



In 2023, CSRFB conducted a global, comprehensive survey analysis of Cushing's Disease and Cushing's Syndrome patients. The experience of living with Cushing's presents a multifaceted challenge: patients often feel isolated and uninformed about the condition, while physicians are not armed with comprehensive information for holistic diagnosis and treatment.

Below is the survey in French used by us and our other patient advocacy partners around the world.

Global survey on quality of life in patients with Cushing's disease

SYMPTOMS AND CONDITIONS

I'm curious if there is any evidence of a trend for leg and hip muscle weakness, pain, and poor stamina to improve.

It is vital that symptoms are considered as part of a package vs individually.

I was negatively impacted by the complexity of having to manage multiple symptoms.

I have experienced low libido from Cushing's and want to know what I can do about it.

I have been diagnosed with diabetes insipidus / arginine vasopressin deficiency

It was/is difficult to manage my diabetes insipidus.

I lost physical strength with Cushing's.

I experience(d) pain.

I experience(d) insomnia.

I have problems with vertigo that seem or are confirmed to be from Cushing's.

After Cushing's I have bad balance.

I suspect I have had an increase in dental problems because of Cushing's.

I have not had any dental issues related to Cushing's.

I developed kidney disease because of Cushing's.

DIAGNOSIS

In the beginning, it is almost impossible to fully comprehend a Cushing's diagnosis and everything that goes with it.

It took less than two years to diagnose my Cushing's.

It took 2-5 years to diagnose my Cushing's.

It took 5-10 years to diagnose my Cushing's.

It took more than 10 years to diagnose my Cushing's.

I experienced fat shaming or bias in my quest for diagnosis.

I experienced gender bias in my quest for diagnosis.

PHYSICAL APPEARANCE

I did not have the classic Cushing's appearance and I feel like that delayed my diagnosis.

The classic Cushing's image is helpful because I saw myself in it and it was useful to help explain what was happening to me.

People did not recognize me with Cushing's.

People did not recognize me after surgery.

I want and need to gain confidence back about my body and appearance.

I went or currently go to a dermatologist because of very bad acne or other skin conditions from Cushing's.

RELATIONSHIPS

Cushing's changed expectations and needs in my closest relationships.

You can almost literally be a different person after treatment than you were before and during, and that can cause challenges with relationships where you once had a clearly defined role and now it's different.

My children seemed negatively impacted by my sickness.

I am negatively impacted by a family that does not understand or has lost patience with a treatment process that has been going on for a long time.

Relationships suffered because I lost respect for people who refused to believe my illness.

I'm worried my marriage will end because of this experience.

My marriage or long-term relationship did not survive Cushing's.

My partnership/marriage has gotten stronger as we have gone through this journey together.

MENTAL HEALTH

I believe that my emotional and mental health is just as important as my physical health.

Mental health support should be part of a treatment "package" recommended for all patients.

I experience or did experience anxiety and/or depression.

There is a need to process trauma afterwards.

I developed excuses for my feelings and behaviors rather than validating the disease and healing process and being kind to myself.

I believe that therapy can be helpful even if a patient has good coping skills.

I have supportive family and friends, but that does not prevent me from having negative thoughts and feelings.

Apathy is sometimes stronger than symptoms of depression.

I have had suicidal thoughts.

Grief has been constantly present from diagnosis to recovery.

NEUROPSYCHOLOGICAL

My job depends or depended on my ability to learn and retain information; cognition impairment affects this.

My short-term memory has been negatively impacted.

My long-term memory has been negatively impacted.

Memory problems have led me to use adaptations such as lists and notes to myself, and I did not do this before.

I have had neuropsychological testing because of Cushing's.

DIET, NUTRITION, AND EXERCISE (9)

I would like to improve nutrition absorption problems associated with Cushing's.

If there were dietary changes I could make that would help with stamina, energy, and brain fog, I would do it.

I would consider an anti-inflammatory diet if it could truly help with arthritis and joint pain.

I recognize that I do not know how to start a healthy diet after having bad habits for years.

I would consider a diet that can reduce gastrointestinal issues related to Cushing's.

I struggle with diet and exercise.

I tried or considered extreme diet or exercise to lose weight while in active Cushing's.

I am very knowledgeable about healthy food and how it plays a direct role in my health.

I would follow an exercise plan adapted for physical limitations and weak muscles.

SUPPORT

It is helpful and important to the patient for their loved ones to be present throughout their journey, even if they don't know what to do.

Beyond the medical care team, I believe it "takes a village" to support a Cushing's patient – family, friends, workplace, etc.

I attend or have attended a support group specifically for Cushing's.

I have not but wish I could attend a support group.

It is beneficial to share experiences with other patients.

A "peer sister" or "peer brother" to guide me along the way would be helpful.

I work with a mental health therapist.

I do not speak with a therapist because of negative stigma.

I do not speak with a therapist because of financial barriers.

I need or needed a caregiver in active Cushing's to help with things like bathing, shopping, household chores.

I need a caregiver's help now after Cushing's to help with personal tasks and errands.

I would like to have access to an online discussion group that is only open to verified patients so I know that I am talking to people who actually have or had Cushing's.

TOOLS

I am very interested in learning more about the cortisol-lowering medications available to Cushing's patients.

