The New Zealand
Acromegaly Society

Pituitary Surgery

Supporting & Educating those affected by Acromegaly and their families

INFORMATION BOOKLET SERIES

Introduction

The New Zealand Acromegaly Society is a charitable organisation supporting patients with Acromegaly, and their families.

Website: www.acromegaly.org.nz
Email: info@acromegaly.org.nz

The aim of this leaflet is to provide general information about Pituitary Surgery. 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.

A very special thank you The UK Pituitary Foundation for allowing us to reproduce their Information Booklet and adapting it to the New Zealand's health system.

The Pituitary Foundation

www.pituitary.org.uk

Medical Advisors

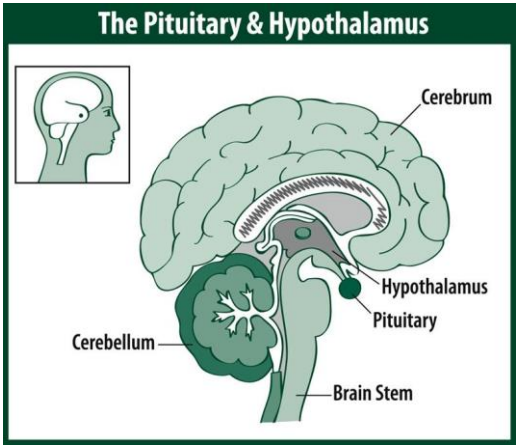
The New Zealand Acromegaly Society gratefully acknowledges the contributions from medical professionals to the development of this series of Information Booklets (listed in alphabetical order):

- Dr Richard Carroll – Endocrinologist, Wellington
- Sandra de Vries – Radiation Therapist, Dunedin
- Professor Ian Holdaway – Endocrinologist, Auckland
- Dr Penny Hunt – Endocrinologist, Christchurch
- Dr Lyndell Kelly – Radiation Oncologist, Dunedin
- Mr Martin MacFarlane – Neurosurgeon, Christchurch
- Dr John North – Radiation Oncologist, Dunedin

Where is my Pituitary Gland, and What Does It Do?

Your pituitary gland is about the size of a bean and is situated in a bony hollow about 6cm behind the bridge of your nose. It is not part of the brain but is connected to it by a stalk (infundibulum), which contains a tuft of special blood vessels and nerves through which the brain sends the hormonal messages that control the functions of the gland.
Across the space above and between the gland and the brain lie the optic nerves and the optic chiasm - the nerves that connect the eyes to the brain.

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.
- Urine output from the kidneys.

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 adenoma may either not function at all (called a non-secretory adenomas), or may function excessively, producing excessive amounts of a hormone and without the normal control by the brain (called secretory adenomas). Adenomas do gradually enlarge and 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 comprises of several different lesions. The most common being meningiomas and craniopharyngiomas. All of these tend to cause

similar symptoms to a non-secretory 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).

***SIZE** - When pituitary tumours are very small, (less then 1cm) they are called **microadenomas**. Large tumours (over 1 cm) are called **macroadenomas**. If they measure more than 2.5cm in their maximum diameter they are called giant adenomas.*

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.

What is Acromegaly?

A significant number of pituitary tumours are discovered because they cause the over-production of one particular hormone. These are the Secretory-adenomas.

Acromegaly is a condition caused by excessive secretion of growth hormone (GH), from a growth hormone secreting pituitary tumour.
Please see our *"Acromegaly Leaflet"* for more information.

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 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 (especially to the outer sides, known as a bi-temporal hemianopia) and can worsen to make it seem as if you are looking down a tunnel. It often affects one eye more than another.
- 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, 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.

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

- Prolactin-secreting tumours (prolactinomas)
- 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).
- Acromegaly: Growth hormone-secreting adenomas

The groups of pituitary adenomas which fail to produce one or more hormones are called non-functioning or non-secretory pituitary adenomas. They are often diagnosed late because they don't produce specific symptoms of hormone excess, and may not be diagnosed until they start to cause a gradual loss of vision.

Any type of pituitary adenoma can cause symptoms of hormone deficiency due to the mass effect of the tumour pushing onto the normal pituitary gland, leading to a failure of normal hormone production, e.g. hypothyroidism, cortisol deficiency, diabetes insipidus (DI).

Headache

Pituitary tumours can cause headache and the larger the tumour the more likely it will be to cause headaches, presumably by stretching of the tissues surrounding the tumour. Giant tumours however can block the outflow of cerebrospinal fluid from the cavities (ventricles) in the brain and this will cause increasing pressure with enlargement of the ventricles (hydrocephalus), and surgery is necessary in such cases. Very occasionally a spontaneous haemorrhage/bleed (called pituitary apoplexy) can occur within the tumour. This can cause a sudden headache and also an impairment of the ability of the pituitary gland to produce its normal hormones and the patient can become generally unwell over a short period of time and need semi-urgent medical assessment and treatment.

