

# Cushing Patient Social Listening

Exploring Rare Disease Landscape Using Social  
Media Listening to Assess Patient Voices

# A Look At Social Media listening Setup Process

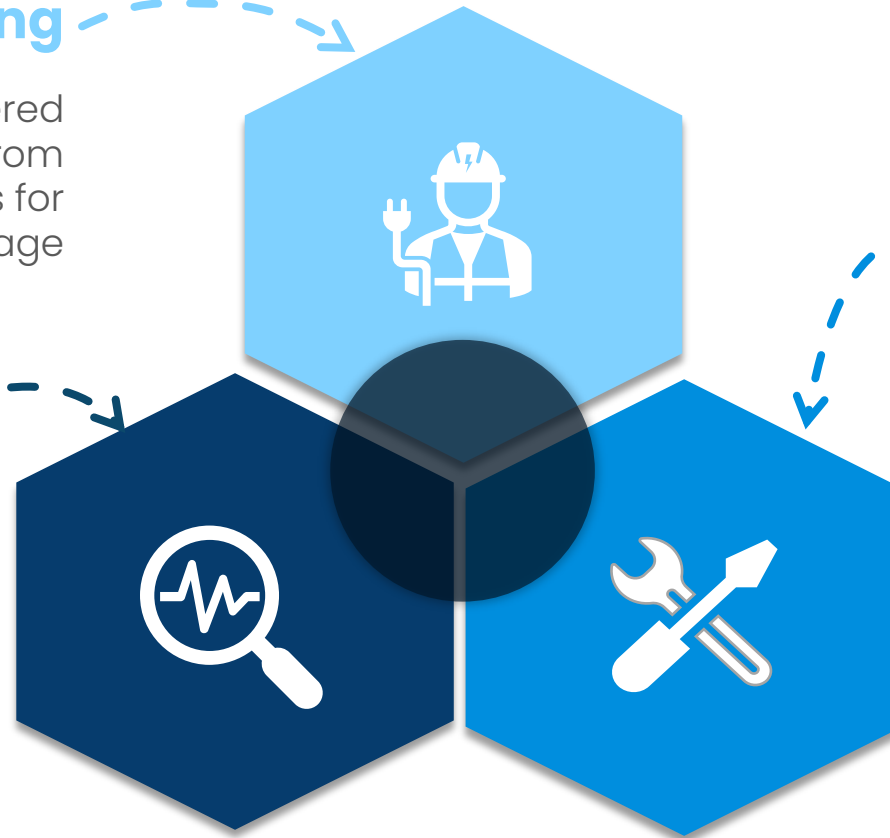
Underpinned by our extensive experience in patient research and deep knowledge of the healthcare industry, our unique approach combined humanizing the voice of patients with telling visually compelling stories.

## Manual Data Gathering

Manually gathered secondary data from public websites for comprehensive coverage

## Social tool

Keyword list that accounted for topics related to Cushing patients were prepared using secondary search and a keyword planner. Through the keyword list, a query was prepared which was entered into our social monitoring tools to crawl data



## Web scraper

Used scraper tool to extract channel specific data. This tool assisted in web data extraction to scrape sites with multiple levels of navigation like categories and pagination

**TEST**  
**SYMPTOMS**  
**SURGERY**  
**disease**  
**treatment**  
**no idea**  
**cushings**  
**appointment**  
**tumor**  
**RECOVERY**  
**results**  
**HELP**  
**anxiety**  
**HUMP**  
**endocrinologist**  
**BLOOD**  
**WEIGHT**  
**pituitary**  
**MRI**  
**swollen**  
**HOPEFUL**  
**insomnia**

I am in final stage of dignosis  
 I can't help but feel scared  
 can you please tell about pregnancy  
 my diagnosis is delayed  
 I am lost  
 been in pain  
 I have been having  
 I don't know  
 my mother has  
 I have been suffering  
 my fellow cushies  
 I have been experiencing symptoms



## Signs and Symptoms (24%)

- Online users are enquiring about the early symptoms of CS\* suspecting they are suffering from the disease
- Patients are discussing common disease symptoms like purple stretch marks, irregular periods, buffalo hump that led to symptom progression and mimicked other disease conditions like PCOS and prolactinoma



