



CUSHING'S TALKING POINTS

when you've only got a brief moment of someone's attention

This is in no ways exhaustive. A chat with a member of the media could be a three second sound bite, or a thirty minute sit down interview. The main points are in bold, and if you need to go into more detail, those are listed below each point.

1. **Your story is the best tool!** Just be mindful that you probably have a very short period of time if you are given an opportunity, and you need to balance elements of your experience with useful data that the audience can use to think about if they might need to be tested, and how to do that.
2. **There are many types of Cushing's Syndrome, but they all fall into broad categories:**
 - a. Pituitary source
 - b. Adrenal source
 - c. Ectopic source meaning in the lung or elsewhere on the endocrine system
 - d. Exogenous, the type Amy Schumer has, usually caused by steroid use for other things
 - e. Rare endocrine cancers where Cushing's Syndrome is a "side effect"
3. **All Cushing's symptoms are non-specific and are shared by many hormonal disorders. Some of the most common:**
 - a. Unexpected weight gain
 - b. Rounded face, a hump at the base of the neck, thickening around the shoulders
 - c. Sweatiness, hot all the time
 - d. Swelling in the lower legs and ankles
 - e. Sudden onset or worsening of high blood pressure
 - f. Sudden onset or worsening of diabetes
 - g. Quick to anger, even rage
 - h. Problems sleeping, insomnia, "waking up every morning at 3:15"
 - i. Easy bruising
 - j. Weak arms and legs, dropping things, falling if trying to run
4. **A trusted PCP, general endo, or GYN can do the testing if they can get past their likely minimal knowledge of Cushing's and resulting low pre-test suspicion. Most general practitioners will need to refer to an expert. Things someone should do to prepare for a first appointment when they suspect Cushing's Syndrome:**

- a. Gather 3 or 4 photos that show the progression of physical symptoms
- b. Keep a few days' food journal of things you eat, because they will likely ask
- c. Make a list of all medications and supplements you take, even if you think they don't need to be included
- d. Be prepared for a LOT of questions as the endocrinologist goes through signs and symptoms of dysregulated hormones.
- e. Know the first tests and how they are administered just in case the doctor doesn't. You don't want even one unreliable lab result in your medical file.

5. Natural cortisol rises and lowers throughout the day to meet your physiological needs. If you test during a time there is stress on your body, you can wind up with false positives. The definition of Cushing's is high cortisol, persistent over time, and operating independently of the body's needs. There are three reliable tests that will be helpful to establish a path forward in the pursuit of a Cushing's diagnosis:

- a. **1mg dexamethasone suppression test** – the patient takes 1mg dexamethasone at bedtime then gets a blood draw at 8am the next day looking at cortisol and dexamethasone level in the blood. Dexamethasone does not show up on labs, and this dose would suppress the natural creation of cortisol in the body so a healthy person would have a very low cortisol reading the next morning. Someone with Cushing's will not see that expected low number.
- b. **Bedtime salivary cortisol tests** – “one test” is actually 2 or 3 salivettes, small cotton tubes that you soak with saliva at bedtime (one per night) and return all together to the lab at the same time. Do NOT go to sleep with an alarm set for 11pm, or midnight, because someone told you it has to be done then – your cortisol is lowest at the time you are going to sleep, and that is what you are trying to measure. The act of waking up raises your cortisol.
- c. **24hr urine collection** – the patient gets a jug or two to collect all urine for a 24 hour period. This must be kept in the refrigerator at all times and transported to the lab from the fridge. This test is not as reliable for mild forms of Cushing's Syndrome.

6. Your best chance at diagnosis is to be prepared and educated:

- a. Do some internet research on Cushing's and the endocrine system, but make sure your information comes from an academic or scientific source, or is backed up by a medical review or advisory board.
- b. Connect with a patient support group – CSRF is a great one! csrf.net, 404-791-5483, cushinfo@csrf.net, they will know all the programs available to patients
- c. Don't overwhelm a new doctor with a manual of tests from the last 20 years and every last exhaustive detail. Healthcare is messed up in the US right now – doctors have 15 minutes with a patient and such large workloads that you can't get in for months. Start with the strongest points that support the need to do some testing.