Burning Mouth Syndrome: Why Women Are Dismissed & What May Actually Help Transcript

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Introduction to Burning Mouth Syndrome

People with burning mouth syndrome are on their computers and on the internet more than any other group of patients I've ever seen in my 40 year career.

And all I can say is that if you have a problem and you know you a have problem, keep searching. Do not believe people who say it's all in your head or you had nothing happening here.

You need to keep looking because there are solutions out there. Do you feel like your hormones have turned against you? Trust us, you're not alone. We're Dr.

Serena and Dr Heidi and on Hormone Heroines we explore all the root causes that are behind hormone imbalances and we teach you how to thrive through them.

Join us for real talk, expert tips and even a few laughs. Hi and welcome back to Hormone Heroines. Today we're going to be talking about burning mouth syndrome with Dr.

Susan Sklar who is the founder and medical director of the Sklaar Center for Restorative Medicine in Long Beach, California. She is a Harvard-trained physician who practiced as an OB-GYN for 25 years before retraining in anti-aging and regenerative restorative medicine.

Welcome, we are so excited to have you. Thank you! Yes, and I actually am not the head of the Sklar Center anymore. There is another doctor who's taken over, so I don't want to confuse people.

And I am focusing totally on burning mouth syndrome. So currently we call it Dr. Susan Sklars hope for burning mouths because a lot people really feel hopeless after going through the usual system.

I like it. I love that you're doing that. That's perfect. Well, let's dive right into it because, you know, I've definitely heard of burning mouth syndrome, but it's not on my radar.

We definitely learned about it in med school, So I'm impressed that you learned about it. Cause you know what? I was OBGYN for 25 years and never remembered hearing about, it learning about.

And didn't get into it until I got into, you.

How Dr. Sklar Got Into Treating It

Quote anti-aging therapies and. Like if you want, I can tell you kind of how it kind evolved. Yeah, absolutely. Let's do that. OK. So I had one of my very early patients.

I got kind a burnt out on OBGYN and conventional medicine. Not patients, but the whole schema, 30 patients a day, very limited appointment times. And I was just like, i can't do this anymore.

so i got into a new model of doing things, which was longer appointment time, not insurance based. And so familiar with women and their hormones with some extra education started doing longevity or anti-aging medicine.

And I had one of my very first patients was somebody who was in perimenopause and she was actually a trainer. So she wasn't, she's in great shape and everything.

But she wrote a little testimonial and this was in 2007 and I don't know if you remember 2007, but there wasn't a lot on the internet. And so my son had maybe this little like one page website.

It didn't have tabs or anything. it was just like a single page. And we put her testimonial on there and she said, after two months on my hormone program, my energy is better, My mood's better.

My muscle definition is, better because you know, she was a trainer. So she, was really aware of her muscularity and my burning mouth isn't nearly as bad.

And I honestly, I kind of posted that and didn't really think much of it. And then people started contacting me, you treat burning mouth syndrome, and I was like, well, guess I better learn about it because I have no idea what it is.

I don't know what hormones have to do with anything that has to with pain. And so I started reading the scientific literature just like deep dive into brain research reviews and neuro endo immunology literature kind of piece together like what would hormones have to do with pain and nerve function.

And it seemed like, yes, it could be helpful. Hormones are anti-inflammatory. We use DHEA and pregnenolone. Progesterone has actually been looked at in terms of post-concussive treatment to help brain function.

And so it seems like hormones had a good piece together, a fair amount to do with potentially nerve function and pain relief. And so that was kind of my entrance into it.

Well, let's back up a little bit and let us talk about what is mouth on fire, burning mouth syndrome? Just trying to get into the details of that. Sure.

So if you've ever drunk into your coffee that's way too hot and your mouth feels scalded afterwards, that is how it feels all the time. And it can be severe enough that it impacts people's lives.

They have very limited foods they can eat. Like anybody with a severe chronic pain condition, their lives, you know, really become contracted. People don't know are they going to feel well enough to socialize?

