

# The Pituitary Gland

Its conditions & hormones explained



*The Pituitary Foundation Information Booklets*

The  
**Pituitary**  
FOUNDATION

*Working to support pituitary patients, their carers & families*

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

Our aims are to offer support through the pituitary journey, provide information to the

community, and act as the patient voice to raise awareness and improve services.

### **About this booklet**

The aim of this booklet is to provide information about the pituitary, the disorders that can affect the gland and the hormones that are produced.

You may find that not 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 and endocrinologist.

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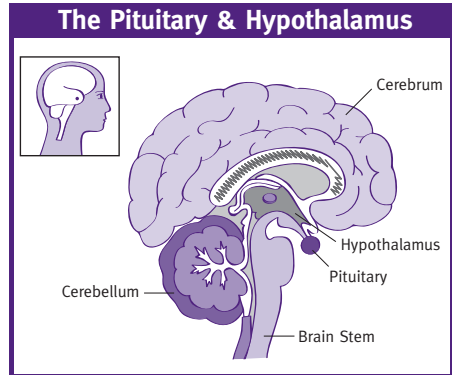
# What is the **pituitary gland** and what does it do?

Your pituitary gland is about the size of a pea and is situated in a bony hollow, just behind the bridge of your nose. It is attached to the base of your brain by a thin stalk. The hypothalamus, which controls the pituitary by sending messages, is situated immediately above the pituitary gland. The pituitary gland is often called the master gland because it controls several other hormone glands in your body, including the thyroid and adrenals, the ovaries and testicles.

It secretes hormones from both the front part (anterior) and the back part (posterior) of the gland. Hormones are chemicals that carry messages from one cell to another through your bloodstream. If your pituitary gland is not producing sufficient amounts of one or more hormones this is called hypopituitarism. If on the other hand you are over producing certain hormones, then you would have features due to the over production of the specific hormone concerned.

## The Hypothalamus

This serves as a communications centre for the pituitary gland, by sending messages or signals to the pituitary in the form of hormones which travel via the bloodstream and nerves down the pituitary stalk. These signals, in turn, control the production and release of further hormones from the pituitary gland which signal other glands and organs in the body. The hypothalamus influences the functions of temperature regulation, food intake, thirst and water intake, sleep and wake patterns, emotional behaviour and memory.



## What can go wrong with my pituitary gland?

The most common problem with the pituitary gland occurs when a benign tumour (used to describe a 'growth'), also called an adenoma, develops. Pituitary tumours are not 'brain tumours'. The term benign is used by doctors to describe a swelling which is not cancerous. Some pituitary tumours can exist for years without causing symptoms and some will never produce symptoms. Most pituitary tumours occur in people with no family history of pituitary problems and the condition is not usually passed on from generation to generation. Only very occasionally are tumours inherited - for example, in a condition known as multiple endocrine neoplasia (MEN1).

By far the most common type of tumour (about half of all cases) is the 'non-functioning' tumour. This is a tumour which doesn't produce any hormones itself. It can cause headaches and visual problems or it can press on the

# What is The **pituitary gland** and what does it do?

pituitary gland, causing it to stop producing the required amount of one or more of the pituitary hormones. This effect can also occur following treatment you are given for a tumour, such as surgery or radiotherapy. Alternatively, your pituitary tumour may begin to generate too much of one or more hormones.

The more common pituitary conditions include Acromegaly, Cushing's, Diabetes Insipidus, Hypogonadism, Hypopituitarism and Prolactinoma - please see our individual booklets about these conditions for further information.

## Other pituitary conditions

### **Craniopharyngioma**

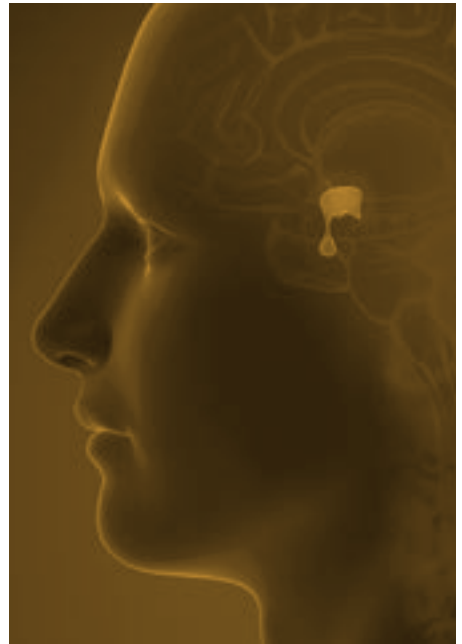
This type of tumour or cystic mass is quite rare and congenital (from birth). It exerts pressure on the hypothalamus which lies just above the pituitary gland and is responsible for releasing hormones that start and stop the release of pituitary hormones. Faster growing craniopharyngiomas affect children whilst slower growing ones affect adults. This type of tumour can cause headaches and vision problems and can affect hunger, thirst and sleep patterns. Onset of puberty and growth hormone production in children can also be affected, plus growth hormone production may also be affected in adults.

