

Cushing's Disease

Causes, symptoms, diagnosis, and treatments

This handout explains Cushing's disease, its causes, symptoms, and how it is diagnosed. It also includes a short section on what to expect if your doctor advises you to have surgery to treat your condition.

What is Cushing's disease?

Cushing's disease is a condition that is caused by too much of a hormone called *cortisol* in the body. It is often caused by a tumor in the pituitary gland. The tumor secretes *adrenocorticotropic hormone* (ACTH), which causes the adrenal glands to produce extra cortisol.

What is cortisol?

Cortisol is a hormone made by your adrenal glands. It helps your body respond to stress, regulate blood sugar, and fight infections. In most people, cortisol levels are highest in the morning and lowest around midnight.

Your body also makes extra cortisol when you are anxious or under a lot of stress. Over time, high levels of cortisol can affect your health.

What are the symptoms of Cushing's disease?

Symptoms of high levels of cortisol include:

- Vision problems
- Headaches
- Fatigue (being very tired)
- Trouble sleeping
- Muscle weakness
- Infections, high blood pressure, and high blood sugar (*diabetes*)
- *Osteoporosis* (weak, brittle bones and bone loss)
- Thin skin that bruises easily



Be sure to tell your doctor about all of your symptoms. This will help your doctor know what next steps to take.

- Pink or purple streaks on the stomach, thighs, or buttocks
- For women, irregular menstrual periods and excess hair on their face and chest

Cushing's disease can also cause changes in how you look. These include:

- Round or red face
- Hump on back of neck
- Weight gain around the belly with thinner arms and legs
- Acne or hair growth on the face

How is Cushing's disease diagnosed?

Your doctor may order several tests to help diagnose your condition.

- **Serum cortisol test:** This blood test measures the level of cortisol in your blood.
- **Urine or saliva tests:** These tests measure the level of cortisol in your urine or saliva.
- **Other blood tests:** Other blood tests can also measure your body's response to certain hormones to help find the cause of your high cortisol levels.
- **Imaging scans:** You may also have scans to look inside your body for growths or tumors that can affect cortisol levels. These tests may include:
 - *Computed tomography (CT) scan*
 - *Magnetic resonance imaging (MRI) scan*

Serum Cortisol Test

For this test, a needle will be used to draw a blood sample from a vein in your arm. The timing of the test is important, because cortisol levels change during the day. Most times, we test serum cortisol twice in the same day – early in the morning and again around 4 p.m.

Are there any risks in having this test?

Taking a blood sample with a needle carries risks that include bleeding, infection, bruising, or feeling dizzy. When the needle pricks your arm, you may feel a slight stinging sensation or pain. Afterward, the site may be slightly sore.

How do I get ready for this test?

- You may need to rest before the test to lower your stress level.

- You will need to avoid medicines that can affect the results of the test. Tell your doctor about all medicines, herbs, vitamins, and supplements you are taking. This includes medicines that don't need a prescription and any other drugs you may use.

What do my test results mean?

The results of your blood tests show the level of cortisol in your blood at the time of the test. Normal cortisol levels are usually highest early in the morning and lowest about midnight. Normal ranges vary depending on the type of test. For most cortisol tests, normal ranges are:

- **From 6 a.m. to 8 a.m.:** 10 to 20 micrograms per deciliter (mcg/dL)
- **Around 4 p.m.:** 3 to 10 mcg/dL

Many things may affect your test results. These include the method used to do the test.

If your test results are different from the normal value, it may not mean there is a problem. Talk with your healthcare provider to learn what your results mean.

What might affect my test results?

Many things affect cortisol levels in the blood:

- If you work nights and sleep during the day, your cortisol levels may not be in the normal range.
- Your cortisol levels may be high because of stress, physical trauma, depression, alcoholism, malnutrition, or a panic disorder.
- Women in their last 3 months of pregnancy and highly trained athletes may have high levels of cortisol.
- Some medicines, especially oral contraceptives and medicines that contain *glucocorticoids* or *steroid hormones*, can also affect your cortisol levels. These types of medicines may be taken to control asthma, autoimmune diseases, or inflammation.

Urine Cortisol Tests

A urine cortisol test measures the amount of cortisol in your urine. This test may help your doctor diagnose Cushing's disease. The test also screens for other diseases that affect your pituitary and adrenal glands.

How is this test done?

This test requires a urine sample. If your doctor needs a 24-hour sample, you will receive instructions about collecting all of your urine for 24 hours.

What do my test results mean?

Normal values for cortisol in a urine test are 10 to 55 micrograms a day (mcg/day). If your urine test shows high levels of cortisol, you may have Cushing's disease.

Many things may affect your test results. These include the method used to do the test.

If your test results are higher than the norm, it may not mean there is a problem. Talk with your care provider to learn what your results mean.

What might affect my test results?

Cortisol levels may be high in people who are very obese, or who have mental illness, or alcoholism. This is called *pseudo-Cushing state*.

Cortisol Saliva Test

How do I take this test?

We will give you a kit to use for your saliva test. Follow these steps closely:

- For 30 minutes before collecting your saliva sample:
 - Do **not** eat or drink, or put anything in your mouth.
 - Do **not** brush your teeth.
- Collect your sample between 11 p.m. and midnight.
- To use the Salivette swab:
 - Remove the top cap of the container to expose the swab.
 - **Do not touch the swab with your fingers.**
 - Place the swab directly into your mouth. To do this, tip the container so the swab falls into your mouth.
 - Keep the swab in your mouth for about 1 minute. Roll the swab in your mouth, but do not chew it.
 - After 1 minute, spit the swab back into its container. Do **not** touch the swab with your fingers. Replace the cap.
 - Write the time you took the sample on the container label. Also write your name and date of birth.

Your provider may have asked you to take more than 1 saliva sample. If so, you will have more swabs and containers in your kit. Each time you take a sample, collect it in a separate container. Write the time, date, your name, and your birthdate on the label.

Save all your samples in a refrigerator. Take them all to the lab at the same time.

How is Cushing's disease treated?

Your doctor will review your test results to find out why you have too much cortisol:

- If you have too much cortisol because of medicines you are taking, your doctor will check to see if you can stop taking the drugs, or take a lower dose.
- If a tumor is causing your Cushing's disease:
 - You will likely have other tests to find the tumor before deciding on your treatment. Please see the handout "Inferior Petrosal Sinus Sampling (IPSS)."
 - Surgery to remove the tumor may be your best treatment option. Please see the handout "Pituitary Gland Surgery."
 - Or, your doctor may be able to shrink the tumor with radiation or medicine.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

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