

Patient information from BMJ

Last published: Sep 20, 2021

Cushing syndrome caused by an internal problem

Cushing syndrome is caused by high levels of a hormone called cortisol. This can be caused by a tumor on one of your glands. The usual treatment is surgery to remove the tumor. Most people improve or recover with treatment.

What is it?

Cushing syndrome is caused by high levels of a hormone called **cortisol**. The medical term for this is hypercortisolism. It can happen if you have a tumor that affects a gland in your body called the **pituitary gland** or, rarely, your **adrenal glands**. The main symptom of Cushing syndrome is weight gain.

A common cause of Cushing syndrome is long-term treatment with medications called **corticosteroids**. To find out more see our information on *Cushing syndrome caused by medication*.

The pituitary gland is a pea-sized gland that is found at the base of the brain. Your adrenal glands are in the middle of your lower back, just above your kidneys.

When these glands are working normally they regulate your body's production of certain hormones, including cortisol. But if either the pituitary gland or one or both of the adrenal glands are affected by a tumor they can produce too little or too much of some hormones. These tumors are usually not cancer.

Cushing syndrome can be serious. This is usually because the weight gain that happens with the condition increases the chances of serious problems affecting the heart and blood vessels (cardiovascular disease).

What are the symptoms?

One main symptom of Cushing syndrome is weight gain, especially around the middle, the upper back, between the shoulder blades, and in the face. Other symptoms that sometimes go along with the weight gain can include:

- Stretch marks on the skin

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- Skin that is thin and bruises easily
- Long healing times for broken skin (such as with cuts, grazes, and insect bites)
- Extreme tiredness
- Muscle weakness.

The symptoms can also affect men and women differently. For example, if you are a woman you might notice:

- Increased body hair or facial hair
- Changes in your menstrual periods: for example, your periods may become irregular, or might stop completely.

If you are a man you might notice that:

- You are less interested in sex
- You find it more difficult to get an erection.

Your doctor will also want to do some tests. These might include testing your saliva or your urine for high levels of cortisol. If the results suggest that you might have Cushing syndrome your doctor might refer you to a specialist (called an endocrinologist) for more tests to make sure.

If your doctor thinks that you may have high levels of cortisol caused by a tumor you will need to have a scan to check.

What treatments work?

The treatment you are offered will depend on which of your glands is affected, the pituitary or the adrenal.

Cushing syndrome caused by a tumor on the pituitary gland

Most people need **surgery** to remove the tumor. You can talk with your doctor about whether surgery is the right option for you.

This operation works well for most people but it doesn't help everyone. And, even if the operation works in the short term, some people need a second operation a few years later. The operation is more likely to be successful if your tumor is small.

Your surgeon will try not to damage the pituitary gland itself when removing the tumor. But this is not always possible, especially if the tumor is large.

If you need to have a large part of your pituitary gland removed it will no longer be able to produce the important hormones that it used to. So you may need to take these hormones as pills or shots after your operation.

As well as surgery you might be offered **medication** to reduce the effects that cortisol is having in your body.

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If medications and surgery don't help you enough, or if you have a tumor that can't be operated on, your doctor might suggest **radiation therapy**. Radiation therapy is a type of x-ray treatment that can be used to shrink the tumor.

If you have this treatment you might need to have several sessions over a number of weeks. This reduces the chance that the treatment will cause harm to your brain.

Radiation therapy can be an effective treatment for Cushing syndrome, but it tends to take effect slowly. So it may be a few months before you notice improvements in your symptoms.

Cushing syndrome caused by a tumor on the adrenal gland

The usual treatment for this type of Cushing syndrome is surgery to remove the tumor. To do this, the surgeon also needs to remove the adrenal gland itself. Removing the affected adrenal gland cures your Cushing syndrome.

In some cases both adrenal glands need to be removed. If this happens you will need to take hormone treatments to replace the hormones that are no longer produced by the adrenal glands.

Some people choose not to have this operation. If you don't wish to have this surgery you may be able to take medications that reduce the effects of cortisol instead. But this is not as effective as surgery.

What will happen?

Without treatment, about half of people with Cushing syndrome caused by a pituitary tumor will die within five years, usually because of cardiovascular disease.

But treatment for Cushing syndrome works very well for most people. For example, as cortisol levels return to normal, most people lose most or all of the weight that they have put on. This greatly reduces the chance of heart disease and diabetes.

Your bones should also become stronger, meaning that you are less likely to have fractures, and your blood pressure should return to a healthier level.

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