### **Rathke's Cleft Cyst**

The Rathke's pouch eventually forms the pituitary gland and normally closes early in foetal development. A remnant may persist as a cleft that lies within the pituitary gland

and occasionally this remnant gives rise to a fluid-filled large cyst called Rathke's Cleft Cyst (RCC). This condition is more usually seen in adults but can occur at any age.

Arachnoid Cysts and Cystic Pituitary Adenomas are other rare cyst-like tumours.



### **Empty Sella**

Empty Sella Syndrome (ESS) is a disorder that involves the 'sella turcica' – a bony structure at the base of the brain that surrounds and protects the pituitary gland. ESS would show up on an MRI scan revealing a sella turcica that appears to be empty. There are two types of

## Other **pituitary** conditions

ESS: primary and secondary.

Primary ESS happens when a small anatomical defect above the pituitary gland increases pressure in the sella turcica and causes the gland to flatten out. The pituitary gland may be smaller than usual. Primary ESS can be associated with obesity and high blood pressure in women. The function of the pituitary gland is usually normal and may be an incidental finding when a brain MRI scan is done for other reasons.

Secondary ESS is the result of the pituitary gland regressing within the cavity after an injury, surgery or radiation therapy. Individuals with secondary ESS may have symptoms that are due to the loss of pituitary functions, for example loss of periods, infertility, fatigue and intolerance to stress and infection. In children, ESS can be associated with early onset of puberty, growth hormone deficiency and pituitary tumours. MRI scans are useful in evaluating ESS and differentiating it from other disorders that produce an enlarged sella.

### **Sheehan's Syndrome**

Sheehan's Syndrome is also known as postpartum hypopituitarism, or postpartum pituitary insufficiency and may occur in a woman who has severe uterine haemorrhage during childbirth. The resulting severe blood loss causes tissue death in her pituitary gland and leads to hypopituitarism following the birth.

If a woman's pituitary gland is starved of blood due to her bleeding severely during

childbirth, the gland may lose its ability to function properly. Conditions that increase the risk of an obstetric haemorrhage include multiple pregnancies (twins or triplets) and abnormalities of the placenta. Blood tests would establish hormone levels and a scan to rule out other abnormalities of the pituitary such as a tumour.

### **Multiple Endocrine Neoplasia (MEN)**

MEN syndromes are inherited disorders (passed down in families). The disorder causes more than one gland in the body's endocrine system to develop growths. The affected glands may then produce abnormally increased amounts of hormones which in turn cause a variety of different symptoms.

Diagnosis is made when a patient has two or more growths common to MEN, or a patient has only one growth, but there is a family history of MEN. There is a patient group dedicated to providing support to those affected by MEN, for further information please see [www.amend.org.uk](http://www.amend.org.uk).

### **Lymphocytic Hypophysitis**

Another cause of hypopituitarism that may be associated with pregnancy is lymphocytic hypophysitis. This is due to inflammation in the pituitary caused by immune cells. The reasons why this occurs is not understood. With modern obstetric practice the occurrence of hypopituitarism after childbirth, though uncommon, is more frequently due to this condition than Sheehan's syndrome.

# Treatment of **pituitary tumours**

## **Surgery**

Many pituitary problems are caused by a benign tumour and an operation is often the best course of action - and surgical methods are continually improving. We can reassure you that surgery carried out by a specialist neurosurgeon is safe and a relatively straightforward procedure. Most tumours are removed by making a small incision inside your nostril, or under the upper lip. This surgery is called 'transsphenoidal surgery'. By using this route, the surgeon can see your pituitary without disturbing the main part of your brain. The operation will usually require about five days in hospital and you should be up and about the day after surgery, eating normally. You will be on a drip for a day or two and may also be given antibiotics to prevent any infection in your nose.

