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 Cushing’s.

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 Cushing’s and why do we get it?

Cushing’s syndrome develops if your body makes too much cortisol hormone.

Symptoms usually develop gradually and so the diagnosis may not be clear for some time. The condition is named after Harvey Cushing, an eminent American neurosurgeon, who described the first patients with this condition in 1912.

Cortisol is a hormone made by the adrenal glands (two small glands which lie just above each kidney) and it is vital for life. It has several functions including:

• Helps to regulate blood pressure
• Helps to regulate the immune system
• Helps to balance the effect of insulin to keep blood sugar normal
• Helps the body to respond to stress

The most common reason for Cushing’s overall is glucocorticoid treatment - for example taking a steroid such as prednisolone for asthma, arthritis or colitis.

Spontaneous Cushing’s, originating from within the body is rare, but occurs when the adrenal glands are making too much of a hormone called cortisol (the body’s natural glucocorticoid steroid hormone). This may happen for one of several reasons so you will have tests to find out which reason applies to you. The quoted incidence of Cushing’s is 1 in 200,000 but it is now being found more frequently when it is specifically investigated. The difficulty is that the symptoms of Cushing’s can be very wide ranging and thus the diagnosis may not necessarily be considered; it can be difficult to establish, at the earlier stages and this can cause a delay in diagnosis.

Far more women than men suffer from Cushing’s but it isn’t known why; it is most commonly diagnosed between the ages of 30 to 40. Although it is rare in children, some as young as 6 have been diagnosed. There are no environmental triggers known and it’s not hereditary.

The commonest cause of spontaneous Cushing’s (around 70%) is a small benign tumour (growth) of the pituitary gland (a small gland at the base of the brain, behind the bridge of the nose). This produces the hormone called ACTH, (adrenocorticotrophic hormone), that goes through the blood stream to the adrenal glands and causes them to release too much cortisol. In this case there is a good chance that an operation on your pituitary gland will solve the problem. Alternatively, there could be a small growth in another part of your body which is having the same effect (this is called ectopic ACTH). If so, removing this growth will usually solve the problem. Lastly, there may be a small growth in one of the adrenal glands themselves, in which case an operation will be needed to remove that gland. In some circumstances it may be necessary to remove both adrenal glands to solve the problem.

Strictly speaking, if the source of the problem is the pituitary gland, then the correct name is Cushing’s Disease. Whereas, if it originates anywhere else, then the correct name is Cushing’s Syndrome. The term ‘Cushing’s’ is used throughout this booklet.

Sometimes, the amount of cortisol causing the condition can vary greatly. This is called ‘Cyclical Cushing’s’ with symptoms varying
What does it feel like to have Cushing’s

often over months or even years depending on the levels of cortisol. This can cause difficulty and delays in diagnosis. Occasionally, repeated testing by your endocrinologist will be needed to assess whether you have this more uncommon type of Cushing’s.

What are the symptoms of Cushing’s?

Symptoms of having Cushing’s are very varied, and usually several are present; these can include:

• Excessive and sudden (or at times more gradual) onset of weight gain around your trunk (your arms and legs may remain unchanged and can become quite thin compared to your body)
• Weak muscles, especially in your legs
• Your face tends to be rounder and redder than normal (a classic symptom of Cushing’s known as ‘moon face’) and you may have developed acne
• Your bones may have become weaker (an X-ray may show a fractured rib for instance), due to steroid-induced osteoporosis (thinning and brittleness of bones) and therefore you have an increased risk of fracture
• Your blood pressure may be higher than normal (hypertension) and you could have developed diabetes mellitus (‘sugar diabetes’) and excess thirst
• Some people may also notice a tendency to bruise easily and have deep red/purple stretch marks (striae) appearing on the abdomen, similar to those which occur during pregnancy but are more pronounced
• Some women experience irregular periods or stop having them altogether
• You may also experience excessive hair growth on parts of the body and usually the face in women
• Men can experience decreased fertility and both men and women can feel a reduction, or absence of sex drive (libido)
• You may be feeling generally unwell, and more susceptible to infections
• Mood swings - such as being more irritable, feeling depressed or anxious. In some cases, psychological problems can be severe, even being diagnosed as a nervous breakdown
  • In children it may show itself by growth stopping and weight increasing

Cushing’s affects many parts of the body, both mentally and physically, and affects different people in different ways.