*"In March I went to an Endocrine office to get a general idea of what may be causing my symptoms since I've been suspicious of Cushing's disease for awhile. I have excessive pink/purple stretch marks on my abdomen, arms, breasts, and thighs."*

*"...have fibromyalgia, chronic fatigue, IBS, and other issues, I am also wondering if I have Cushing's disease. I have the buffalo hump and what looks like a beer gut, even though I don't drink or really even overeat."*

*"I'm suspecting I have Cushing's bc I developed the following symptoms over the last few years even tho I was originally diagnosed with PCOS: menstrual irregularities, hirsutism, acne, moon face, small Buffalo hump, weight gain esp in upper body..."*



## Diagnosis (21%)

- Patients are feeling frustrated by **repetitive tests** for definitive Cushing's diagnosis due to cyclic symptoms causing false negative results, often leading to delays or misdiagnosis."
- HCPs\* are prescribing incorrect Cushing specific diagnostic test and refusing to acknowledge their patients Cushing's specific symptoms.



*"doctor ordered a 1.5T MRI with no contrast (the nurse at the hospital said this is a waste of time, it's the wrong one) and the hospital also lost my 24 hour urine sample, but because my MRI came back clear they have told me no further action!"*

*"...Hi all, I'm 21 years old, my mum has Cushing's disease (under control now) that was caused by pituitary tumour) I have been endocrinologist twice when I was 17/18 but they refuse to give an MRI as my dexamethasone tests & cortisol tests (bloods & 24 urine) continuously come back as normal..."*

*"It took about 4 years for me to be diagnosed with Cushing's disease. The whole time, I knew something was wrong. I had body pain that I couldn't explain. I couldn't go a day without washing my hair because it felt so greasy. I had issues with digestion, high blood pressure, hair loss, insomnia, weight gain..."*



## Patient-Physician Interaction (21%)

- Patients are feeling **frustrated with early appointment cancellation** and the lack of empathy from HCP's\*
- Delayed appointments are leading to progression of disease and patients are resorting to seek moral support from Cushing's community



*"...I was able to get in early on a cancellation to see the endocrinologist. Unfortunately, the appointment went just as a feared. Completely rushed, wasn't really listened to, the doctor didn't bother to say anything."*

*"..In 14 days I will go to endocrinologist. But how am I supposed to wait that long? I feel like I'm 80 years old, always very weak and tired and sleeping all day. I feel like I'm dying. My heart rate goes up and down like a rollercoaster."*

*"Hi all! I have my first endo appointment tomorrow and I'm nervous, because I am not good at advocating for myself."*

Note\*: CS = Cushing's Syndrome; HCP = Healthcare Professionals



## Treatment (17%)

- Patients are apprehensive to start Cushing's treatment due to lack of its efficacy and are communicating in the online community forums to ask peers for new treatments information
- Many patients are looking for peer experience of managing the Cushing's Syndrome with treatment they're not familiar with



*But I'm curious if that appearance "goes away" for the most part if a case is managed well and responds well to the treatment? Or is the appearance aspect of it a permanent effect?"*

*"I'd be amazing to find someone who is willing to sit down with me and actually look at all my labs, symptoms, and poor responses to interventions or at the very least some new treatment options to try."*

*"Bone loss is a common issue with Cushing syndrome but after a bit of research and experience seeing improvement on DEXA scans I've found that the following over the counter supplements can help treat it."*

Note\*: CS = Cushing's Syndrome; HCP = Healthcare Professionals



## Surgery (9%)

- Patients are enquiring about assessment required to carry out surgery along with treatment to manage Cushing's Syndrome
- Users are complaining about delayed surgical procedure for Cushing's leading to progression of disease



*"My godmother has Cushing's Syndrome, the tumour in her brain is causing too much cortisol. This is a treatable illness but she has been waiting for a life saving operation for a year via the NHS who have prescribing pain killers and anti depressants"*