Recovery times do vary according to the individual, with an average of perhaps four to eight weeks off from work, if employed.

Sometimes pituitary tumours need other surgical approaches and for this and for further and more detailed information please read our **Surgery & Radiotherapy Booklet**.

## **Radiotherapy**

This treatment is sometimes used as a follow up to surgery, or it can be recommended instead of surgery. Please be assured that the use of radiotherapy does not mean that you have cancer.

Most radiotherapy is accomplished over several weeks with an initial visit to have an individual mask made which guides the

radiotherapist accurately to where the X-rays will be focussed. Radiotherapy can also be given in a focused beam (e.g. 'Gamma knife' or 'X-knife-Linac') as a single treatment, but this is not appropriate for all tumours.

For further and more detailed information please read our **Surgery & Radiotherapy Booklet**.

## **Medical therapy**

Most people with a pituitary condition will require treatment with drugs, either on their own or in addition to surgery and/or radiotherapy. These drugs may be used to reduce the levels of a hormone that your pituitary is overproducing, or to replace a hormone that your pituitary is under producing. Please see our following section on hormones.

## **Follow-up treatment**

Most people with a pituitary tumour and/or condition will have regular check-ups at a specialist endocrine clinic for the rest of their life. These check-ups enable the specialist to monitor your condition and pick up any changes as soon as possible. In most patients their condition remains stable after initial treatment(s). Regrowth of a pituitary tumour can occasionally occur if it was not possible to remove the entire tumour during surgery. The chance of this happening is lower if you had radiotherapy after your operation. If regrowth does occur, you may need another operation, or radiotherapy; all cases are individual and can vary.

# Why do I need replacement therapy?

If your pituitary gland isn't functioning properly due to any of the causes mentioned on the previous page, you may not produce hormones that are essential for your well-being and vital bodily functions. Our table below gives a quick guide to pituitary hormones.

| Hormone Anterior - Front Part   | Target                       | Function   |
|---|------------------------------|--|
| <b>Adrenocorticotrophic Hormone (ACTH)</b>                            | <b>Adrenals</b>              | Stimulates the adrenal glands to produce a hormone called cortisol. ACTH is also known as corticotrophin. Cortisol promotes normal metabolism, maintains blood sugar levels and blood pressure. It provides resistance to stress and acts as an inflammatory agent. Cortisol also helps to regulate fluid balance in the body.   |
| <b>Thyroid Stimulating Hormone (TSH)</b>                              | <b>Thyroid</b>               | Stimulates the thyroid gland to secrete its own hormone called thyroxine (T4). TSH is also known as thyrotropin. Another hormone produced from the thyroid is called tri-iodothyronine or T3. Thyroxine controls many bodily functions, including heart rate, temperature and metabolism. It also helps metabolise calcium in the body.  |
| <b>Lutenising Hormone (LH) and Follicle-Stimulating Hormone (FSH)</b> | <b>Ovaries</b>               | Control reproduction and sexual characteristics. Stimulate the ovaries to produce oestrogen and progesterone and the testes to produce testosterone and sperm. LH and FSH are also known collectively as gonadotrophins. <b>Oestrogen</b> helps with growth of tissue of the sex organs and reproductive parts. It also strengthens bones and has a positive effect on the heart. <b>Testosterone</b> is responsible for the masculine characteristics including hair growth on the face and body and muscle development. It is essential for producing sperm and strengthening the bones. |
| <b>Prolactin</b>  | <b>Breasts</b>               | Stimulates the breasts to produce milk and is secreted in large amounts during pregnancy and breastfeeding. It is however present at all times in both males and females   |
| <b>Growth Hormone (GH)</b>  | <b>All cells in the body</b> | In children this hormone is essential for a normal rate of growth. In adults it controls energy levels and well-being. It is important for maintaining muscle and bone mass and appropriate fat distribution in the body.  |
| Hormone Posterior - Back Part   | Target                       | Function   |
| <b>Anti-diuretic Hormone (ADH)</b>                                    | <b>Kidneys</b>               | Controls the blood fluid and mineral levels in the body by affecting water retention by the kidneys. This hormone is also known as vasopressin.  |
| <b>Oxytocin</b>   | <b>Uterus<br/>Breasts</b>    | Affects the uterine contractions in childbirth and the subsequent release of milk for breast feeding.  |

# Underproduction **pituitary hormones**

**Underproduction of one or more hormones by the pituitary gland is known as hypopituitarism. It is generally treated by replacing the hormones normally produced by the glands which your pituitary controls. Panhypopituitarism means that all hormones are replaced.**

## **Adrenocorticotrophic Hormone (ACTH)**

ACTH controls the adrenal glands which are situated just above the kidneys, and steroid hormone production. The symptoms of lack of ACTH are due to the lack of the steroid hormones from the adrenal, in particular cortisol, and include fatigue, feeling dizzy and a loss of physical well-being and energy. Some patients also suffer from nausea and diarrhoea. If you have severe ACTH deficiency a single blood test may show this, but usually you would need to attend an endocrine specialist unit for tests which are more dynamic to help diagnose you accurately.

