



Cushing's New Diagnosis Tips

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 our personal stories, we aim to offer insights into dealing with this condition that are not always readily available in medical literature. How cortisol has affected our bodies made each of our journeys unique, just as yours will be, but you'll also find many commonalities.

- Seek out an expert endocrinologist. Not all endocrinologists specialize in Cushing's, so finding an experienced specialist is crucial. If there isn't one in your area, look for a physician who is open to learning about Cushing's and isn't dismissive of your condition.
- Identify the source of your high cortisol. Determining whether the excess cortisol production originates from the pituitary, adrenal glands, other neuroendocrine tumors, or a medication / "outside" source is essential.
- Be prepared for comprehensive testing. This will include frequent appointments, repeated blood work, an MRI or CT scans, and possibly more advanced explorations to help determine location (example inferior petrosal sinus sampling).
- Explore surgical options. If surgery is appropriate once the source is identified, it's almost always the preferred treatment.
- Explore cortisol-lowering and -blocking medication options. Not everyone will need medication but it can be a useful tool such as in mild cases or delayed surgery.
- Educate yourself on the journey ahead; managing Cushing's can be a lengthy and volatile process. Consider seeking psychological support to cope with the emotional aspects.
- Think ahead to continuing to monitor after treatment - it may be necessary to continue regular testing including late night salivary cortisol tests, EKGs, and checks of calcium, bone density, blood pressure, and blood sugar.
- Remember, you're not alone on this journey, and there is a supportive community ready to help you navigate the challenges of Cushing's Syndrome. You can start by reaching out to the contacts listed below! There are Zoom Support Groups for everyone, accessible monthly or more frequently.
- Support your caregiver with communication. It is heartbreaking, confusing, and overwhelming to watch your loved one go through a scary disease that you can't really understand. There is support for caregivers too, please reach out if this can help you.



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
- CSRFB Monthly Support Zoom Sign-Up: <https://www.surveymonkey.com/r/2024CSRFBsupportcalls>
- Up To Date: <https://www.uptodate.com/contents/cushing-syndrome-treatment-beyond-the-basics>

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