*"Certain labs were redone to "assess current condition in case of surgical and corresponding treatment accommodations needing to be made based on lab results". Included bloodwork and updated MRI."*

*"How long did it take you to lose weight after getting treatment (meds, surgery, etc) for Cushing's? I'm in the process of trying to get diagnosed for this. I have basically all the symptoms. Weight loss is very hard for me and I just want to feel like myself again."*



## Quality of Life (8%)

- Many patients are complaining of depression and anxiety with Cushing's symptom progression and post surgery
- Many users are sharing that treatment has resulted in progression of symptoms suggesting difficulty in coping with the disease



*"But her doctor is pretty sure it's Cushing's syndrome. She has literally every symptom. Upper body weight gain, striated stretch marks, rounding of her face, buffalo hump, excessive hair growth, deepening voice, fatigue, inability to focus. Her physician is pretty sure it's adrenal Cushing's.."*

*"So I'm currently tapering off my hydrocortisone after my (so far) successful surgery. I'm down to 10 mg in the morning right now. I've always struggled with depression but it's been pretty bad for the past few months (and extremely bad for the past week).."*

*"I have all the textbook symptoms of Cushing's tho and i'm getting very anxious(as if I wasn't already). I have moon face, slight buffalo hump, incredibly large striae from my armpits down to my calves, depression/anxiety thats treatment resistant, fatigue, muscle weakness, weight gain..."*

# Disease Management Amongst Cushing Population Segments

“ I've been diagnosed with Cushing's. It's a rare diagnosis affecting energy, depression, anxiety, unnatural weight gains, and much more. I have a tumor on my adrenal gland we finally found after several years and extensive testing by doctors from multiple specialties. All the while I was struggling and scared. I am being scheduled for surgery hopefully within the next month which I am so grateful for. The recovery is harsh and full recovery may take up to one year. I so look forward to returning to the bedside as an ICU nurse in the next few months With as much energy and determination as my body allows!”

“ I was diagnosed with Cushing's a couple months ago. And its been rough. One of my symptom was diabetes type 2 which came very sudden. Like within a month. Ive been in the hospital for the past 4.5 weeks and have had my adrenal glands removed and a tumor removed from my pituitary gland. My sick period have been about 7-8 months. So for you to have had for years, i can imagine it being hell. But I'm happy you're doing good now.”

“ I got diagnosed with Cushing's a couple days ago and waiting for a ct-scan. My doctor wants me to take metopirone while waiting for the surgery. Have you got any help from it? It's super expensive.”

“ Alli, I'm so grateful for your story. I've been searching for answers for the past 2 years: seeing specialists, doing tons of bloodwork - but every time the tests were "normal" and the Dr's discounted my concerns. An MRI for another issue revealed the pituitary tumor. That's what started my research. I have virtually every one of the symptoms of Cushing's.”

“ today i did tests and im diagnosed with Cushing's i think i have it since 2016 its almost 8 years , now i have myopathy , numbness , fasciculations , heart palpitations , ... especially fasciculations is it common and how you managed it ? its the worst period of my whole life.”

“ So I'm tapering off my hydrocortisone after my surgery. I'm down to 10 mg in the morning right now. I've always struggled with depression, but it's been bad for the past few months. There are other factors that I'm sure have contributed to this but I'm wondering if the decrease in steroids could be one of them”



# Patient Unmet Needs And Gaps

Reduced quality of life, lack of support from HCPs\* and peers, delayed diagnosis, and misdiagnosis are some of the major patient concerns



## Quality of Life ~ 29%

“ I look disgusting. When I see myself I want to stop eating to punish myself for looking like this. I feel like I don't deserve to eat. My gut will still stick out, I will still get new stretch marks. I truly hate myself even when I know it's not my fault. Does anyone else feel like this?”  
– Patient

“ I feel angry and agitated by anything! I am also feeling really panicked. My buffalo hump also feels like it is tingling, almost like pins and needles sensation. Is this typical of a high?”  
– Patient

