

## Information for patients with Cushing's Syndrome

### What are Cushing's disease and Cushing's syndrome?

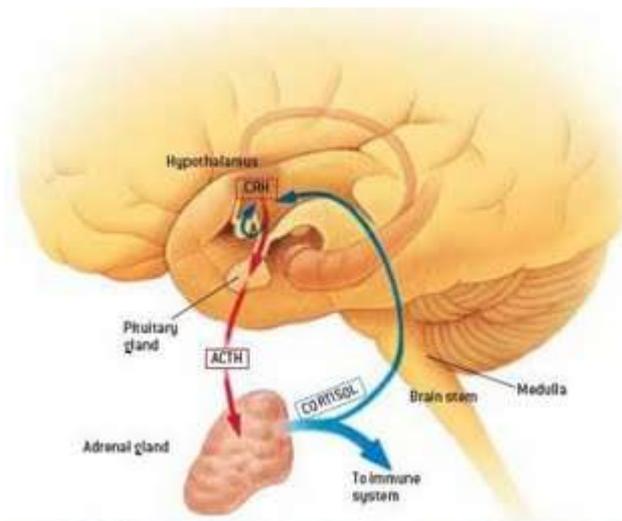
A pituitary tumour producing too much **ACTH** causes Cushing's disease. This is named after Harvey Cushing, a neurosurgeon who first discovered this condition in 1912. **Cushing's disease** is a specific type of Cushing's syndrome, and is caused by a pituitary tumour producing too much of the hormone ACTH.

**Cortisol** is a steroid hormone produced by the adrenal glands, which sit on top of the kidneys. The body needs normal levels of cortisol to manage stress (such as a significant illness or an operation), to regulate blood pressure, to fight infection (immune system) and to regulate weight, particularly fat distribution. ACTH from the pituitary gland tells the adrenal glands to produce cortisol.

**Cushing's syndrome** describes any patient with symptoms or signs of high cortisol levels. The most common cause is patients taking **steroid medication** (glucocorticoids) for inflammatory conditions such as rheumatoid arthritis or asthma. Looking at cases of Cushing's syndrome not due to excessive steroid medication, **pituitary ACTH-producing tumours** account for approximately 70% of cases. In about 15% of cases, high levels of ACTH are produced by a **non-pituitary tumour**, most frequently arising in the lung (ectopic ACTH). The remainder of cases are due to adrenal abnormalities, largely **adrenal tumours**, producing high levels of cortisol.

### What are the symptoms of Cushing's syndrome?

- Weight gain (especially around the abdomen)
- Rounded face
- Fat pad between the shoulder blades
- High blood sugar (diabetes)
- High blood pressure
- Thin bones (osteoporosis)
- Muscle weakness eg getting out of a chair
- Thin skin and easy bruising
- Violet-red stretch marks over the abdomen
- Low mood, mood swings
- Irregular/absent periods, poor libido (sex drive), excess facial hair and acne
- Poor libido, erectile difficulties



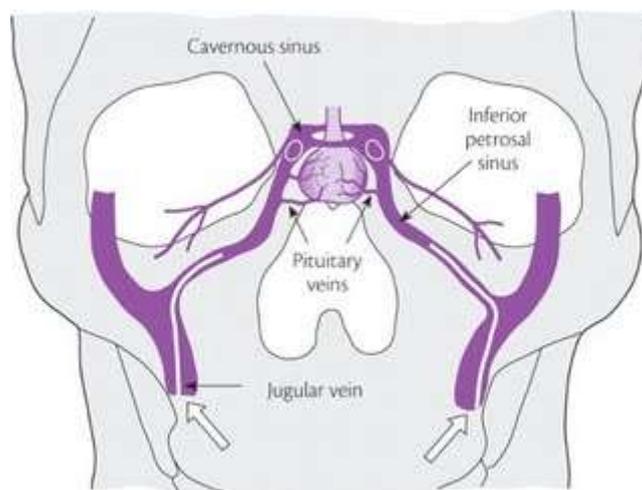
### How would I be investigated for Cushing's syndrome?

After careful evaluation by an endocrinologist, a series of investigations will be performed. The first type of investigation is to confirm that cortisol levels in the blood are too high.

You may be asked to collect all the **urine** that you produce over a 24 hour period in a special collecting bottle to allow measurement of cortisol levels in the urine. In addition to this, you may be admitted to our Clinical Investigation Unit to allow us to measure cortisol levels at specific times in the day. You may also undergo a special test called a **low dose dexamethasone suppression test**. During this test, you will receive a series of dexamethasone tablets at specific times over a 48 hour period. Dexamethasone is a man-made, synthetic steroid. In patients with Cushing's syndrome, blood cortisol levels at the end of this test remain high, whereas in healthy people, dexamethasone can transiently switch off cortisol production.

Once we have confirmed that you are making too much cortisol, subsequent investigations focus on finding out the cause of the problem ie a pituitary tumour, ectopic ACTH or adrenal tumour.

If we suspect a pituitary tumour making too much ACTH, you will have a pituitary MRI scan and have a special test called **inferior petrosal sinus sampling**. This test is only available in specialist centres and we have considerable expertise in this technique. A highly experienced x ray specialist (radiologist) will thread a small tube up through the large veins in the leg until they reach the small veins that drain blood away from the pituitary gland. Measurement of ACTH levels in blood samples from the pituitary gland allows us to confirm that the pituitary is making too much ACTH.



If this test shows that ACTH is coming from outside the pituitary gland, we will plan certain tests to establish where the ACTH is coming from eg a CT (computed axial tomography) scan of your lungs. If we suspect a adrenal tumour is causing your Cushing's syndrome. You will undergo a CT scan of the adrenal glands.

### How is Cushing's syndrome treated?

The treatment of Cushing's syndrome depends on the cause.

- Adrenal tumours are often removed **by laparoscopic (keyhole) surgery**, and our endocrine surgeon is very experienced at this technique. You will receive medication to lower the cortisol levels for six weeks prior to surgery to allow the wound to heal well after surgery.
- If your Cushing's syndrome is due to a pituitary tumour making too much ACTH, you will be offered **trans-sphenoidal pituitary surgery** by our dedicated, experienced pituitary surgeons.
- You may be offered the choice of having **both adrenal glands** removed by laparoscopic surgery. If you choose this option, you will need lifelong daily medication (hydrocortisone and fludrocortisone) to replace your adrenal hormones.