Because Cushing’s progresses slowly and gradually, in most cases, it can go unrecognised for quite some time, sometimes resulting in depression. Looking back, many patients realise that there were clues to the condition two or more years before they were referred to an endocrinologist. However lack of Cushing’s knowledge, at the time meant they were unaware of the condition.
How is Cushing’s diagnosed?

The tests used to diagnose Cushing’s are complicated and may take some time; they may also need to be repeated on several occasions. You may have them as an inpatient or an outpatient.

The first tests are to establish that Cushing’s is present. If Cushing’s is likely then further tests establish the location. This is because most people who gain weight and who have high blood pressure or diabetes or problems with excess hair do not actually have Cushing’s. To see if you have Cushing’s you will probably be given a tablet called dexamethasone. In people who do not have Cushing’s, taking this tablet will completely suppress the production of the hormone cortisol. You may also have a series of blood tests and urine tests and even saliva tests. The urine test involves collecting all the urine you pass during 24 hours (for example, between nine o’clock one morning and nine o’clock the next morning). The hospital will provide a special container for this and you will be told how to take accurate and clean samples.

If these initial tests indicate that Cushing’s is likely, you will then need further tests to find its location. You may be admitted to hospital for these, and it is likely that you may be referred to a hospital where they are very familiar with Cushing’s. Tests include blood samples taken throughout the day; a higher dose of dexamethasone; an injection of corticotrophin-releasing hormone (CRH) which stimulates the pituitary; and lastly measuring the blood coming from the pituitary gland.

Your doctor may decide to treat you in the meantime with drugs, such as metyrapone or ketoconazole, to reduce the amount of cortisol produced by your adrenal glands. If so, you may have to spend two or three days in hospital to assess your response to the tablets or attend regularly as an outpatient. At the end of all these blood tests your arms might be quite bruised, a tendency to bruise easily is typical of Cushing’s. This tendency will diminish after the Cushing’s is successfully treated by reducing cortisol levels. ‘Success’ is achieved in around 70% of patients.

You will also have your pituitary and/or adrenal glands scanned, using a type of magnetic scan called an MRI scan, or by a form of X-Ray called a CT scan. You may be given an injection during the scan to improve the results. A minority of patients are allergic to this injection; so do tell the specialist if you have asthma or any allergies. The scan does not hurt but the MRI machine can be very noisy and it
Treatment of Cushing’s

may involve being inside the scanner for around half an hour. If you think this will make you claustrophobic or nervous, tell your GP who may give you something to help you relax.

If ectopic ACTH is a possibility you may be scanned from head to toe to look for the cause.

Another test which may be carried out initially, or possibly during the follow-up to treatment, is a bone mineral density test. This will establish whether you have lost bone density and might be at risk of developing osteoporosis (thinning and brittleness of the bones).

How is Cushing’s treated?
If your Cushing’s is caused by a pituitary tumour (Cushing’s disease), you will usually need an operation. It is carried out under a general anaesthetic and involves making a small cut - either in front of the upper teeth behind the upper lip or inside the nose. This is called transsphenoidal surgery. By going behind the nose in this way, the surgeon can see your pituitary gland without having to operate on the main part of your head.

Sometimes the back of the nose needs patching with tissue taken from under the skin of the thigh or abdomen during the operation which will leave a small scar there. Please see our leaflet on Surgery & Radiotherapy.

Most people are up and about and eating normally the following day and are back at home within a few days. Recovery times can vary. Depending on your particular job and circumstances, you should plan to be away from work for four to six weeks, maybe longer. You will need to avoid blowing your nose for three weeks or more while it heals and your front teeth may feel a bit numb for a while, occasionally permanently. You may also lose your sense of smell for weeks or months - although this usually returns to normal as the nerves re-grow. For a few days after the operation some patients feel very thirsty and need to pass urine more than normal. This condition, Diabetes Insipidus (DI), is usually temporary but occasionally can become permanent. It can be treated by using a drug called desmopressin. Please see our leaflet called Diabetes Insipidus. You may also notice peeling of the skin as the cortisol levels fall (this is a good sign). Occasionally it is necessary to carry out a second operation if the first is not completely successful. This can sometimes be done within seven to ten days.

