

Symptoms of Cushing's disease

Patients with Cushing's disease typically:

- Gain weight, especially in the upper body
- Have a rounded face and extra fat on the upper back
- Have high blood sugar (diabetes)
- Have thin bones (osteoporosis)
- Muscle loss and weakness
- Thin, fragile skin that bruises easily
- Purple-red stretch marks, especially on the abdomen and upper arms
- Depression & unable to focus
- Abnormal facial hair in women
- Irregular or absent periods
- Reduced sex drive

Treatment for Cushing's disease

The goal of treatment is to lower cortisol levels by:

1) Surgery: Surgery to remove the pituitary tumour is the first treatment.

If pituitary surgery alone isn't enough or if you aren't a candidate for surgery, radiation, medications, or removal of the adrenal glands may be needed:

- **Pituitary irradiation** (radiation therapy on the pituitary gland) to destroy tumour cells.
- **Medication:** To lower cortisol levels. The most common medication is ketoconazole but others include metyrapone and mitotane.

CUSHING'S DISEASE PATIENT & FAMILY GUIDE



St. Paul's Hospital and
Vancouver General Hospital's
Neuropituitary Program

Vancouver, British Columbia

"Life is the answer. We keep going on....undaunted and ever hopeful"—
quote from patient with Cushing's
disease

Supported by an educational grant:

EMD Serono

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Also ask us for these materials:

- Adrenal insufficiency book
- Cushing's disease record book
- Medication guidelines & coverage
- Cushing's disease lab tests
- Transsphenoidal Surgery
- Endocrine links & support groups
- Adrenal insufficiency travel letter
- Medical alert bracelet

Adapted from:
Hormones & You: Cushing's
Syndrome. **The Hormone
Foundation.**

Cushing's disease and You

What is Cushing's disease?

Adrenal Glands

The adrenal glands, located on top of each kidney, secrete the hormone cortisol. The pituitary gland controls the release of cortisol by making a hormone called ACTH.

Cortisol is needed for the metabolism of sugar and protein, maintaining blood pressure, and it also helps the body recover from infection and stress.

In Cushing's disease, the adrenal glands produce too much cortisol. This is often caused by a hormone-secreting tumour in the pituitary. In the pituitary, the tumor produces too much ACTH—the hormone that tells the adrenal glands to make cortisol.

Statistics show that there are about 2-3 new cases of Cushing's disease per million people each year.

What causes Cushing's disease?

Pituitary Adenoma

A **non-cancerous** tumour in the pituitary gland is called a pituitary *adenoma*. This tumour produces too much ACTH which raises the level of cortisol in the blood.

How is Cushing's disease diagnosed?

A blood test to check your level of cortisol is done between 11pm to midnight. Normally, cortisol levels are lowest at this time of day but with Cushing's it will be high. Cortisol levels can also be measured in the urine over a 24hr period.

Another test is the *dexamethasone suppression test*. Your levels of cortisol in the blood are measured the morning after taking a late night dose of dexamethasone (a steroid). Normally, the dexamethasone causes cortisol levels to drop very low but with Cushing's, this does not happen.

Imaging studies, such as MRI and CT scans, also help locate the pituitary tumour.

Other Resources

- www.hormone.org or call 1-800-467-6663
- The Endocrine Society (www.endosociety.org)
- <http://www.cnetscanada.org/index.html> (Neuroendocrine tumour society Canada)

- www.pituitary.org.uk (The Pituitary Foundation)
- www.pituitarydisorder.net
- www.pituitarysociety.org
- <http://www.nichd.nih.gov/health/topics/cushingssyndrome.cfm>
- <http://www.endocrineweb.com/>
- www.IdentifyYourself.com

"You are not alone with your Cushing's disease"