Incidental Discovery

Pituitary tumours are sometimes discovered when a patient has a scan for some other reason. This is happening more commonly now 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 duration of hospital stay depends on the type of surgery (see below).

The choice of surgeon is crucial to the likelihood of successful removal of the tumour. The more experience the surgeon is with pituitary surgeries, the better the outcome together with lower risk of complications.

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 (microadenomas) but complete removal of large tumours (macroadenomas) can be difficult and inaccessible areas of the tumour will be left in place.

For many patients surgery is an essential part of their treatment to achieving restoration of hormone balance, including normalisation of Growth Hormone in Acromegaly patients. Surgery is a common first line treatment for Acromegaly, as successful surgery eliminates or reduces the need for further treatment such as medications or radiotherapy.

What sort of surgery is undertaken?

Most operations on the pituitary gland are now carried out through the nose. This is called Transsphenoidal surgery. 'Trans' means across and 'sphenoid' is the air cavity in which the pituitary gland sits. Transsphenoidal surgery is traditionally performed using an operating 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 and maybe used in conjunction with the operating microscope.

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 also 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. You may also have been seen by an opthalmologist to examine your eye sight (includes visual acuity and visual field). 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.

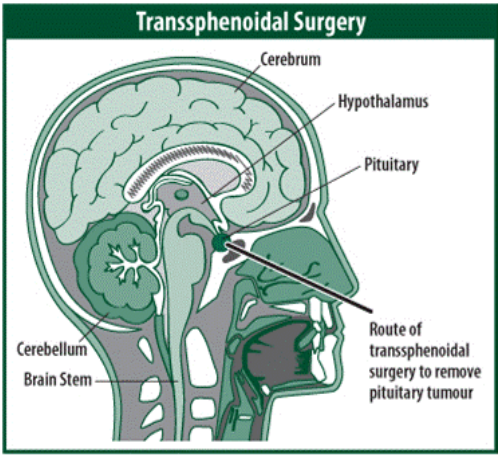
You maybe admitted to the ward the day before your pituitary operation, or you maybe pre-admitted on a separate appointment and then admitted on the morning of your surgery. The arrangements varies from centre to centre.

Pituitary operations are performed under a general 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.

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, depending on your progress and the type of work you do. 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 a little longer. Following craniotomy you will be advised that you cannot drive for a period of time – from several weeks to a year. (see section on driving).

Transsphenoidal Operation

Transsphenoidal surgery is performed through the nose. Traditionally, the operation has been performed using an operating microscope (standard transsphenoidal surgery). Endoscopes are now also being used routinely, with or without the operating microscope (Endoscopic transsphenoidal surgery).



The transshenoidal operations are sometimes performed jointly by an Ear, Nose and Throat (ENT) surgeon and a neurosurgeon, both of whom specialise in such operations.

Standard transsphenoidal surgery: The procedure is performed using an operating microscope. An endoscope (a 4 to 5 mm diameter tube with a light source enabling the site of operation to be seen on a TV screen) is also often used to facilitate the access through the nasal cavity. There are 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.
- *Sublabial:* An alternative approach is through an incision under the upper lip, just above the front teeth. This approach is less common now and has been superseded by the nasal approach.

In the next step, the nasal septum can be partially removed or moved to one side. A speculum will be placed inside the nasal cavity, and with the neurosurgeon looking down the microscope, surgical instruments are then used to remove the pituitary tumour (or as much of it as possible).

At the end of the procedure some repair work will be needed at the site through which the tumour has been removed and any empty space in the pituitary fossa (from where the tumour was removed) may be packed with a small piece of a fat graft which may be surgically removed from your thigh or abdominal wall (tummy) during the same operation and this is held in place so that no cerebrospinal fluid (CSF) leak will occur after the operation. Your nose may or may not be packed as well, but if packed then the packs will be removed a couple of days after the operation.