Treatment is by taking the adrenal hormone called cortisol which is referred to as hydrocortisone when it is made into a tablet. The tablet is usually taken two or three times daily. Your GP will prescribe these but you will need to see your specialist from time to time for monitoring and ensuring that you are having the correct dose that you need. Occasionally alternative drugs to hydrocortisone are prescribed such as prednisolone or cortisone acetate.

Your endocrinologist should explain how to increase your dose of hydrocortisone yourself, during any other serious or stressful illness (for example, flu, vomiting, diarrhoea and routine operations).

This is very important as the body normally would make a lot of steroid hormone to cover you for stressful situations. You should also carry a blue steroid card (from the hospital) and /or a medical emblem bracelet or necklace to warn other doctors that you need steroid replacement during illness. There is also a *Patient Care Card* available from The Foundation. Many endocrine specialists recommend that you also have a home injection pack of hydrocortisone in cases of emergency, and endocrine nurse specialists can provide training for their use.

If you take hydrocortisone, The Pituitary Foundation suggests that you obtain a copy of our *Hydrocortisone Advice Booklet* - please see our website [www.pituitary.org.uk](http://www.pituitary.org.uk) or call **0117 370 1333** for a free copy.

## **Growth Hormone (GH)**

This hormone controls growth in children and aspects of general metabolism in adults. Lack of growth hormone inhibits a child's growth, making the child smaller and younger looking (but of normal proportions), than other children of his or her age. About a third of GH deficient children are also overweight because GH controls the fat under the skin. The children are not necessarily overeating but it is important that they receive a balanced diet and a reasonable amount of exercise.

In adults GH is involved in the maintenance of normal body weight and energy levels; it also helps maintain the strength of muscles and bones. GH deficient patients have more fatty tissue than lean body mass (muscle) than people without pituitary disease. This fatty tissue



# Underproduction **pituitary hormones**

is deposited in the abdomen increasing the size of the waist which is known to increase heart disease risk.

Lack of GH causes changes in blood cholesterol concentrations plus a number of other factors in the blood which in studies have been associated with an increased risk of heart disease. Adults deficient in GH have been found to suffer loss of energy, tiredness, depression, anxiety and feelings of social isolation with a tendency to be easily upset - which can all lead to a decreased quality of life. Sometimes these factors can be severe enough to lead to an inability to work or to enjoy a basic, acceptable lifestyle.

The most frequent cause of adult GH deficiency is a benign tumour of the pituitary gland - either due to the tumour itself, or by the surgery/radiotherapy used to treat the tumour. It is estimated that about three in every 10,000 of the adult population are GH deficient. Around one third of these adults will have developed the deficiency as a child. Idiopathic (no known cause) is the most common cause in children, followed by radiotherapy used to treat a brain tumour, or leukaemia. Radiotherapy effects in both children and adults may not be apparent for some years, so it is important that pituitary function is monitored regularly by specialists after treatment.

The risk of severe GH deficiency increases, as the number of other pituitary hormone deficiencies increase, so a patient on sex steroids, hydrocortisone and thyroxine will almost certainly have GH deficiency. A dynamic blood test usually an insulin tolerance test (ITT), will confirm if you are deficient in GH.

GH is given by injection only; this is injected by the patient each evening just under the skin and is virtually painless. You will receive instruction on how to prepare the device and inject yourself, usually from an endocrine nurse. You will have regular reviews to determine response, any side effects and any necessary dose alterations.

The GH used is known as recombinant human growth hormone (rhGH) which is a synthetic preparation.

