found it helped, to overcome her stress and worrying, to simply ‘go with it’ and let the experts take control and care for you.

Immediately post-operatively, there can be other fears, such as what did they find? Will my surgery be obvious to others – physically; will my brain function as it did before? These are normal thoughts and fears and with correct information from the various medical experts, prior to surgery, hopefully your fears may be allayed.

Your surgeon should be able to confirm how your operation went, and how successful it was. This information is reassuring. Some people cannot wait to be discharged home and for others this stage might make you feel anxious, as you’ll wonder how you will manage at home after you’ve had 24-hour care from expert staff. The staff will be quite satisfied you are ready to continue your recuperation at home; it can be quieter and more comfortable for you to be in your own environment. In reassurance, if you have any issues once home, you will have the telephone numbers to contact the ward you were on, for advice.”

### **The Pituitary Foundation**

[www.pituitary.org.uk](http://www.pituitary.org.uk)

Helpline: 0845 450 0375 Monday to Friday 10:00am - 4:00pm

Endocrine Nurse Helpline: 0845 450 0377 Mondays 10:00am to 1:00pm; 6:00pm to 9:00pm and Thursdays 9:00am to 1:00pm

*The cost of calls from mobiles and other networks may vary; please check with your provider regarding calls to 0845 numbers.*

### **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.

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