Endoscopic transsphenoidal surgery:

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

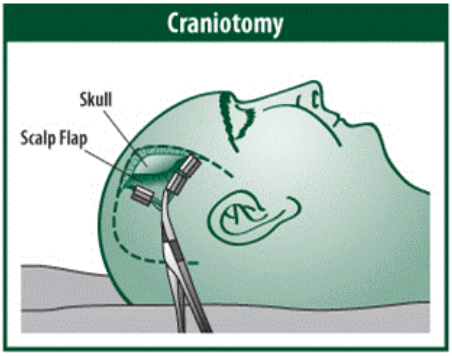
There is no need for an external incision. There is often no need to place a speculum into the nose. An endoscope is inserted through one of the nostrils. As in the standard technique some nasal cartilage and bone from the nasal septum may be removed. The rest of the procedure is the same as the standard approach although slightly different instruments are used. The endoscope provides the light and vision and the whole operation can be performed using the endoscope although sometimes the operating microscope is used as well. The main potential advantage is that less nasal cavity dissection may be required than with the standard procedure, and the endoscope can be positioned right up into the tumour cavity and this may have an advantage in being able to remove more tumour when operating on large macroadenomas and giant adenomas.

As with the standard transsphenoidal operation, 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 but usually the empty space in the pituitary fossa (from where the tumour was removed) is packed with a small piece of a fat graft, which may be surgically removed from your abdominal wall (tummy) or from your thigh and sometimes with an additional small piece (postage stamp size) of a membrane, and this is held in place in the pituitary fossa so that no cerebrospinal fluid (CSF) leak will occur after the operation. Your surgeon should tell you about the details of such repairs before surgery. Nasal packing maybe used afterwards to reduce the risk of CSF leaks.

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

Craniotomy is an operation performed through an opening in the skull. This is also performed under a general anaesthetic. This type of operation is reserved for large and difficult to access tumours only.

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. The operation is performed through the forehead, usually on the right side.



A window or man hole cover 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 by opening the covering under the skull and gently lifting the brain by 2cm away from the roof of the eye socket, uses the operating microscope to remove as much of the tumour as possible.

When you wake up a small drain maybe placed 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. The skin will be closed either by metal staples or fine stitches and these will be removed between four and seven days following the operation.

How long will the operation take?

The anaesthetic induction will take 20 to 40 minutes, depending on a number of different factors.
Transsphenoidal surgery usually takes approximately 2-3 hours. These are guidelines only and in some cases the surgery may take much 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/secretory tumours (acromegaly, prolactinoma, and Cushing's disease) the aim of treatment is a cure*, this is a complete 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 complete reduction. However, most patients experience life changes that 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 remove the pressure from the optic nerves and so 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.

In very large tumours which may have caused hydrocephalus (increase pressure inside the brain caused by the tumour obstructing the drainage of cerebrospinal fluid from the ventricles (cavities) in the brain), partial removal of the tumour can relieve the obstruction. 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.

There are some patients without visual impairment where surgery is recommended to prevent the residual squashed, but still functioning pituitary gland to retain normal functioning and therefore prevent progression to a non-functioning gland with the need for hormonal replacement therapy.

What Can Go Wrong During & After the Operation?

Very serious but rare complications:

There are 3 potential complications which are very serious but rare. These are loss of life, disabling stroke, and blindness. Fortunately these occur rarely (<1% of patients).

Other potential complications:

CSF Leak: The most common problem post-op is a leak of brain fluid. This fluid is known as CSF (cerebrospinal fluid). If it occurs, a clear fluid can drip out 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 surgeon for a review 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 piece of fat from the abdomen or fat and a piece of membrane from the thigh, to seal the leak.

Meningitis: If the CSF continues to leak, bacteria can creep up from the nose 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.

Bleeding from the nose (epistaxis) can sometimes occur in the weeks following the operation and this is managed by the ENT surgeon.

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/DI (see below 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): Seizures (Epileptic fits) can occur in patients who have had craniotomy although this is fortunately not common. Because of the risk of seizures, patients who have undergone craniotomy should not drive for a period of several weeks to up to a year after surgery. If a seizure occurs then treatment with antiepileptic medications may be necessary and additional rules about driving applies (see under driving).

What Happens After the Operation?

Immediate

If you have had standard transsphenoidal surgery, you will wake up from the operation and there maybe packing inside each nostril in your nose. Some units use special sponges, some units prefer to use long ribbons and some silicone tubes filled with packing. How long these are left in place varies and they are removed 1 to 3 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 while the packs are in and removal can be painful for some, but it is a short procedure and once removed you will be able to breathe through your nose.

When you wake up from the operation, you are likely to have a slightly 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 may not be allowed to drink for a while. Because you may 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 that 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 has no connection 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/Minirin®), which mimics the natural anti-diuretic hormone (ADH) 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, and not passing excessive amounts of urine, the most common reason is because you are breathing through your mouth.

About ten days following surgery, usually when you have returned home, a problem can occur with fluid balance, called SIADH (syndrome of inappropriate ADH secretion). The pituitary becomes 'confused' and releases too much of the natural ADH (anti-diuretic hormone). 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 readmit you for a short while you sodium is very low.

