

WHAT SYMPTOMS REQUIRE IMMEDIATE ACTION?

If you feel too unwell to carry out daily tasks, consult your healthcare provider.

Symptoms like **vomiting, severe dizziness, or faintness** could indicate an emergency. Call your healthcare provider immediately. They may tell you to give yourself a **glucocorticoid shot** in these situations to prevent **adrenal crisis**, a life-threatening emergency.

If vomiting persists or you are unable to administer glucocorticoids, **seek emergency medical care** immediately. Tell the emergency care provider you are being treated for Cushing's syndrome.

Inform your healthcare provider if you are taking medication for high blood pressure or diabetes and experience low blood pressure or low blood sugar. These are signs your medication doses might need to be adjusted.

"After surgery, my appetite decreased on its own and within 6 months I was back to my normal weight... While my muscles are still fragile, my skin is in much better shape. My eyes are clear for the first time in years.

At 3½ years post-surgery, I am once again beginning a new level of wellness. My moods are not frantic anymore. Inside I feel calm no matter what the circumstance. My energy levels are still not 100% but I am able to fully function as I continue to recover.

I am once again present for my life"

Refer to your healthcare provider regarding safe methods to reduce your cortisol replacement doses or modify your Cushing's medications during treatment

Exercise within the limits of your body's capability

Communicate with family and friends that returning to normal will require time

Opt for rest when your body needs it

Visit your healthcare provider as needed for support through your recovery

Eat a healthy and balanced diet to promote healing

Remember that the efforts you put into regaining your health will pay off

You are worth it!

RECOVERY FROM CUSHING'S SYNDROME & MANAGEMENT OF GLUCOCORTICOID WITHDRAWAL

Getting Ready for Your Recovery Journey



Funding provided by an unrestricted educational grant from Recordati

WHY IS TREATMENT FOR CUSHING'S SYNDROME IMPORTANT?

With Cushing's syndrome, your body produces too much cortisol. Excess cortisol makes you sick and results in health issues like fragile skin, weak muscles and bones, and high blood sugar and blood pressure.

Cushing's syndrome is usually treated with medication and/or surgery. With time, these treatments bring your cortisol levels back to normal and improve your symptoms. Cortisol may drop slowly or quickly.

Medical treatment will lower your cortisol to normal levels over time.

If a tumor caused your high cortisol levels, successful surgery to remove the tumor will quickly reduce your cortisol levels. After the tumor is removed, it will take several months to years for your body to produce cortisol at normal levels again.

WHAT ARE THE BENEFITS OF TREATMENT?



Improved Sleep



Weight Loss



Reduced Blood Pressure



Decreased Hunger



Improved Memory & Mood



Strengthened Muscles & Bones



Clearer Skin

"My mood swings and emotions were out of control... I felt incredibly weak and could not do the simplest things for myself like even opening a bottle of water or preparing my own meals. I spent most of my days just lying in bed... I began suffering muscle weakness, fatigue, and a lot of aches and pains including pains I hadn't had before..."

The knowledge to expect these symptoms by both me and my family is essential to getting through them...

I understood the devastation of the disease and that it would be a long recovery. I had the support of my provider and was on a Cushing's Recovery website."

WHAT CAN I EXPECT DURING TREATMENT & RECOVERY?

It is normal to feel worse before getting better when treating Cushing's syndrome. Most people have these symptoms, showing that the treatment works.

During treatment and recovery you might feel unwell, with body aches, weakness, mood swings, and sleepiness. If your cortisol gets too low, your provider may prescribe a glucocorticoid medication, i.e., a steroid, to replace cortisol and help you feel better.

RECOVERY PERIOD

The expected signs and symptoms happen because the treatment is working!