You will need further hormone tests, either immediately and/or four to six weeks after the operation. Again, this may involve a few days in hospital. These tests are designed to
show whether or not the operation has been a success, and whether you have developed deficiencies of other pituitary hormones, known as hypopituitarism, which may need replacement tablets. Please see our leaflet called *The Pituitary Gland; Its Disorders and Hormones Explained*.

Paradoxically, after successful surgery you may feel worse for several weeks and occasionally months before you begin to feel better. Eventually, however, your strength and mood will improve over time and the other symptoms will gradually diminish. This usually takes several months, but be patient - it will happen. You may have to take replacement cortisol (which is called ‘hydrocortisone’ when it is in tablet form) or another steroid tablet such as prednisolone, for some time after your operation to compensate for a temporary reduction in your body’s ACTH production. This occurs because the normal control mechanisms are ‘switched off’ after being exposed to too much cortisol for so long. Hydrocortisone is taken in the form of tablets, usually two or three times a day. If prescribed and you don’t take the tablets (or when they are deliberately not given immediately after the operation or during reassessment tests) you will probably feel generally weak, tired and ‘ill’. However you will feel better after you begin to take the tablets again.

### After surgery

Many patients will be completely cured - their cortisol levels are no longer high - after pituitary surgery but your doctor may prefer to be cautious and call this “remission” until some years have passed. However, if the treatment of your pituitary gland is not fully effective, then there are other solutions. You may need to have both adrenal glands removed. This is called an adrenalectomy. In previous years this was a larger operation performed through the abdomen or side with a longer hospital stay. With modern ‘keyhole’ techniques, however, recovery from the operation is quick and inpatients stay only a few days. After an adrenalectomy you will need hydrocortisone tablets and an additional salt-retaining hormone tablet (called fludrocortisone), both of which you will need to take for the long term and very probably for life. To prevent any recurring problems in the future, or if pituitary surgery is only partially successful, you may also be given pituitary radiotherapy. Please see our leaflet on *Surgery & Radiotherapy*.

Your endocrinologist may recommend adrenal surgery or possibly injections with pasireotide rather than pituitary surgery as a first-line treatment, or if pituitary surgery has not cured the problem. Pasireotide is a relatively new treatment that works by reducing the production of ACTH by the pituitary.
Treatment of Cushing’s

After unsuccessful pituitary surgery - where not all of the tumour can be removed initially and the cortisol levels remain high, or if pituitary surgery has not cured the problem, the choice between adrenalectomy, pituitary radiotherapy and ongoing drug treatment for Cushing’s is a very complicated one - make sure you discuss this fully with your endocrinologist and understand the reasons why a particular treatment has been recommended.

In non-pituitary cases of Cushing’s syndrome (see ‘What is Cushing’s?’ above), treatment depends on the cause.

- In ectopic ACTH the underlying tumour may be removed during an operation or treated with radiotherapy or even chemotherapy
- With adrenal tumours causing Cushing’s, the offending adrenal gland(s) is usually removed
- If the cause cannot be clearly identified then an adrenalectomy may be recommended

Will I be cured or will I need further treatment?

The treatment described above is successful in the majority of cases. The cure is usually permanent, with no further treatment being needed, but it is essential that you have specialist follow up as in some cases Cushing’s syndrome may recur. It is for this reason that your specialist will continue to monitor you on a regular basis to ensure symptoms do not return. Even if you are not cured, most patients find the symptoms improve. You may have to take hydrocortisone permanently, but your specialist may decide that it is worth withdrawing the drug every now and then in the first two or three years after the operation. It is most important that you do not do this yourself as specialist guidance and advice are essential. Please see our Hydrocortisone Information Leaflet. In addition to hydrocortisone you may need to take several additional hormone replacement medications, such as thyroxine, HRT and growth hormone, to replace any lost pituitary function. Your endocrinologist will arrange this for you.
Cushing’s aftercare

Patients who have had Cushing’s always require long-term monitoring and this will be shared between your endocrinologist and GP. Because pituitary conditions are relatively rare, you might find that you will be the only patient with Cushing’s that your GP is treating and they might find it helpful to have a copy of our Pituitary Disease Fact File for General Practitioners.

Psychological aspects
Cortisol is linked to mood so, not surprisingly, more than half of Cushing’s patients have a major depressive disorder (MDD). Usually this depression is atypical in presentation: gaining weight and being restless or agitated are common symptoms. Memory and sleep patterns can also be affected. The degree of depression is linked to the level of cortisol.