You may discover some stitches in your nostril or under your upper lip used to close the incision. These stitches are usually dissolvable and will not require removal. The wound will be completely healed in two to three weeks.

Cortisol/Steroid Replacement

Most patients will be given cortisol replacement as a drug called hydrocortisone (or sometimes dexamethasone) during and after the operation. In some hospitals, all pituitary patients are given these hormones; other hospitals restrict it to those patients with large tumours.

Hydrocortisone 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, hydrocortisone 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 hydrocortisone before going home. Some patients will be sent home on hydrocortisone or prednisone. If so, make certain you contact your GP so that you can continue the prescription until reviewed in clinic.

For those who are still on cortisol/steroid replacement 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. If the hydrocortisone is needed long-term, patients should wear a medical alert necklace or bracelet. *(See our Information Booklet – Hydrocortisone)*

After Care

You will need to return to the hospital both shortly after the surgery and on a regular basis.

After surgery, you will receive follow up with your neurosurgeon, endocrinologist, and sometimes with the ear nose & throat surgeon. Possibly even a radiotherapist (if you need or have had radiotherapy - your endocrinologist and/or neurosurgeon will explain this) at the same time.

Radiotherapy

Radiotherapy is sometimes needed following surgery. Radiotherapy may be recommended for treating larger tumours (especially giant adenomas) where only partial tumour removal was possible, and may be a treatment option for recurrent tumours if further surgery is not possible or recommended. It also has a role for the occasional smaller secretory tumour (microadenoma) if surgery has not been possible or has been unsuccessful in removing the microadenoma.
(Please see our Information Booklet on "Radiotherapy")

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.

How Will Surgery Affect My Life?

Driving

Many patients with pituitary conditions will find there are no restrictions on their driving, but you should check with your GP or specialist.

The main condition likely to affect your driving is problems with your eyesight. The other factor that determines ability to drive is the risk of seizures (epileptic fits).

Those who have had transsphenoidal surgery driving may be resumed as soon as there is satisfactory recovery provided there are no residual disabling symptoms and that their visual status is assessed as satisfactory.

Those who have had a craniotomy should not drive for a period of between several weeks and up to a year, and for at least 12 months for commercial drivers. Your neurosurgeon will advise you of the driving restrictions if necessary. Factors that influence the length of driving restrictions include your visual status, whether or not you have had a seizure and the speed and the rate of your general recovery following your craniotomy. If any epileptic seizures occur you must abstain from driving until you have been seizure free for a 12-month period.

However, it is not a good idea to rush back to driving after any major operation, regardless of whether it is legal or not. Try to leave driving for a week after returning home and only drive for short journeys to start with.

Your specialist or GP will be able to give you full advice. You may also seek extra advice from the NZTA (New Zealand Transport Agency) by calling their contact centre on 0800 822 422 ext 8089.

Alcohol and Replacement Hormones

There is no interaction between alcohol and these drugs, and you are allowed to drink in moderation. You should restrict yourself to one to two units of alcohol a day.

However if you have diabetes insipidus (DI) and are being treated with DDAVP/Minirin you will need to take special care with regard to your fluid balance requirements.

Insurance

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).

Employment Problems

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

Loss of Libido, Infertility and 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.

Personal Medical Identification

If you are taking hormone replacement medication, it is a good idea to carry a card in your purse or wallet, listing your medications and dosages.

If you are taking cortisol/hydrocortisone, it is a good idea to wear a medical information bracelet or pendant, as the information will help medical staff if you have an accident and are unconscious. The main provider in New Zealand is MedicAlert, phone 0800 840 111, or go to www.medicalert.co.nz

Advice for Staying in Hospital

Here are some very useful tips from members on how to prepare for and what to take with you for your stay in hospital. Take with you:

- Pyjamas or Night dress
- Comfortable day clothes
- Comb or brush
- Toiletry items e.g. Toothpaste and toothbrush
- Sanitary items (for ladies only), if required
- Small tin of Vaseline or balm (for the lips)
- Slippers (best with non-slip soles)
- Cardigans are better than over the head sweaters - in case it gets a bit chilly
- Books / puzzle books
- Mobile phone and charger
- MP3 or an old CD player and two or three of your favourite CDs
- **Don't take** jewellery
- No more than $20 should be kept with you.

We would like to say a special thank you to The Pituitary Foundation UK, for allowing us to reproduce their Information Booklet. The New Zealand Acromegaly Society takes sole responsibility for producing this publication in New Zealand

Disclaimer: *All information is general. If you or your carer have any concerns about your treatment or any side effects please consult your GP, endocrinologist or neurosurgeon*