


Understanding Cushing's Syndrome

Conditions such as weight gain, diabetes and high blood pressure—which together are termed Metabolic Syndrome—are increasing dramatically in the population. In some cases, these and a multitude of other symptoms are caused by a little known disorder called Cushing's Syndrome. Many reports in the medical literature have shown that 1-3% of patients with diabetes mellitus have unsuspected Cushing's syndrome and that Cushing's is more common in those with hypertension or osteoporosis, particularly at a young age. Approximately 10-20% of patients with adrenal nodules found on CT imaging may have evidence of excessive cortisol secretion.



- Abdominal Weight gain
- Red, Round Moon face
- Thinning extremities
- "Buffalo" hump
- High blood pressure
- High blood sugar
- Muscle weakness
- Osteoporosis/Fractures
- Infections
- Blood clots
- Easy bruising
- Thin skin
- Poor wound healing
- Acne
- Purple stria
- Hirsutism
- Female balding
- Menstrual irregularity
- Sleep disorders
- Excessive hunger
- Excessive thirst
- Frequent urination
- Sweating
- Anxiety
- Confusion
- Memory loss
- Concentration loss
- Depression
- Suicidal thoughts
- Panic attacks
- Decreased growth with increasing weight in children

What is Cushing's Syndrome?

Cushing's Syndrome results from exposure of the body to too much of an adrenal hormone called cortisol. While the most common cause of Cushing's is the prolonged use of cortisone drugs, such as prednisone*, commonly prescribed for asthma or arthritis, approximately 10–15 people per million are affected by Cushing's due to over production of cortisol by the body's adrenal glands. Cushing's Syndrome in adults affects more females than males and, while rare, Cushing's can also occur during childhood.

Normally, the pituitary gland stimulates the adrenal gland to release the exact amount of cortisol that is needed. Over-production of cortisol can be caused by:

- A pituitary tumor that causes the pituitary gland (located at the base of the brain) to stimulate the adrenal glands to secrete high levels of cortisol
- A tumor in the adrenal glands
- A benign or malignant tumor on the lung or some other organ.

What are the symptoms?

The primary symptoms are listed in the box, but it is important to recognize that each Cushing's patient presents slightly differently. Not all patients experience every symptom and symptoms do not seem to appear in any particular order. While some patients experience very rapid changes, others report a gradual onset. At some point during Cushing's, virtually all patients will experience a change in appearance, including weight gain, a redistribution of fat to the face ("moon face") and the upper back ("buffalo hump"), and thinning extremities due to muscle weakness. Early in the disorder these symptoms may be mild, but they progress the longer the disorder goes undiagnosed.

It is essential that Cushing's be diagnosed, for if left untreated, Cushing's Syndrome can be fatal.

* Rapid discontinuation of steroid medication can be life threatening and needs to be done under the supervision of a physician.



With Cushing's Normal Appearance

Cushing's Syndrome has many symptoms, including weight gain and a change in appearance.



Normal Appearance

With Cushing's

Patients often report the weight gain as being unstoppable:

"I went to every weight loss center, exercised, underwent hypnosis, tried every diet imaginable, but could never lose any weight."

Other patients focus on the muscle weakness:

"I got so weak I could barely climb stairs, had a hard time getting out of a car, and needed two hands to hold a glass of water."

Sleep disorders, easy bruising, bone fractures, poor wound healing, menstrual problems, facial hair growth (hirsutism), depression, and cognitive difficulties are also common. The purple stretch marks (striae) experienced by many patients are considered to be somewhat more specific for Cushing's than some other symptoms.

How is Cushing's Syndrome diagnosed?

The diagnosis of Cushing's requires laboratory tests to determine if cortisol levels are increased. Cortisol levels are normally highest in the morning and very low at night time. Thus, one common screening test involves the collection of urine over a 24-hour period. Salivary cortisol tests done at 11pm and overnight dexamethasone tests are also used as screening tests and can be ordered by any physician. Mild and cyclic cases of Cushing's can be difficult to diagnose. Anyone with an abnormal test should be referred to an endocrinologist, a physician who specializes in hormonal disorders. The endocrinologist will complete more testing to determine the cause of the abnormal result and recommend treatment. Generally, treatment for pituitary and adrenal tumors involves surgical removal of the tumor and patients experience an increased quality of life following treatment. More information on testing can be found on the Cushing's Support and Research Foundation website at www.CSRF.net - Understanding Cushing's - Diagnostic Testing and in The Endocrine Society Guidelines for the Diagnosis of Cushing's (Journal of Clinical Endocrinology & Metabolism, May 2008, 93(5): 1526-1540).

About the CSRF

The Cushing's Support and Research Foundation was established in 1995 to provide information and support to Cushing's patients and their families. Incorporated as a non-profit organization in the state of Massachusetts, the CSRF is an Associate Member of NORD, maintains a Medical Advisory Board consisting of very experienced surgeons and endocrinologists who are world renowned for their expertise in Cushing's, publishes a newsletter, exhibits at medical conventions to increase awareness, and provides a networking service to put patients and families in contact with each other.

This brochure was reviewed for accuracy by Dr. James Findling, Professor of Medicine, Endocrinology, Medical College of Wisconsin.



Normal Appearance

With Cushing's

"It took 3 years, visits to 21 doctors, and a long struggle with a multitude of symptoms to get a diagnosis. I'd never had high blood pressure or blood sugar before. I couldn't sleep, got very depressed, and was so weak that it was an effort to move at all. I couldn't concentrate enough to read, and actually quit driving. My diagnosis was such a relief!"