Before you are accepted for GH replacement therapy, guidelines set by National Institute for Health and Clinical Excellence (NICE) have to be adhered to. If you are over 25 you will be asked to complete a questionnaire that asks how you feel and how you function on a day-to-day basis. If you achieve an appropriate score (and blood test results confirm you are deficient) then you will be offered a trial of GH replacement therapy. After 9 months you will be asked to complete the same questionnaire to demonstrate a beneficial change in your quality of life. If there is sufficient improvement, then you will be allowed to continue on GH. If not, you will be asked to stop your GH.

The Foundation advises patients to complete the questionnaire as if they were having their 'worst day', as a tendency to think positively when answering questions may lose the opportunity for having GH. For more information, please see our ***Growth Hormone Fact Sheet***.

# Underproduction **pituitary hormones**

## **Anti-Diuretic Hormone (ADH or Vasopressin)**

ADH controls the production of urine. If you are lacking in this hormone you will have a condition called Diabetes Insipidus. You would feel very thirsty - for example, possibly drinking more than 3 litres of fluid a day and constantly having to pass urine, even during the night. The condition can be treated by taking a drug called desmopressin, or DDAVP.

Please see our *Diabetes Insipidus Booklet* for more information.

**Underproduction of one or more hormones by the pituitary gland is known as hypopituitarism. It is generally treated by replacing the hormones normally produced by the glands which your pituitary controls. Panhypopituitarism means that all hormones are replaced.**

## **Gonadotrophins (LH and FSH)**

In women, lack of gonadotrophins usually causes disturbance to the menstrual cycle, or even loss of periods. You may also find that you experience a lack or loss of libido. In men, loss of sex drive and impotence may occur. Infertility can be experienced in both sexes. You may notice a loss of under arm, pubic, facial and body hair - particularly men. Lack of sex hormones can make you feel generally under the weather too. Prolonged loss of sex hormones over many years can lead to brittle bones or osteoporosis. Blood tests can indicate whether your sex hormone levels are below normal.

Treatment is by replacing oestrogen (and often also progesterone) for women, by tablets, gel or patches. For men testosterone can be replaced by

a number of means, including regular injections, gel, tablets or patches.

If you are trying for a family, extra specialist help will be needed to help eggs mature in the ovaries, or to produce sperm in the testes.

Please see our *Prolactinoma Booklet*, also our *Male Hormones & Infertility Issues Booklet*.

## **Thyroid Stimulating Hormone (TSH)**

TSH controls the thyroid gland and thyroid hormone production.

Fatigue is a very common symptom when your thyroid is underactive. You may also gain weight without eating more or exercising less; your hair and skin may become dry and you may feel the cold more than usual. You may have less interest in sex and generally feel listless and unwell.

A blood test, available from your GP or at an endocrine clinic, will measure your level of thyroxine hormone (not just TSH). If this is found to be lacking you will be prescribed the thyroid hormone, called thyroxine, which is taken in tablet form once a day. Your GP can prescribe these and any dose adjustments can be made following regular blood tests and according to your symptoms. It is important that if you are advised to take thyroxine by your endocrine specialist, that the dose is not reduced at your GP's surgery on the basis of just a TSH being measured, as that test is done for patients who have a thyroid problem alone without pituitary disease. The Pituitary Foundation recommends that any adjustment in dose of thyroxine is made only on the advice of your endocrinologist.

# Overproduction of **pituitary hormones**



## **Prolactin**

This hormone stimulates milk production and suppresses the effects of gonadotrophins. There are several likely causes of raised prolactin levels, including certain medications, such as anti-depressants or anti-sickness tablets, or an underactive thyroid. If these causes are excluded, a doctor would consider the possibility of a prolactinoma (a benign prolactin secreting tumour in the pituitary gland).

For more information please see our ***Prolactinoma Booklet.***

## **Growth Hormone**

Overproduction of growth hormone in adults can lead to a condition called acromegaly. Symptoms can include headaches, visual problems, sweating and an increase in shoe or ring size as well as some changes in facial

features, such as increased prominence of the jaw and forehead. These changes can be very gradual and may go unnoticed by family and friends. Acromegaly is usually treated by one or more of surgery, radiotherapy and drug treatment.

For further information please see our ***Acromegaly Booklet.***

## **Adrenocorticotrophic Hormone (ACTH)**

If your pituitary gland is sending too much of this hormone to the adrenal glands, these glands will then produce too much cortisol. This condition is called Cushing's disease and is more common in women than in men and most commonly diagnosed between the ages of 20 to 40.