EXPECTED SIGNS & SYMPTOMS

Slight Dizziness
Mood Swings
Fatigue & Sleepiness

Improved Blood Pressure
Improved Blood Sugar

Mild Nausea
Reduced Appetite
Weight Loss

Weakness
Aches in Joints & Muscles

WHEN TO CALL YOUR PROVIDER

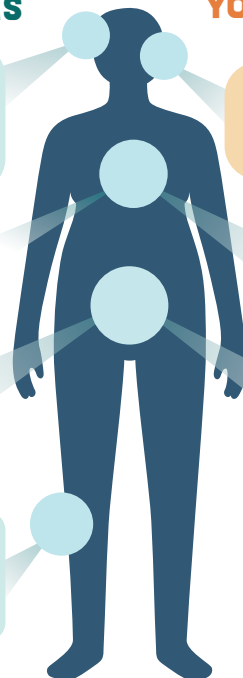
Severe Dizziness
Feeling Faint/
Passing Out

Low Blood Pressure*
Low Blood Sugar**

Vomiting

*Blood pressure medication may require adjustment

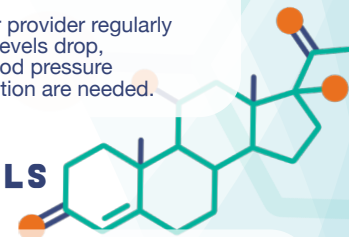
**Diabetes medication may require adjustment



HOW CAN YOU GET THROUGH THIS?

- Keep in mind that these recovery symptoms are temporary! It usually takes 6 to 12 months or more for recovery. The symptoms will slowly get better and disappear, restoring your health.
- Seek support from family and friends to stay focused on your recovery.
- Engage in exercise within your limits to boost your strength and aid in healing.
- Listen to your body and rest when needed.
- Talk to your provider if you're having trouble dealing with the treatment symptoms. Medication can help with pain and depression. Physical therapy can help with muscle weakness.
- Communicate with your provider regularly because when cortisol levels drop, adjustments to your blood pressure and/or diabetes medication are needed.

CORTISOL LEVELS LOW & HIGH



After successful surgical or medical treatment of your Cushing's syndrome, your cortisol levels drop from very high to very low, and may stay low for a while. To help your body adjust to this change, your provider will prescribe a glucocorticoid (i.e., steroid) to help you feel better. Your provider will gradually decrease the amount of glucocorticoid you take to help achieve the right cortisol balance for you.

The dose and timing of glucocorticoid replacement is different for each person. Some may start with 25 or 30 mg of hydrocortisone in the morning and 20 mg in the early afternoon, while others might need lower doses, like 20 mg twice daily. **Most patients do not need higher doses post-surgery.** The graphic below shows how doses decrease over time, but this can be different for each person. In some cases, patients might also need prednisone or dexamethasone instead of hydrocortisone. Your provider will customize your schedule and medication for you.

*For example purposes only. Glucocorticoid drug, starting dose, and taper schedule may vary between patients. Your doctor will determine what is appropriate for you.

	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6+
Morning	30 _{mg} * Hydrocortisone*	25 _{mg} Hydrocortisone	20 _{mg} Hydrocortisone	20 _{mg} Hydrocortisone	20 _{mg} Hydrocortisone	15 _{mg} Hydrocortisone
Afternoon	20 _{mg} Hydrocortisone	20 _{mg} Hydrocortisone	20 _{mg} Hydrocortisone	15 _{mg} Hydrocortisone	10 _{mg} Hydrocortisone	10 _{mg} Hydrocortisone

Continue treatment until your body's cortisol is normal.

After each decrease in glucocorticoid dose, if symptoms are not tolerable, then go back to the dose used the week before.

During the glucocorticoid taper, your body will not produce enough cortisol to respond to illness. If you experience an illness like a fever or infection, or if you have surgery, you may need to double or even triple your glucocorticoid dose to prevent a life-threatening condition known as "adrenal crisis." Adrenal crisis can happen when your body does not produce sufficient cortisol during times of increased demand, such as during illness, and it requires urgent medical attention.

If you are taking hydrocortisone (including when you reach the final dose), your provider will test your morning cortisol levels before you take your medication to find out if your body is making enough of its own cortisol. If you are taking glucocorticoid medication, you will take it until your cortisol levels fully recover. You may need to take it again if you feel sick or experience high levels of stress.

Do not stop your medication without talking to your provider.