N=10 K



## Ineffective HCP Communication ~ 25%

“ Things aren't adding up and my current endocrinologist doesn't seem interested in figuring it out. I'm not convinced what I have is Cushing's, but it looks like it wasn't properly ruled out so it's back on the list of possibilities and I really need to find an endocrinologist in the Boston area.” – Patient

“ My doctor said it's unlikely to be Cushing's because two out of three of my ACTH tests as well as salivary tests came back in normal range. Good to know that you had similar tests though, that might push me to be more insistent with my doctor. I have not asked about an MRI just because she seemed pretty adamant about it not being Cushing's.” – Patient



## Emotional/Peer Support ~ 17%

“ After talking to other patients, I now realize that I am actually doing well, and I do not want to burden my family.. They do not want to talk to me about it!!”  
– Patient

“ This just made me cry watching this, I got diagnosed a few months ago and have my surgery date to remove the tumor this Tuesday! I thought I was crazy for the longest time and have been going to doctors for 3 years now looking for answers that no one had. I finally have them and I feel so relieved but also so angry. It's nice to know that there are people who have gone through the same thing and I really appreciate you sharing this.”  
– Patient



## Delayed Diagnosis or Misdiagnosis ~ 15%

“ I'm always extremely stressed and anxious for seemingly no reason. I also have easily bruising and scarring skin, and extremely painful rashes on my ankles (though rarely). I've been diagnosed with PCOS as well, which I've heard is a common misdiagnosis with women for Cushing's.”  
– Patient

“ The PTSD is real. It took so long to get the diagnosis and finally to feel validated when I did. I fought for my life for 4 years. 10 years in remission. There is hope. Great job and kind of you to share. I looked for anyone like you 10 years ago.” – Patient



