

## Patient information

### Cushing's Disease

Diabetes and Endocrinology

#### What is Cushing's disease?

Cushing's disease is the result of the body producing too much of the hormone Cortisol; this is the main glucocorticoid made by the body. Glucocorticoids are a type of steroid hormone.

Cortisol is the hormone we produce to help our bodies cope with any stresses we face in our daily lives. It also helps to regulate blood pressure, helps the body respond to stress, helps to regulate the immune system and helps to balance the effect of insulin to keep blood sugar levels normal.

It is produced by the adrenal glands, which are two little glands that sit above each kidney. Cortisol production is stimulated by the release of Adrenocorticotrophic hormone (ACTH) from the pituitary gland.

The cause of the overproduction can be either due to a benign (non-cancerous) tumour in the pituitary gland or the adrenal glands. The cause will have to be investigated in hospital to allow your doctor to find out which gland is causing the problem.

#### If there is a tumour, have I got cancer?

No - in more than 99% of cases, Cushing's is caused by a benign (non-cancerous) tumour in the pituitary gland. These tumours grow very slowly within the pituitary gland. Patients with Cushing's have often had the condition for several years before diagnosis is confirmed.

#### If I don't have cancer why do I need treatment?

Although the tumour is not cancerous, it is important that you receive treatment in order to reduce the amount of cortisol produced. Untreated Cushing's will increase your risk of developing hypertension (high blood pressure), diabetes and strokes.

#### How will I know if I have Cushing's?

You may notice that you put on weight, especially around your middle. Your face may become round and 'moon' like.

Women may notice their body hair increasing and may begin to develop facial hair too. You may notice you tend to bruise more easily and that your skin becomes thinner and more fragile when damaged. You may notice that it takes longer for injuries to heal.

As the disease progresses you may have increasing muscle weakness, especially in your legs (proximal myopathy). You may notice it becomes harder to stand from a sitting position without help and climbing stairs or getting in and out of a car becomes more difficult. You may be more prone to developing osteoporosis (brittle bones), high blood pressure (hypertension) and diabetes.

### **How is it diagnosed?**

As already mentioned, the cause will need to be identified before treatment can begin. We need to find out if the Cushing's disease is due to the pituitary gland producing too much ACTH, or the adrenal glands producing too much Cortisol. This means the tests you have will be long and varied and may be performed on several occasions. There are separate leaflets available for each test.

The first investigation involves you taking a tablet late at night and attending hospital in the morning to have a blood test. As the investigations continue, you can expect to have other more in-depth tests performed. These tests are usually performed on an outpatient basis, and you may only need to attend hospital for short periods of time for blood, urine tests etc. This enables the medical team to diagnose you accurately.

You may be asked to attend our day ward where staff will explain the tests to you before they begin, and staff are on hand if you have any questions or concerns you wish to discuss.

Some of the drugs used in the tests may make you feel nauseous. While this may be unpleasant for you, it is important to try to continue with the test so that we can find out exactly what is happening to you.

You may also require an MRI or CT scan of your head and possibly your abdomen and chest. These scans are performed with you lying flat on a table. The table is then inserted into the scanner and detailed pictures of the internal organs the doctors want to look at are shown. It is painless and is completed in less than 30 minutes.

The staff on the day ward will explain the tests to you before they begin, and are on hand if you have any questions or concerns you wish to discuss.

Some of the drugs used in the tests may make you feel nauseous. While this may be unpleasant for you, it is important to try to continue with the test so that we can find out exactly what is happening to you.

### **What happens after the tests?**

It can take several days for all of the results to be available for the doctors to review them. Once they have been seen, the doctor will be able to tell you whether the problem is with your pituitary gland or adrenal glands. When this is known, treatment can begin.

The first line of treatment is usually surgery; however, the doctors may want to treat your high cortisol levels before you have your operation. They do this by giving you a course of tablets, usually Metyrapone.

If you need surgery on the Adrenal glands, then this is usually performed at Royal Liverpool University Hospital.

If the cause of the Cushing's is the pituitary gland, then you will be seen at the Walton Centre NHS Foundation Trust.

If you need surgery on your pituitary gland, this is usually performed at the Walton Centre NHS Foundation Trust. A separate leaflet is available about the surgery. Please ask for PIF 1066.

### **What happens after surgery?**

If you have pituitary surgery then you will need to take cortisol replacement. This is given in tablet form known as **Hydrocortisone. This is important and you must remember to take it.**

We will repeat the investigations that you had to confirm your diagnosis, so that we can assess if surgery has been successful.

If you need surgery to remove your adrenal gland/s; and only one adrenal gland is removed you will be allowed to recover and then investigations similar to those used to confirm the diagnosis will be performed. This is so that we can be sure you have been effectively treated.

If both adrenal glands are removed you will need to take replacement cortisol. This is given in tablet form known as **Hydrocortisone. This is important and you must remember to take it.**

We will also perform further investigations to be sure that you have been treated effectively for Cushing's disease.

You will be given a blue coloured steroid card that you should carry with you to alert anyone involved in your care that you take a steroid replacement. You will also be given a red coloured steroid card that you must also carry with you, to show to health professionals if you become unwell. This card advises health care professionals on the management of adrenal crisis.

This is because you will need an increased dose of hydrocortisone if you are ill. There is a separate leaflet available describing how to manage illness or stress when taking Hydrocortisone.

You should continue taking your medication until you are seen again in hospital for your postoperative assessment. This will take place approximately eight weeks after your surgery.

You will then have an appointment made to see both the Surgeon and Endocrinologist in clinic.

### **Will I be cured or need further treatment?**

Surgery is successful in many cases. You may be cured and no longer need treatment, this is most likely if the problem was in one Adrenal gland only. You will still be monitored on a regular basis to ensure your symptoms do not return.

If you are not completely cured, you should be feeling better and find that some of your symptoms will improve.

You will need further investigation and treatment, with surgery or radiotherapy, to become fully cured.

If you are taking Hydrocortisone, your specialist may want you to stay on this treatment permanently. Your specialist will monitor this and they will tell you of any changes they need to make to your regime.

Except for periods of illness or stress please do not adjust the dosage yourself. Always get advice from your specialist, Endocrine nurse or family doctor (G.P) before making any changes.

You may also like to get a Medic Alert bracelet or necklace as they are recognised worldwide, and the information will help doctors if you have an accident or are unconscious.

### **Related Trust patient information leaflets:**

PIF 019 Hydrocortisone replacement therapy.

PIF 1021 Hydrocortisone/Prednisolone Replacement Therapy What to Do During Illness and / or Stress

PIF 1020 Hydrocortisone replacement-instructions on reducing or discontinuing therapy.

### **Feedback**

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your Outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

### **Further Information**

**Please feel free to contact the Endocrine Specialist Nurses with any questions you may have. There is an answer machine where you can leave your name and contact details. We will return all calls.**

**The Endocrinology Specialist Nurses**

**Tel: 0151 706 2417**

**Text phone number: 18001 0151 706 2417**

**There is also a very good patient support group, which offers excellent advice via leaflet and telephone contact. They also hold local area group meetings.**

**The Pituitary Foundation**

**PO Box 1944,**

**Bristol, BS99 2UB.**

**Tel: 0845 450 0375**

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

Royal Liverpool Hospital

PIF 994 V7

## Medical alert jewellery (some examples)

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

[www.medicaltags.co.uk](http://www.medicaltags.co.uk) (SOS talisman)

[www.theidbandco.com](http://www.theidbandco.com)

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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