



# Cushing Syndrome: What You Need to Know

**Cushing syndrome is a rare disorder in which the adrenal glands (small glands on top of the kidneys) make too much of a hormone called cortisol. In this handout, learn the causes and symptoms of Cushing syndrome, and how doctors diagnose and treat the disorder.**

## WHAT IS CUSHING SYNDROME?

**Cushing syndrome** is a rare disorder in which the **adrenal glands** (small glands on top of the kidneys) make too much of a hormone called **cortisol**.

In normal amounts, cortisol (sometimes called the **stress hormone**) helps the body respond appropriately to stress. Cortisol also helps maintain blood sugar levels and blood pressure. In children, too much cortisol can cause poor growth in height in combination with marked weight gain. It can also interfere with metabolism and cause high blood sugar levels.

## WHAT CAUSES CUSHING SYNDROME?

Cushing syndrome can be caused by endogenous (internal) and/or exogenous (external) factors.

### Endogenous

- Tumor of the adrenal gland
- Too much **adrenocorticotropic hormone (ACTH)**, a hormone made by the pituitary gland, that stimulates the adrenal glands to make cortisol
- Other tumors that make too much ACTH
- High levels of other hormones that increase ACTH production (such as CRH)

## WHAT CAUSES CUSHING SYNDROME? (CONTINUED)

### Exogenous

- Long-term use of moderate to high doses of medications called **glucocorticoids**. Glucocorticoids include hydrocortisone, prednisone, prednisolone, dexamethasone and other similar medications. These medications are used to reduce inflammation in conditions such as asthma, arthritis, inflammatory bowel disorders and connective tissue disorders. While taking these medications by mouth is the most common cause of Cushing syndrome, this condition also occurs with prolonged and heavy exposure to glucocorticoids applied on the skin or inhaled. Thus, it is very important to follow the directions of a health care professional to avoid overuse of such medications.

## WHAT ARE THE SYMPTOMS OF CUSHING SYNDROME?

The most common symptom in children with Cushing syndrome is weight gain without an appropriate increase in height. This is the most common symptom of Cushing syndrome in children who are still growing.

Symptoms may vary among patients with Cushing syndrome. Here are the most common symptoms and signs:

- Weight gain, particularly around the abdomen (belly area)
- Slow or no change in height (this is not useful if your child has completed growth.)
- Round and red appearance of the face (sometimes called "moon face")
- Fat deposition in the neck and upper back
- Thin arms and legs
- Muscle weakness
- Purple or red stretch marks

***More symptoms on the back >>>***

## WHAT ARE THE SYMPTOMS OF CUSHING SYNDROME? (CONTINUED)

- Skin that bruises easily
- Hair loss
- High blood pressure
- Darkening of the skin on the back of the neck, armpits, elbows and other regions

## HOW DO DOCTORS DIAGNOSE CUSHING SYNDROME?

The doctor will go over your child's health history and do a physical exam. They might also do screening tests to figure out if your child's body is making high levels of cortisol.

Screening tests may include:

- A 24-hour urine collection for cortisol measurements
- Late-night saliva sample (11 p.m. to midnight) for cortisol measurement
- Assessment of a morning (8 a.m.) cortisol level following administration of oral dexamethasone at 11 p.m. the previous night

If 2 out of the 3 screening tests show high cortisol levels, the doctor will do more tests to figure out the cause of endogenous cortisol production, such as a pituitary tumor making an excess of ACTH (also called Cushing disease), an adrenal tumor, or a tumor at a different site making too much of ACTH or a hormone that stimulates ACTH production (**ectopic Cushing syndrome**). These tests include:

- An ACTH level
- Imaging studies, such as an MRI or CT scan (to look at the pituitary gland, adrenal glands or other places for tumors)
- Other tests that depend on the results of the previous tests

## HOW DO DOCTORS TREAT CUSHING SYNDROME?

Treatment of Cushing syndrome depends on the cause. For causes related to exogenous exposure to glucocorticoids, a member of your child's care team might change the dose and/or how often your child takes this medication.

For tumors of the pituitary gland, adrenal glands, or ectopic tumors, surgery is the first option for treatment. In some cases, your child might also need radiation or medications to lower the amount of cortisol the body makes.

## WHAT OTHER CONDITIONS CAN HAPPEN IN OR BE ASSOCIATED WITH CUSHING SYNDROME?

- Long-term use of glucocorticoids can lead to diabetes and high blood pressure.
- Certain conditions are associated with an increased risk of Cushing syndrome. These include multiple endocrine neoplasia type 1 (MEN1) and Carney Complex. Some studies have reported a relatively high prevalence of Cushing Syndrome among women with obesity and polycystic ovarian syndrome.

## WHEN SHOULD I CALL THE DOCTOR?

Call the doctor if your child shows symptoms of Cushing syndrome, especially if they are gaining weight quickly without a change in height.

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