

Overview

Receiving a Cushing's diagnosis can be quite a pivotal moment when it finally provides an explanation for the often devastating symptoms most patients experience. Now, you're on a quest to regain your health and well-being. Drawing from personal stories, the CSR Patient Advisory Committee aims to offer insights into dealing with this condition that are not often available in medical literature. Each of our journeys is unique, and that includes how cortisol has affected our bodies, but we have many commonalities.

Tips for Diagnosis

- Seek out a physician, preferably an endocrinologist, who has experience diagnosing Cushing's Syndrome. US and European Endocrine Societies have guidelines that can technically be followed by any physician who isn't dismissive of your condition, though it's best if you can get an appointment with a Cushing's specialist at a large center.
- The source of your high cortisol will need to be determined through testing and will dictate treatment. The most common source of high cortisol is steroid use (steroid shots, inhalers), but it can also be due to many common conditions or a tumor on the pituitary, adrenal, lung, or elsewhere on the endocrine system.
- Be prepared for comprehensive testing. This will include frequent appointments, repeated blood work, urine and saliva tests done at home, an MRI or CT scans, and possibly more advanced explorations to help determine location.
- Explore surgical options. If surgery is appropriate once the source is identified, it's almost always the preferred treatment.
- Explore the medications that lower or block cortisol. Not everyone will need medication but it is a tool to consider in mild cases, when surgery is delayed, in remission, or under other circumstances (discuss with your doctor but be independently aware of options).
- Managing Cushing's can be a lengthy and volatile process. Consider speaking with a therapist or joining a support group to help cope with the emotional aspects. Cushing's can be lonely, but you do not have to be alone on this journey - there is a supportive community ready to help you navigate the challenges of Cushing's Syndrome.
- Prioritize communication with your caregivers and loved ones. It is overwhelming, confusing, and heartbreaking when your loved one goes through a scary disease that you don't understand. There is support for them, too!

Helpful Resources



SCAN FOR LINKS

Cushing's Support and Research Foundation website: <https://csrf.net/>

Leslie Edwin, President: leslie@csrf.net - Gretchen Jordan, Associate Director: gretchen@csrf.net

CSR Monthly Support Zoom Sign-Up:

2024 - <https://www.surveymonkey.com/r/2024CSRFSupportcalls>

2025 - <https://www.surveymonkey.com/r/2025CSRFSupportcalls>

Up To Date: <https://www.uptodate.com/contents/cushing-syndrome-treatment-beyond-the-basics>