For further information please see our ***Cushing's Booklet.***

# Aspects of pituitary disease

## Coping with the stress of a pituitary tumour

In addition to physical issues, many people find pituitary illness emotionally traumatic - particularly if you were unwell for some time before a correct diagnosis was made. There may be stress caused either by specific physical aspects (for example: loss of libido, overproduction of cortisol) or by factors such as change to body image, exhaustion, anxiety and so on. In addition, both the fear of anticipated surgery, so close to the brain, and the fact that, for some people recovery can take quite a while, can be stressful. All these issues can be just as difficult for family and close friends as for the patients themselves. Your GP will be able to arrange counselling if this is required. You may also

find it useful to make contact with the Patient Support team on **0117 370 1320** and/or with your nearest local support group (details from our website or **0117 370 1333**) where you will find many people keen to help and support you.

The University of the West of England (UWE), in partnership with The Pituitary Foundation, has conducted research which has identified several psychosocial issues related to pituitary disease. These include: increased levels of depression, anxiety; appearance-related concerns; a reduced quality of life and well-being. These are associated with impact of diagnosis, treatment, and the realisation that the condition is long-term.

Please see our *Psychological Booklet Series*.



## Aspects of **pituitary disease**



### **Infertility**

Infertility is a very common problem that affects up to one in six couples that are trying to conceive. In addition, something like one in ten couples with normal fertility take at least a year to conceive.

Hormone problems cause around a quarter of all infertility cases and the pituitary gland is very important in this connection, as it provides the gonadotrophins (LH and FSH), which are necessary for the ovaries and testicles to function properly. The most common cause of pituitary-related infertility is a raised level of prolactin, usually due to a tumour called a prolactinoma. This can be treated fairly easily with medicines, prescribed by a specialist, which reduce prolactin production by the pituitary. There are three of these currently in use: cabergoline (brand name Dostinex), bromocriptine (brand name Parlodel) and quinagolide (brand name Norprolac).

For further details please see our ***Prolactinoma Booklet*** and our ***Male Hormones and Infertility Issues Booklet***.

Many other pituitary conditions can cause your levels of sex hormones to be too low. The treatment you are given for your particular condition may restore your fertility. If not, you will usually be treated with gonadotrophins, either by injections or by use of a small pump, which is worn with a belt. These methods are only needed until you are pregnant.

### **Visual problems**

Because a pituitary tumour can sometimes press on the optic nerve, which passes over it, you may have problems with your vision. You may find that your field of vision gets smaller – rather as if you were wearing blinkers. This can happen to one eye or both, and may be accompanied by headaches. The treatment you are given for your tumour (usually drug treatment for prolactinoma and surgery for other types) has a good chance of helping this. Your vision may improve and could even return to normal. You may be seen by an eye specialist (ophthalmologist) as well as by your endocrinologist if you have visual problems.

# Aspects of pituitary disease

## Weight issues

The natural urge to eat can be greatly increased in the presence of pituitary and hypothalamic disease. This explains why diseases of the pituitary gland (particularly when the adjacent part of the brain, the hypothalamus, is affected), may lead to weight gain and sometimes marked obesity. Disease confined to the pituitary alone generally causes relatively minor weight disturbances. Pituitary tumours, pituitary surgery or radiotherapy often impair the production of pituitary hormones and therefore can affect weight. Deficiencies of thyroid, gonadotrophins and growth hormone all have subtle effects on the accumulation of body fat.

A common question asked by patients who have put on weight, is whether pituitary (or hypothalamic) disease has been responsible

for their unwanted weight gain. The answer is usually clearer if there is an issue of marked weight gain dating from the time of diagnosis and treatment.

To address weight gain, it is important to ensure that the levels of pituitary hormones are adequate; otherwise this may impair weight loss. Weight gain can also occur if the pituitary hormones (in particular, cortisol) are too high. Increasing of low impact physical activity, such as walking and swimming (where you are able), and generally reducing amount of food eaten should limit further weight gain and, over time, produce some weight loss.

Your GP or specialist can refer you to a dietician if appropriate. For further details, please see our *Weight Control and Nutrition in Adults with Pituitary Conditions Booklet*.