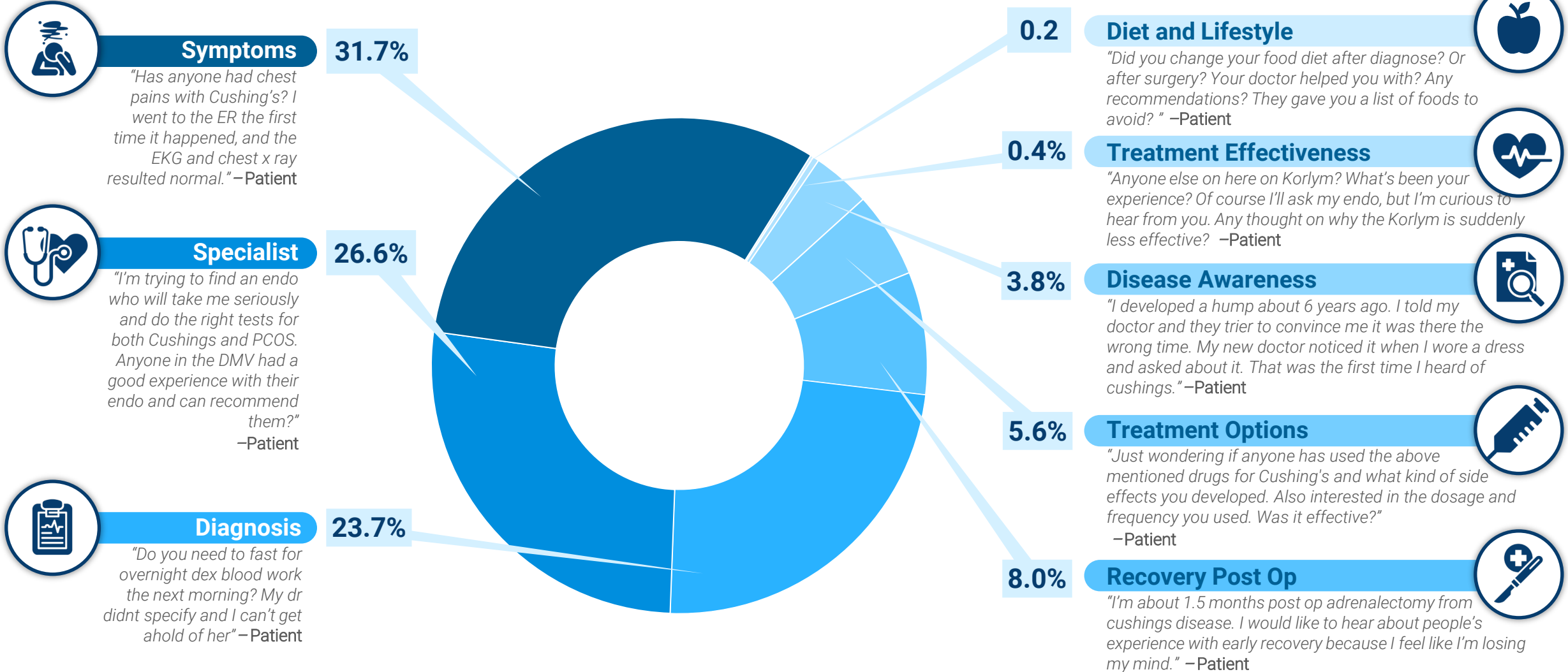
## Caregiver Support ~14%

“ Hi my name is Ivey. I'm asking in regards to my mother, she has Cushing's. I'm looking for any support groups in Arizona”.  
– Caregiver

“ Our 14 year old shepherd mix was diagnosed with Cushing Disease a little over a year ago. She is still strong and acts like her normal self. I know as her mama and caregiver, it will be my responsibility for end of life to prevent any suffering. I of course want as much time as possible with her but don't want to be blind to her suffering.”  
– Caregiver

# Patient Information Gaps

Patients are seeking information about symptoms, specialists, post-surgery recovery, diagnosis and assistance in choosing the right treatment



**Symptoms**  
*"Has anyone had chest pains with Cushing's? I went to the ER the first time it happened, and the EKG and chest x ray resulted normal."* –Patient

**Specialist**  
*"I'm trying to find an endo who will take me seriously and do the right tests for both Cushings and PCOS. Anyone in the DMV had a good experience with their endo and can recommend them?"* –Patient

**Diagnosis**  
*"Do you need to fast for overnight dex blood work the next morning? My dr didnt specify and I can't get ahold of her"* –Patient

**Diet and Lifestyle**  
*"Did you change your food diet after diagnose? Or after surgery? Your doctor helped you with? Any recommendations? They gave you a list of foods to avoid?"* –Patient

**Treatment Effectiveness**  
*"Anyone else on here on Korlym? What's been your experience? Of course I'll ask my endo, but I'm curious to hear from you. Any thought on why the Korlym is suddenly less effective?"* –Patient

**Disease Awareness**  
*"I developed a hump about 6 years ago. I told my doctor and they trier to convince me it was there the wrong time. My new doctor noticed it when I wore a dress and asked about it. That was the first time I heard of cushings."* –Patient

**Treatment Options**  
*"Just wondering if anyone has used the above mentioned drugs for Cushing's and what kind of side effects you developed. Also interested in the dosage and frequency you used. Was it effective?"* –Patient

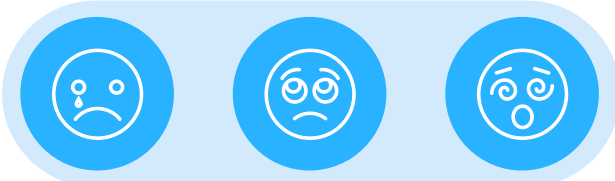
**Recovery Post Op**  
*"I'm about 1.5 months post op adrenalectomy from cushings disease. I would like to hear about people's experience with early recovery because I feel like I'm losing my mind."* –Patient



# Quality Of Life Implications

Majority of the patients are reporting that body pain, fatigue, depression, and frustration are negatively impacting their quality of life which is resulting in reduced productivity and frustration

## Physical Quality of Life\* (32%)



Bodily Pain

Unable to Work

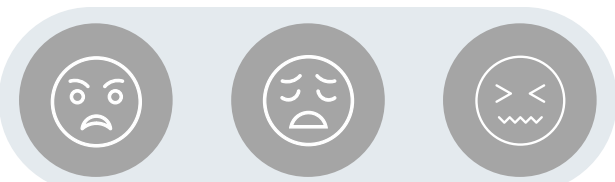
Fatigue

“Anybody else getting shooting pains all over your body. They’re mostly in my hands, arms, chest, and legs. But the pain is so severe it makes me yell. Its gone within four seconds and I’m back to normal. I’m assuming its harmless but its happening so frequently its weirding me out.”

