

Cushing Syndrome

A plain-English guide for you and your family

WHAT IS HAPPENING

Your body makes a hormone called cortisol in two small glands that sit on top of your kidneys (the adrenal glands). Cortisol helps you wake up, handle stress, keep your blood sugar steady, and fight swelling. A tiny pea-sized gland at the base of your brain (the pituitary) sends a signal—called ACTH—that tells the adrenals exactly how much cortisol to make, so you never have too much or too little. In Cushing syndrome, that careful balance breaks. You end up with way too much cortisol every day, for months or years. The flood can come from three places: a tumor in the pituitary making too much ACTH (that specific cause is called Cushing disease), a tumor somewhere else in the body secretly pumping out ACTH (like in the lung), or a tumor in the adrenal gland itself making cortisol without waiting for any signal. The fourth cause is taking steroid medicine—prednisone, dexamethasone, or others—at high doses for a long time to treat asthma, lupus, or arthritis; your body cannot tell the difference between its own cortisol and the pill, so the same damage builds up. Because cortisol touches almost every cell, you see a whole collection of changes: your face gets round and red, a hump of fat grows between your shoulders, purple stretch marks appear on your belly, your arms and legs get thin because muscle wastes away, your bones become fragile and break easily, your skin bruises from tiny bumps, and your blood sugar and blood pressure climb. The goal is to find the source—pituitary, lung, adrenal, or medicine—and stop it, so your cortisol level can drop back to normal and your body can start to heal.

What you might feel

- Weight gain in the center of the body (trunk obesity) with thin arms and legs
- Round, full face (moon face) and fat pad on the back of the neck (buffalo hump)
- Purple or red stretch marks (striae) on the belly, thighs, breasts, or arms
- Thin skin that bruises easily and heals slowly
- High blood sugar or new diabetes
- High blood pressure
- Weak muscles and trouble standing up from a chair or climbing stairs

- Extra hair growth on the face, chest, or back (in women) and irregular or missing periods
- Mood changes—feeling anxious, irritable, or depressed
- Weak, brittle bones that break easily (osteoporosis)

Call the doctor right away if...

- Sudden severe headache or vision changes (may mean a pituitary tumor is growing and pressing on the optic nerves near the brain)
- New bone fracture from a minor injury (sign that bones have become dangerously weak)
- Severe high blood pressure that does not come down with medicine (can lead to stroke or heart attack)
- Signs of infection that get worse quickly, such as fever and confusion (high cortisol weakens the immune system so the body cannot fight germs)
- Chest pain or trouble breathing (may signal a blood clot in the lungs, which is more common when cortisol is very high and blood clots more easily)

What the care team will do

- Monitor blood pressure every 4 hours and notify the provider immediately if systolic is above 180 or diastolic is above 110
- Check blood glucose (finger stick sugar) before meals and at bedtime, and give sliding scale insulin exactly as ordered
- Inspect skin every shift for new bruises, tears, or pressure areas; use foam padding on bony areas and turn the patient every 2 hours if on bedrest
- Implement fall precautions including non-skid socks, bed alarm, and assist with all walking; keep call light within reach at all times
- Monitor for signs of infection including temperature every 4 hours, and report any fever, cough, pain with urination, or confusion immediately
- Teach the patient to report mood changes, trouble sleeping, or feeling very anxious or sad to the nurse
- Give prescribed medications to block cortisol production at the exact scheduled times, and never hold a dose without calling the provider

Medicines you may be given — and why

Ketoconazole

Blocks the enzyme machines inside your adrenal glands so they cannot turn cholesterol into cortisol. Picture a factory that makes stress hormone — ketoconazole locks the machines so the assembly line stops.

Metyrapone

Blocks the very last step that turns a precursor molecule into cortisol. Think of an assembly line — metyrapone stops the line just before the final product rolls off.

Osilodrostat

Stops the enzyme that makes the final change to build cortisol. Like flipping off the power switch at the last factory station so the product cannot be finished.

Mifepristone

Does not lower cortisol in your blood. Instead, it blocks cortisol from locking onto its receptor inside cells, so even though cortisol is high, it cannot flip the switches that cause damage.

Pasireotide

Mimics somatostatin, a natural brake signal that tells pituitary tumor cells to stop releasing ACTH. Only works if the tumor has the right receptor locks to receive the signal.

Cabergoline

Mimics dopamine, a brain chemical messenger that puts the brakes on hormone release. Tells pituitary tumor cells to quiet down and release less ACTH.

Mitotane

Poisons and kills the cells in the adrenal cortex that make cortisol. Think of it like a targeted weed-killer that destroys the hormone-making tissue.

Etomidate

Blocks cortisol production very fast by jamming the enzyme 11 β -hydroxylase. Used only in the hospital for life-threatening Cushing crisis when cortisol must drop within hours.

Where this information comes from

- Endocrine Society Clinical Practice Guideline 2015
- AACE/ACE Disease State Clinical Review 2020

- UpToDate
- NEJM Clinical Practice

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