### Useful Links - other organisations:

|                                      |  |               |
|--------------------------------------|--|---------------|
| Addison's Disease Self Help Group    | <a href="http://www.adshg.org.uk">www.adshg.org.uk</a>                           |               |
| AMEND (Multiple Endocrine Neoplasia) | <a href="http://www.amend.org.uk">www.amend.org.uk</a>                           |               |
| British Thyroid Foundation           | <a href="http://www.btf-thyroid.org">www.btf-thyroid.org</a>                     | 01423 709707  |
| Changing Faces                       | <a href="http://www.changingfaces.org.uk">www.changingfaces.org.uk</a>           | 0300 012 0275 |
| Child Growth Foundation              | <a href="http://www.childgrowthfoundation.org">www.childgrowthfoundation.org</a> | 020 7608 0257 |
| Kallman's Syndrome                   | <a href="http://www.delayed-puberty.com">www.delayed-puberty.com</a>             |               |

# General Information for patients



## Employment

For your stay in hospital if you have had surgery, the ward staff will give you a certificate for your employer and advise you how long you will be expected to remain off work. Your GP can issue further certificates if you require these.

If you are experiencing any difficulties in retaining or returning to your employment, at any stage of your pituitary condition we suggest that you contact The Foundation's Helpline or your local **Citizens Advice** for the most up-to-date information about employment rights and where to get advice about benefits. If you need extra employment support because of a disability your local Jobcentre Plus can put you in touch with one of their Disability Employment Advisers. Our website forum has a section where you can read about employment queries and receive other patients' experiences if you wish

to register and post your own messages. We also have a booklet called **Employment & Benefits** for further information.

## Prescriptions

If you have to take hydrocortisone, thyroxine or desmopressin permanently you will receive free prescriptions for all medicines. Ask at your GP's, pharmacist or endocrine clinic for form **FP92** or **EC92A** if you live in Scotland.

The form (which will need to be signed by your doctor) tells you what to do to apply for exemption and you will receive an exemption certificate. These certificates need to be renewed and you should receive an application when this is due for renewal. The full list of medical conditions and information about free prescriptions can be found in leaflet **H11**, available from pharmacies and main post offices or on [www.dh.gov.uk](http://www.dh.gov.uk).

If you aren't sure whether you are entitled to free prescriptions, you must pay for your prescription and ask for a NHS receipt (form **FP57** in England or **EC57** in Scotland) when you pay; you can't get this at a later date. The above form will explain how to claim your money back and must be within three months of paying.

If you don't qualify for free prescriptions and need more than five prescription items in four months, or more than 14 in a year, ask your pharmacist about a pre-payment certificate, which is more economical for you.

For Wales: All patients registered with a Welsh GP, who get their prescriptions from a Welsh pharmacist, will be entitled to free prescriptions.

# General information for patients

## Insurance & pensions

Your current insurance provider will require medical reports and each case will be assessed individually to make any adjustments found to be necessary on your premiums. Company policies do vary widely and you may need to shop around. Don't be disheartened if the first response is disappointing.

Please call The Foundation or see our website for up-to-date insurers' contact information (based on feedback from other patients' experiences) and we can also provide travel information.



## Driving

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

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

Information for drivers can be obtained from the DVLA website by requesting leaflet INF94

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/383385/INF94.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/383385/INF94.pdf)

Or: [www.gov.uk/driving-medical-conditions](http://www.gov.uk/driving-medical-conditions)

By phone: **0300 790 6806** between 8am and 5.30pm Monday to Friday, and between 8am and 1pm on Saturdays.

If you have hearing or speech difficulties, contact us by textphone on **0300 123 1278**.

By post: **Drivers Medical Group DVLA Swansea SA99 1TU**.

By email: [www.gov.uk/contact-the-dvla](http://www.gov.uk/contact-the-dvla)

*For Northern Ireland:*

**Driver and Vehicle Licensing Northern Ireland, Castlerock Road, Coleraine, BT51 3TB.** Tel: 028 4703 41369

## Personal medical identification

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

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



# Common questions

## Common questions

**Q:** *Will I have to take my hormone replacement tablets forever?*

**A:** Yes, most probably. The exception may be sex hormone replacement in the elderly, but there is no real 'upper age limit'.

**Q:** *Are there any long-term side effects?*

**A:** Replacement therapy is replacing what your body doesn't produce naturally, and there are usually no problems as long as treatment is monitored regularly.

**Q:** *Do I need to keep my medication in the fridge?*

**A:** Growth Hormone commonly needs to be kept refrigerated except for a disposable version. Desmopressin Intranasal needs to be kept in the fridge, but the tablets, DDAVP Melts and spray don't.

Other pituitary hormones don't need to be kept in the fridge, but check with your doctor or chemist for full details of how you should store your medication.