“I love working and I am trying my best, but I can barely make 30 hours a week to support myself. I was taking 20mg hydrocortisone for 3 months. I need to take an extra five or I cannot function. And then I have to spend every second Im not at work in bed so that I can go to work the next day...”

“Anybody else getting shooting pains all over your body. They’re mostly in my hands, arms ,chest, and legs. But the pain is so severe it makes me yell. Its gone within four seconds and I’m back to normal. I’m assuming its harmless but its happening so frequently its weirding me out.”

## Mental Quality of Life\* (33%)



Impaired Cognition

Brain Fog

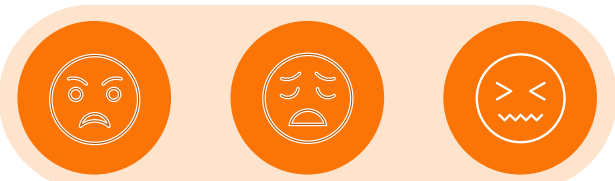
Stress

“I feel angry and agitated by anything! I am also feeling really panicked. My buffalo hump also feels like it is tingling, almost like pins and needles sensation. Is this typical of a high?”

“I slowly started to crumble and I remember studying for my surgical technology exam feeling so brain fogged I could hardly remember anything I was studying for the past two years. That’s when it really clicked for me. Somethings wrong..”

“I have developed a moonish face but not as severe as what i see on google. My hair is starting to thin out although I have had thick asf hair my whole life and has been greasy for years. I feel depressed and anxious everyday. I get exhausted from doing basic activity...”

## Emotional Quality of Life\* (35%)



Frustration

Fear

Sorrow

“I had Cushing’s Disease and had my tumor removed at the end of March! The process to be diagnosed was frustrating but once I found my endocrinologist all the pieces came together. My appearance changed so drastically over a few years and I refused to let people photograph me...”

“I love working and I am trying my best, but I can barely make 30 hours a week to support myself. I was taking 20mg hydrocortisone for 3 months. I need to take an extra five or I cannot function. And then I have to spend every second Im not at work in bed so that I can go to work the next day...”

“Anybody else getting shooting pains all over your body. They’re mostly in my hands, arms ,chest, and legs. But the pain is so severe it makes me yell. Its gone within four seconds and I’m back to normal. I’m assuming its harmless but its happening so frequently its weirding me out.”

# Patient-Physician Interaction

Note\*: HCPs = Healthcare professionals PCPs = Primary Care Physicians



*"@medictests Any tips to get docs to help diagnose cushings who think you are lazy and fat and that you are the problem?"*



## Awareness



*"So I've suspected for many years that I have Cushings, but despite my bringing this up to my PCPs\* it has all fallen on deaf ears. Like so many, I was diagnosed with PCOS and everything gets attributed to that."*

*"My story began when I was 18 I was always a natural UK size 6. And suddenly I was a textbook case of cushings by looking at me. But it took 18 months to find out the cause of my weight gain, mental health and symptoms because my local doctor didn't have a clue what cushings was till I googled it and presented it to him."*



## Misdiagnosis



*"I am in the process of trying to get diagnosed... previously diagnosed with PCOS but my REI (reproductive endocrinologist) just ordered the first few tests for cushings to see if I actually have that instead."*

*"I really need to find an endocrinologist in the Boston area who would be willing to do more than just run a few basic labs and shoo me away. If anyone has any doctors to recommend or strategies for finding a solid endocrinologist, I'm all ears."*



## Doctor Unavailability



*"Ugh. It's hard with doctors, it's scary reading stories of how other people get dismissed by doctors, because I feel like that too. My primary doctor told me that my muscles and joints hurting is because of fast weight gain, but she never even let me explain that it actually hurts, even when I'm lying in bed and not moving."*



## Feeling Unheard

# Thank You.

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