Cushing’s-induced depression is usually relieved by treatment of the Cushing’s but often takes some months or more to recede. There is no convincing evidence of a link between stress causing Cushing’s or other endocrine disease.

For further information, please see our Living with and Managing a Pituitary Condition leaflet from our Well-being series.

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. Please see our booklets called Infertility and Relationships.
How will Cushing’s affect my lifestyle?

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 Bureau 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 patient’s experiences if you wish to register and post your own messages. Please see our Employment Booklet.

Prescriptions
If you have to take any of the following: 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 will receive an application when this is due for renewal. Information about free prescriptions and the full list of medical conditions which qualify for exemption from prescription charges can be found in leaflet HC11, available from pharmacies and main Post Offices or on www.dh.gov.uk. If you are not sure whether you are entitled to free prescriptions, you must pay for your prescription and ask for a NHS receipt (form FP57 in England, EC57 in Scotland) when you pay; you can’t get one at a later date. This form 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.

Alcohol & replacement hormones
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.
How will Cushing’s affect my lifestyle?

**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. Transsphenoidal surgery does not in itself limit your entitlement to drive and your doctor or specialist will give you full advice. DVLA say that patients with a pituitary tumour should tick the ‘brain tumour’ box and put a note at the side of the form, stating ‘pituitary tumour’. DVLA will accept any extra brief notes with the form (or at side of form) regarding the patient’s condition, such as stating ‘pituitary tumour’ etc. and that DVLA should contact their specialist endocrinologist for further information if required.

You may also seek further advice from the DVLA by consulting the

*For England, Scotland and Wales: The Medical Adviser, Drivers Medical Group, DVLA, Longview Road, Morriston, Swansea SA99 1TU.*
Tel: 01792 782337 (medical professionals only) or medadviser@dvla.gsi.gov.uk (medical professionals only)

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

**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 (other patients have used, and told us about these companies) also for travel information we can provide.

**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

Q: Why do I need so many tests?
A: Diagnosis and treatment of Cushing’s is very complicated. If doctors don’t gather all the right information about your case then this can lead to the wrong diagnosis or the wrong treatment.

Q: Are the effects on my bones reversible?
A: If you had Cushing’s for some time before treatment commenced, you may have some loss of bone content. Bone scans can be given to check for osteoporosis. Treatment can improve osteoporosis and limit the consequences but may not restore bone completely to normal.

Q: Are the effects on muscle reversible?
A: Muscle strength should eventually return to normal. This will happen gradually, over a period of months or even a couple of years.

Q: Will I be able to wear my dentures after the pituitary operation?
A: You may find that your dentures do not fit very well until the swelling goes down. This should only take a few days.

Q: I am taking hydrocortisone. What happens if I go on holiday and get an upset stomach?
A: If you have serious vomiting and are unable to keep your tablets down, contact a doctor urgently as you could become ill due to lack of cortisol. The doctor may give you cortisol injections until you recover. Your endocrinologist and endocrine specialist nurse may have provided you with one of these injections and have shown you how to use it before you go away. Please see our Hydrocortisone Information Leaflet.

Q: If I have an operation for any other illness, what happens about my hydrocortisone tablets?
A: You should advise the doctors that you are on hydrocortisone and reiterate this point several times to ensure they understand. They will adjust your dose accordingly.

Q: If I suffer from an infection such as bronchitis, influenza or a kidney infection, will this affect my hydrocortisone?
A: The dose of hydrocortisone will need to be increased for a time while you have the infection. Your specialist should give you clear guidelines as to when you should temporarily increase your steroid dose. If in doubt, consult your GP or specialist. Do not experiment with the dosage yourself.
Q: Will I always have high blood pressure or diabetes?
A: Cushing’s is a major cause of these problems and both are improved after successful treatment. In many cases these conditions disappear and do not need treatment, in others better control will usually be achieved on much less medication than before.

Q: When will my excess facial hair improve?
A: Cure of Cushing’s usually results in a gradual improvement of excess facial hair in women. In many cases this will resolve completely over a few months. However, excess facial hair is also a very common problem in women without Cushing’s, and if you have had a tendency towards this in the past then cure of the Cushing’s may not completely resolve the problem. In this case there are a variety of treatments available which you should discuss with your endocrinologist.