If you are travelling away from home it is advisable to carry any medication needing refrigerating, in a cool bag with frozen blocks. Hotels will usually store your medication in a fridge for you, but do check this with the hotel before travelling.

**Q:** *What if I am ill or forget to take my medication?*

**A:** If you are taking hydrocortisone it is very important to continue and even increase this if you become ill. If you forget to take

a dose of hydrocortisone, you may well be prompted to take it if you start to feel tired or weak. Inadvertently missing the very odd dose shouldn't cause any harm.

For further information please read our ***Hydrocortisone Advice Booklet***.

Other medications should be continued during any illness, unless your doctor advises otherwise. If you do happen to forget a dose of other medication, this should not affect your treatment; it is important though not to 'double up' on the next dose.

**Q:** *Can I still drink alcohol?*

**A:** There is no interaction between alcohol and most replacement hormones and you are allowed to drink in moderation, such as the national guidelines - currently 2 units for women and 3 units for men per day.

**Q:** *Why do I feel so emotional even though my hormones are replaced?*

**A:** It is common to feel a swing of emotions with a pituitary condition. Treatment, tests and having to take regular medication can affect how you cope emotionally. We have a series of booklets which may be able to help you.

If you need someone to talk to, our Helpline and Endocrine Nurse Helpline details are given on the back page. The Foundation also has a variety of services to provide support and information, please contact us to discuss which service may be suitable for you.

# Living with a **pituitary tumour**

## **- One patient's story**

My GP said that the severe headaches I'd been having for weeks were due to migraine and stress. I felt very cold all of the time and had no energy. I was also desperately thirsty and peeing, seemingly all day and night.

Various tests including diabetes mellitus proved negative, and I took more and more painkillers with little effect. After almost a year of feeling so ill and regularly seeing my GP, I saw a gynaecologist because I was told it may be my 'hormones'. I wasn't aware of the words 'endocrinology' or 'pituitary' at that point.

After appropriate hormone tests and a CT scan, I was referred without delay to an endocrinologist who carried out further tests and diagnosed me with a pituitary tumour. I was very shocked and frightened and there was no-one to talk to (The Foundation wasn't around then). My family and I had no understanding of this condition. The only relief I felt was that there was actually something wrong with me and I wasn't losing my mind!

I needed to have the 'tumour' removed quite quickly and I was extremely deficient in cortisol. I had developed diabetes insipidus due to the tumour; my periods had stopped and my other hormones were affected.

None of the specialists treating me knew what type of tumour I had, and I was very

worried about the prospect of surgery to my brain.

The surgery (a craniotomy, which isn't commonly used now) went well and my tumour turned out to be an abscess. I had to have my head shaved completely and I was given high doses of hydrocortisone which made my weight soar.

During the following months I had more tests to introduce hormones I needed replacing. I recovered physically within a few months, but the emotional impact took a lot longer. Physical and mental changes were difficult and I felt quite alone, not to mention ugly and just 'different' from who I was before this started.

Over 20 years later, I take all replacement hormones including growth hormone which was given to me 13 years ago. Once I'd made my first contact with The Pituitary Foundation in 1995 it felt like a door had opened. I learnt so much about what had been happening to me and found talking to others with similar problems was a huge help.

For me, there is 'life' after diagnosis and surgery; I am in full time employment, enjoy holidays and hobbies outside of work and I am a proud grandmother to two beautiful girls. I aim to help others as much as possible who suffer with a pituitary condition.

# Please support The Pituitary Foundation

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

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

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

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

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

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

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

## Helpline

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

## Endocrine Nurse Helpline

0117 370 1317

Please see website for hours.

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

**Email:** [helpline@pituitary.org.uk](mailto:helpline@pituitary.org.uk)

**Text:** 07786 202 249

## More Information

The Pituitary Foundation publishes a library of booklets on pituitary conditions, treatments and well-being issues.

For more information please visit our website, or call our Helpline.

## The Pituitary Foundation 86-88 Colston Street, Bristol, BS1 5BB

Company Limited by Guarantee  
Registered in England and Wales  
No. 3253584  
Registered Office:  
86 Colston Street  
Bristol BS1 5BB

Registered Charity No. 1058968

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your carer, have any concern about your treatment or  
any side effects please read the Patient Information  
booklet enclosed with your medication or consult  
your GP or endocrinologist



*pit-bklt/05/sept2017*

The  
**Pituitary**  
FOUNDATION

*Working to support pituitary patients, their carers & families*