I am very interested in learning more about pumps, patches, test kits, and other devices in the pipeline.

I have access to an online patient portal where I can see my labs, scans, and communicate with my medical team.

CAREER TOPICS

(if employed) I feel MOTIVATED to do my work, but I am physically and/or mentally unable to complete the volume of work I used to do.

(if employed) I feel UNMOTIVATED to do my work, and I am physically and/or mentally unable to complete the volume of work I used to be able to do.

I previously thrived in my career but now either struggle to keep up or have had to change jobs

I had to quit working temporarily because of Cushing's.

I had to quit working permanently because of Cushing's.

POST-SURGERY

I was not prepared for what it was going to be like after surgery.

I think there is a perception by most people that everything does or should go back to normal after surgery.

Knowing what to expect the first month after surgery was a big concern for me.

Following surgery, I felt that I had little to no support from the medical team I'd been with throughout my diagnosis and surgery.

Cortisol withdrawal after a successful surgery is painful and dangerous.

You might need to prepare yourself to take much longer than 6 weeks, or even 6 months after surgery to return to work or normal activity.

I wish I had been told before surgery about hydrocortisone tapering and what to expect.

I was told I would be all better and back to work about 6 weeks after surgery.

All of my pituitary hormones have been tested to see if I need to supplement anything.

ADRENAL INSUFFICIENCY

I have not been given detailed information about adrenal insufficiency from my clinical team other than “double your dose for sick days”.

I have been given excellent, detailed information about how to manage adrenal insufficiency after successful surgery.

I have learned the majority of what I know about how to manage adrenal insufficiency from other patients instead of my doctor.

I have permanent adrenal insufficiency now because of Cushing's.

COPING

I feel that my health problems are all-consuming.

I am familiar with the Spoon Theory, the pain/price index, or another energy management analogy used by patients with chronic illnesses.

There are so many negative things happening with Cushing's that it can be difficult to determine what is related and what is not.

I feel that I need to learn how to retrain my brain to not always expect the worst, or for something else to go wrong, because that is how life has felt with Cushing's.

Before surgery I found so many things stressful, and it was difficult to cope.

After surgery I have found so many things stressful, and it has been difficult to cope.

LONG-TERM CONSIDERATIONS

I am optimistic that things will get better but it would be nice to have realistic expectations.

I want to know long- term health data (20+ years), even if it might be scary.

I would like to know how patients are doing who had radiation 20 or more years ago.

I am concerned about long-term cardiovascular damage from Cushing's.

I am concerned about negative impact from Cushing's on white and grey matter in the brain.

I wonder if the rollercoaster ever subsides – I feel like I feel ok some days but barely able to function on

others.

I am curious about service and emotional support animals and how to get one.
I have recovered back to pretty much my "old normal".

After surgery, "old normal" is gone and I'm still trying to determine what my "new normal" really looks like.

After surgery, I am vigilant for any new sign of illness or return of high cortisol.

Healing is a slow process and does not only include normalization of cortisol.

OBSERVATIONS

It bothers me a lot to not know why I got Cushing's in the first place.

Cushing's can be lonely.

Determining what is "normal" after diagnosis is difficult.

I believe that recovery from Cushing's doesn't truly begin until a patient is completely weaned off steroid replacement.

I have experienced a delay in care when a specialist and a GP/Internist/Primary Care Provider have both stated that an issue was not their responsibility and referred that care to the other.

I think visits to other specialists like pulmonologists and cardiologists should be part of the standard of care to ensure that vital organs are not sustaining needless damage.

I believe that validating the patient experience is one of the most important things doctors can do.

Just because my blood test results fall in normal ranges, that does not mean my symptoms are gone or that I am ok.

I had to fight my insurance company or healthcare provider for one or more treatments I needed for Cushing's.

I have had an unnecessary surgery due to not being diagnosed properly with Cushing's.

I believe it is important to educate primary care providers about this condition.

I believe it is important to educate obesity doctors about this condition.

I believe it is important to educate gynecologists about this condition.

My non-specialist doctors do or did not seem to understand how to interpret cortisol lab results.

This experience has negatively affected my faith in my God/religion/greater power.

I struggle to stay compliant with my medication dosing routine every day.

I believe that all the various names for high cortisol lead to misinterpretation, self-diagnosis, and confusion.

The classic Cushing's image is harmful because not everyone looks like that and it perpetuates the false narrative that we're all going to be overweight with stretch marks and a hump.

I have experienced humiliation or rejection from people I knew while in active Cushing's.

The patient voice and experience must be included in the planning and development of any new product, service, treatment, or clinical trial that is intended for our community.

This is a disease where you must get very sick before it can be diagnosed and treated.

I wish I could get all my doctors to the same table to discuss my case and create a plan across their specialties.

It is exhausting to be a full time patient to so many doctors.

I've been called a hypochondriac.

I have had a hysterectomy because of Cushing's.

I believe to some degree that chronic stress throughout my life might have caused my tumor.

SILVER LINING (4)

My faith has been strengthened throughout the challenges of this disease.

Cushing's has caused me to learn new ways to manage stress and find peace that help me in other areas of my life.

I have decided to take better care of myself as a result of this experience.

My outlook on life has become more focused and intentional after surviving this battle with Cushing's.