

Recovery From Cushing's Syndrome

Following successful surgery, more than likely, the body cannot immediately make cortisol and needs time to recover. During this recovery period, patients take replacement glucocorticoid (cortisol-like) medication to make up for the fact that the ACTH and cortisol levels are low and sufficient cortisol is not being made. The dose is gradually reduced (tapered) until the body is able to make a sufficient amount of cortisol on its own. Some doctors recommend a starting dose and taper based on weight. Others taper by the number of months since surgery or how the patients is doing. There is no single tapering protocol that will work for all patients. The overall goal is to avoid an excessive dose for a long period of time, as this can prevent recovery from the features of Cushing's and also prevent recovery of normal pituitary-adrenal function. To determine when the body makes enough cortisol to discontinue the steroid medications, blood tests are done periodically for serum cortisol and sometimes ACTH, in the morning before the dose of replacement steroid medication is taken. Once certain cortisol levels are reached, an ACTH stimulation test (or rarely, insulin tolerance test) is used to confirm that the body has recovered sufficiently to handle physical stress, such as illness. While on replacement steroid medications, patients should receive instructions about how to increase the replacement dose with illness. Patients should be alert for symptoms of adrenal insufficiency such as vomiting, diarrhea, and low blood pressure, which can lead to shock. Patients should also carry a medical ID card, wear some type of medical alert jewelry and if advised by their physician, carry emergency replacement injectable steroids. The body needs cortisol to function normally and adrenal insufficiency is extremely dangerous. You should NEVER discontinue replacement steroids without consulting your physician.

Most patients experience some "steroid withdrawal" symptoms including aches, pains, nausea and fatigue, but these vary greatly from one patient to another. While these symptoms can be bothersome, they are completely normal and a positive sign that Cushing's has been successfully treated. Some patients have extreme difficulty tapering their replacement dose while others do not and the time involved to discontinue replacement medications varies greatly from patient to patient. It can take a year, or longer to discontinue replacement medications. Most physicians prefer to taper patients off replacement steroids using hydrocortisone (Cortef) rather than medium duration prednisone or longer acting dexamethasone. Use of shorter-acting hydrocortisone or once daily prednisone leaves the patient with low levels during a portion of the day which can assist in stimulating the body to make its own cortisol. Doses can be adjusted based on an individual patient's ability to manage the steroid withdrawal symptoms that occur while the body gets used to lower steroid levels. During this time, it is important to pay attention to how you feel and communicate that clearly to your doctor.

What do doctors tell their patients about recovery?

Dr. Mary Lee Vance, University of Virginia, Charlottesville

Recovery and coping through recovery are tough questions to address; every patient is different. Over the years, I have been impressed that the rate of recovery is related to several things: (a) the duration of Cushing's before treatment, (b) the severity of Cushing's-related problems (amount of weight gain, muscle weakness, diabetes, hypertension, depression) – the more severe the symptoms and medical problems, the longer the recovery process, (c) age: younger patients tend to recover more quickly than older patients. My advice: patience, patience, patience. I tell my patients BEFORE surgery that they will probably feel worse after successful surgery than before the operation. I tell them to expect fatigue, weakness, muscle and joint pains, dry skin and generally feeling "crummy". Also, (a) expect that recovery will be very gradual and slow; do not have "unrealistic expectations", which result in frustration and anxiety; (b) start slow, but try to increase exercise gradually; (c) do pay attention to diet and food intake, count calories; (d) know that things will improve, but improvement will be gradual; (e) if depression is a problem, continue treatment for depression; (f) testing for other hormone deficiencies. If a patient is growth hormone (GH) deficient, replace GH as this may improve the rate of recovery from Cushing's.

Physiological Doses of Replacement Medications

Hydrocortisone ~ 15 - 20mg/day
Cortisone acetate ~ 30 - 37.5 mg/day
Prednisone ~ 3 - 5 mg/day
Dexamethasone ~ .5 - .75 mg/day

Note that replacement doses will be higher than physiological at least for a period of time after successful surgery.

Dr. Anne Klibanski, Massachusetts General Hospital

For coping or to help themselves, patience. Gradual, progressive increases in exercise duration and intensity will help regain muscle function, and assistance with emotional issues as needed are very important. A healthy diet, to help with weight loss along with being sure to get the recommended daily amounts of calcium and vitamin D for bone health is important. It has typically taken many months or even years for Cushing's to be diagnosed and the process of true recovery is gradual. Take things slowly and keep your expectations realistic. Some effects such as high blood sugar or high blood pressure caused by Cushing's may improve quickly after the tumor is gone, so these should be monitored carefully in case medications for these conditions need to be reduced, or in some cases even discontinued. Other symptoms and problems such as weight gain, muscle weakness and emotional and mood effects may take longer to improve; a small number of patients may actually have an exacerbation of psychiatric problems following surgery, but improve over time. Get help from your health care providers, your family and patient support groups. A therapist may be useful in coping with the emotional upheaval associated with this disease. While recovery requires time, the good news is that with patience, exercise, a healthy diet, and support from others, most patients recover well within 12-24 months after surgery.

Dr. Lynnette Nieman, NICHD, NIH Bethesda, MD

I advise my patients that they didn't develop symptoms overnight, and won't recover from the signs/symptoms quickly. It may take a year or more, but that they should improve little by little. Expect the first month or so to be the most difficult. For coping and helping themselves recover, I tell them to get some exercise and make some recommendations about how to do that and how much. I recommend that they push themselves a little more every week, but to not expect big improvements quickly. Healthy food and drink intake and stress reduction techniques are also helpful. I also advise them to make sure that any other hormone deficiencies are addressed and to consider psychological evaluation and intervention for the emotional issues that surface during recovery.

What do patients say about recovery?

"I wasn't prepared for the long recovery process. I thought maybe it takes others that long, but I was certain I'd be fine right after surgery. That was not the case. For me it was over a year before I could discontinue my medications, recover my strength and lose the weight. It takes extreme patience."

"My recovery has been very good and not nearly as bad as I had read or expected. Finding distractions and seeing a psychotherapist for emotional issues were helpful."

"Some things, like my weight, high blood pressure and diabetes improved right away. Other things such as joint soreness and memory lapses, took years to resolve. I used hot baths for the joints aches, crossword puzzles for the memory (don't laugh!), and being in touch with others who had Cushing's before me gave me hope."

"I kept a recovery journal so I could track my gradual improvements. I would also talk with others who had Cushing's to see if what I was experiencing was "normal"; it was helpful to know I wasn't alone."

"I had to learn what "normal" was again after being driven by cortisol for so many years. I had to realize that recovery is a process that takes a long time. I had to enter a new phase of my life and stop focusing so much on getting back to what I thought was my "normal". Over time I realized that I was growing into a new kind of normal. My two year recovery included the psychological adjustment I made in letting go of the old ideas of how I "should" be and learning to appreciate the person I was becoming."

"What helped me the most was being realistic about my limitations and truly believing that there was finally light at the end of a long, long tunnel. I tried to be kind, gentle and patient with myself and prioritized my activities to fit my energy level. I also did the most important things first and guarded how many obligations I took on."

"I joined a gym with a pool; exercising in the pool was so helpful for my aches and pains. I also found things that I could do that were enjoyable. For me, those things were watching old movies or TV episodes, making jewelry, listening to music, and getting massages."

TAKE THINGS DAY BY DAY.... TRY NOT TO GET FRUSTRATED.... TRY TO STAY POSITIVE....

Final approval of this brochure was by Dr. James Findling. Many CSRF Medical Advisory Board members provided valuable input.