

Too Much of a Good Thing

Cushing's disease and Cushing's syndrome are 2 closely related conditions. They affect many thousands of people each year, mostly women. Cushing's disease usually appears in adults age 20 to 50, but it also can affect children and teenagers. It occurs in about 80% of people with Cushing's syndrome. Both conditions are caused by the production of too much cortisol.

Dr Harvey Cushing first identified a chronic obesity-related wasting disease caused by **tumors (adenomas)** in the pituitary gland. Pituitary tumors can be cancerous or noncancerous (**benign**) and they can be functioning or nonfunctioning. Functioning tumors produce excess hormone. In people with Cushing's disease, a noncancerous tumor in the pituitary gland produces too much ACTH. This causes too much cortisol to be produced. The symptoms of Cushing's disease are caused by high levels of cortisol over a long period.

Functional pituitary tumor



Excess ACTH



Excess cortisol



Cushing's disease

“After proper testing, an MRI, and treatment, I'm finally back to my old self.”



Pituitary Network Association
Because Knowledge is the Best Defense.
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For More Information

Cushing's Support and Research Foundation
(www.csrf.net)

Provides information and support for patients with Cushing's syndrome or disease and their families.

American Association of Clinical Endocrinologists
(www.aace.com)

Provides information about endocrine disorders and helps you locate an endocrinologist in your area.

The Hormone Foundation (www.hormone.org)

Answers general questions about various pituitary tumors, medical treatments, and hormone replacement therapy.

MEDLINEplus® Health Information
(www.medlineplus.gov)

Has a medical encyclopedia that contains facts about Cushing's disease and pituitary disorders in general.

National Institute of Child Health and Human Development (NICHD) (www.nichd.nih.gov)

Conducts research on the various processes that determine and maintain the health of individuals, families, and populations.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) (www.niddk.nih.gov)

Provides links to national organizations serving patients concerned about endocrine and metabolic diseases.

Pituitary Network Association (www.pituitary.org)

Provides information about ongoing clinical trials, medical resources and terminology, and links to other organizations.

Living with CUSHING'S DISEASE

*Relieve the Symptoms
Restore Your Life*



There May Well Be a Cure!

Cushing's disease can be a frustrating and debilitating disease. It's more common in women than men and can go without being diagnosed for years. If left untreated, Cushing's disease degrades your quality of life and leads to life-threatening complications. The good news is that it can be treated. You may lose the weight, the hump, the excess facial hair, the moon face, and streaks in the skin. You may even experience a full recovery.

If you have Cushing's disease, relieve your symptoms and suffering and take back your life. What it takes is a proper diagnosis and the right treatment. You need to seek care from an **endocrinologist**, neurosurgeon, or neuroendocrinologist—doctors who specialize in this pituitary disorder. You need to take an active role in your treatment and recovery.

Cortisol—Keeping Systems in Check

The **pituitary gland** or “master gland” is a small, oval organ attached to the brain. It controls many of the body's **hormones**. The pituitary gland also produces many of its own hormones, one of which is adrenocorticotropic hormone, or **ACTH**. This hormone causes the **adrenal glands** (located just above the kidneys) to make cortisol, which affects almost every cell in the body. Under normal conditions, ACTH causes the release of cortisol, which does the following:

- It balances the effects of insulin
- It helps the body respond to stress
- It maintains proper blood pressure and heart function
- It regulates the metabolism of carbohydrates, proteins, and fat
- It manages the immune system



I'm Fat for No Reason!

Cushing's disease has many varied and subtle signs and symptoms. The most common sign is obesity, but not always. The face becomes rounded (moon face), the back of the neck thickens (buffalo hump), and the waist widens (truncal obesity). Other symptoms may include:

- Acne
- Backache
- Bone thinning
- Depression
- Diabetes
- Easy bruising
- Emotional changes
- Facial hair growth (women)
- Fatigue or weakness
- Headaches
- Impotence
- Increased urination
- Irregular or no menstrual periods
- Muscle wasting
- Purple stretch marks
- Skin infections
- Thirst

One Doctor After Another

The symptoms of Cushing's disease are seen in many other diseases, so the disease often is not readily recognized by doctors. Patients frequently suffer for years before a proper diagnosis is made. Diagnosis requires a patient's medical history, a physical exam, and lab tests to see if there is too much cortisol in the body. These tests may include:

- 24-Hour urinary free cortisol and creatinine levels
- **Dexamethasone suppression test** (low dose)
- Serial serum and nighttime saliva cortisol levels

"I gained a lot of weight and developed a moon face and buffalo hump."