Q: Will my periods return and will I be able to have children?
A: Your periods should return soon after surgery and you should be able to have children. If your fertility has been affected by the treatment, you can be given hormones to restore your fertility and enable you to have children.

Q: I have heard that hydrocortisone is a steroid. Will it be bad for me?
A: You will only be given the amount that your body would normally make, so you should not have any of the problems normally associated with steroids. In fact, people usually only need hydrocortisone in Cushing’s because the cause of excessive levels of steroids has been removed.

Q: Will I regain my figure?
A: You should get back to your old self in time, but if you have had Cushing’s for a long time before the diagnosis was made, this may take a couple of years and will require a healthy eating plan, careful dieting and exercise (gentle at first if you are not used to it).

Q: Is a pituitary tumour hereditary?
A: Only in very exceptional cases, less than 1%.
What **Cushing’s** means to me

**One patient’s story**

In six months I had gone from a fit and healthy person, overflowing with joy, to a sad and insecure wreck. It was partly that I seemed to have developed a skin complaint which made my face red and blotchy. It was partly because I had put on so much weight and couldn’t seem to shift it no matter what diets or exercise regimes I followed. But I knew it was more than that, too. I felt sad and depressed most of the time. I began to despise my job and all my material surroundings.

I received a number of different treatments for my skin, firstly from my doctor and later from dermatologists. I scoured health food shops for cures and was tested for various food allergies. I was told I was allergic to almost everything and was put on such a restrictive diet that I became even more depressed about my lifestyle. I was also told that my tiredness was due to overwork, even though I have always worked hard and had previously coped without problems.

I became obsessed by this ‘monster’ which had taken over my life. No one seemed to understand how I felt. Doctors kept telling me tests were negative, implying that my problem was psychological rather than physical, although I felt sure it wasn’t.

My hatred of my job and of my boss grew out of all proportion. I cried in desperation and confusion on many nights. I forced myself to exercise until I dropped in a fruitless effort to lose weight. I looked awful and found I missed the compliments I had once resented. The worst thing was not knowing why I felt so bad. I wanted to die.

My family thought I was having a nervous breakdown and referred me to a psychiatric hospital. I felt they had betrayed me, although I know now that they were trying desperately to help me. Eventually, the psychiatrist saw a photo of me before I was ill and was amazed at the change. Thankfully, he then recognised that I might have Cushing’s and I was sent to a specialist for tests.

After the tests, the endocrinologist sat me down, held my hands and told me I had a rare disease called Cushing’s. When he described the illness I knew he was right. The relief of just being accurately diagnosed at last was tremendous. To be told in addition that my illness was physical rather than psychological, and that it could probably be cured by an operation, was indescribable.

After that, I had all the many tests and two operations. It took me a long time to begin to get back to normal, and I will always have to take replacement medicines, but these problems seemed manageable compared to the time spent living with the ‘monster’ on my pituitary gland for several years before. I only wish I had found my endocrinologist earlier, and hope that The Pituitary Foundation will help other people to avoid going through what I went through.

**Other Support Organisations**

**National Osteoporosis Society** [www.nos.org.uk](http://www.nos.org.uk) Help Line: 0845 450 0230
Please support The Pituitary Foundation

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

✔ Receive our members’ newsletter, 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.
✔ 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 £20.00 for a full year, which is only £1.66 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,
86-88 Colston Street,
Bristol, BS1 5BB

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

I wish to become a Member of THE PITUITARY FOUNDATION

Title: ___________________________ First Name: ___________________________ Surname: ___________________________

Address: ___________________________

Postcode: ___________________________

Telephone No: ___________________________ Email: ___________________________

Please tick (✔) the type of Membership you require:

Individual ☐ £20.00 (annual) Family ☐ £35.00 (annual)
Life Membership ☐ £250.00 Concessionary* ☐ £10.00 (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).

Gift Aid: I am a UK Taxpayer. Please treat all membership payments and donations I have made for 6 years prior to this declaration and all that I make from this date, until I notify you otherwise, as qualifying for Gift Aid (please tick) ☐

You must pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6th April one year to 5th April the next) that is at least equal to the amount of tax that the charity will reclaim on your gifts for that tax year.

Signature: ___________________________ Date: ___________________________