Then the cause of excess cortisol must be determined. Tests that determine the cause are:

- Serum ACTH levels
- Chest x-ray films, MRI scans of the pituitary gland and adrenals, or adrenal ultrasonograms
- Petrosal sinus sampling
- Dexamethasone suppression test (high dose)/corticotropin-releasing hormone stimulation test

Rebalance Cortisol, Relieve the Symptoms

Untreated, Cushing's disease can cause severe illness, complications, and even death. You could have complications such as:

- Bone fractures
- Diabetes
- High blood pressure
- Infections
- Kidney stones
- Psychosis

Cushing's disease is treated in 3 ways: surgery, radiotherapy, and medication. You and your doctor can decide what's best.

Surgery (transsphenoidal resection) can be used to remove the pituitary tumor. This operation reaches the pituitary gland under the lip or through a nostril. Patients are best referred to medical centers that specialize in this procedure. You can have a good outcome with surgery and possibly a full recovery. Only a slight possibility remains that the tumor will return. Another type of surgery called an adrenalectomy (removing the adrenal gland) may also be done.

Radiotherapy involves the use of x-rays to the pituitary gland. Radiation kills off tumor cells and is generally used in patients when surgery fails and medications no longer work or are not tolerated.



Medications are also used to treat the disease. Mitotane may be given to speed recovery. Medications like aminoglutethimide, metyrapone, ketoconazole, and trilostane may be used to help control cortisol levels. All are fairly effective, but they have some side effects.

Progress Happens Slowly

After surgery, your pituitary function may slowly return to normal. A synthetic form of cortisol (hydrocortisone) may need to be taken to replace cortisol. Your doctor will prescribe lower doses to taper (gradually take you off) the cortisol. If the medication is tapered too fast, you may experience "cortisol withdrawal," with symptoms such as:

- Abdominal pain
- Depression
- Dizziness
- Fatigue
- Headaches
- Muscle and joint aches
- Nausea
- Vomiting

Call your doctor if you have these symptoms after surgery. You will need to take the medication for several months or longer.

Am I Really Cured?

Many patients treated for Cushing's disease are pleased after their symptoms resolve. Your weight should drop in the first few months after surgery. Your looks should change slowly. It may take several months for the fatigue and depression to subside. You will still need to be monitored regularly. Here is some advice from a patient previously troubled with Cushing's disease:

- Take an active role in your treatment and recovery
- Keep regular appointments with your doctor
- Keep your family doctor aware of your condition and any returning symptoms
- Read the latest information about Cushing's disease



"Be assertive. Restore yourself."

- Eat healthily and exercise regularly
- Have your hormone levels checked regularly
- Have your blood glucose levels, blood pressure, and bone density checked regularly
- Have your medications adjusted if you also have diabetes, high blood pressure, or osteoporosis

Glossary

ACTH - Adrenocorticotropic hormone is a hormone produced by the pituitary gland that controls the release of cortisol.

adenoma - A noncancerous tumor made up of cells that form glands.

adrenal glands - Small glands located above the kidneys that produce cortisol.

benign - Not malignant, not cancerous.

dexamethasone suppression test - A test used to measure the response of the adrenal glands to ACTH. Dexamethasone is given and the levels of cortisol are measured.

endocrinologist - A doctor specializing in diseases of the endocrine glands and their hormones.

hormones - "Chemical messengers" that are made and released by endocrine glands and that target one or more parts of the body.

pituitary gland - Master gland of the endocrine system that produces several hormones, including ACTH.

tumor - An abnormal growth that may be cancerous or noncancerous depending on the cell type. It may cause visual impairment or may be life-threatening depending on the location.