Are they gonna feel enough well to go out to dinner? Will they have gotten any sleep the night before?

What Burning Mouth Syndrome Feels Like

And so people in chronic pains get, they kind of lose who they are. can't pursue some people their careers, the hobbies and stuff that they love to do.

And so it's a neuropathic pain condition. Like I said, I'm surprised you guys have heard about it. I think that's fantastic. Your education included it because it takes on the average three years for people to get a diagnosis.

They go from doctor, ENT, to dentist, or oral surgeons, dentist, psychiatrist, because people think it's all in their heads. And so the first thing you want to do is rule out mouth conditions that have a cause you can detect, and that's like thrush or candida in the mouth, herpes, There are some autoimmune mouth disorders like bichettes and lichen planus.

And so it is helpful to have an oral surgeon examine you and rule out some of these other things. But once everything looks completely normal and you still have this burning pain that is disrupting your life, the question is, what do you do?

And, so a lot neuropathic pain pharmaceuticals are given, things like gabapentin. which has a lot of side effects that often makes people feel like a zombie.

It doesn't really, for the most part, dramatically reduce pain, although it seems to help some people some of the time. And that goes for any of anti-seizure, antidepressant medications that conventional medicine uses.

So I wouldn't say I don't ever use those. They could certainly be part of a regimen, but they don' generally get people to feeling good. Well, they have a lot of other side effects too.

You know, like gabapentin often will cause diarrhea or, you know gastro issues that nobody wants to have to deal with on top of being in pain. Exactly.

And I have somebody on a medication, I don't know if you've ever heard of it called lacosamide or VIMPAT, which interferes with certain of the sodium channels and can help pain, but it gives her such bad brain fog and fatigue that it's very difficult for her to function.

And the benefit for her is minimal. And that's when studies have been done, really probably only one that is shown consistently to be good, fairly good and maybe half of the people is deloxetine, which is also called Cymbalta, an antidepressant.

So I have not seen those medications, I've seen them be part of a whole protocol, but I haven't seen it be enough for the most part for people to really get their lives back.

And maybe that's just who's seeing me.

Why Itu2019s Often Misdiagnosed

The people who got relief and they're doing okay and not having side effects, they don't come and see me, people that have been everywhere and have gotten relief.

Well, on that note, who gets burning mouth syndrome? So that's the incredible thing. 90% of the people that get it are perimenopausal and menopause women.

And when you look at the literature, and I've read a lot of literature from the last 40 years, When you look at the literature from 1980s and 1990s, it's almost entirely blamed on psychogenic reasons.

There was actually a paper that said it was due to television moans by which it from somewhere in the Far East where they said that women watch these soap operas on TV and get disturbed by them and that causes their mouth pain.

So, you know, Wow, right. And not only in the 80s, I mean, now I have people tell me, you know, the whole round of doctors, dentists, etc. and they finally referred me to a psychiatrist.

What does that have to do? Yes, people get depressed and anxious when they have chronic pain and nobody can solve it, but that's not the cause of their pain.

They're not imagining it. What do you think is the most difficult aspect of burning mouth syndrome? I think being believed. Yeah. It's women. Its women in midlife and older age groups.

The people that get it the Most are women over 70. I'm in that category. We get written off. You're an old lady. You have this thing. I don't know. Your life isn't really that valuable.

We have all these young people here to take care of, you know, if you're on your own. Yeah, we hear that from our patients a lot, actually. Not from us, about us.

Well that means that we talked a little bit about how conventional treatments are available for this and honestly that it's just not well recognized. So what do you do differently as far as helping people you know get the diagnosis and then treatments?

Right so usually by the time I see somebody they have a firm diagnosis because I'm not an expert in the oral cavity. And so, I want to be sure that people have gotten a proper examination, had cultures taken, biopsies if necessary.

And, so when people come to see me, all the other things have generally been ruled out. The foundation of my method is a hormone replacement program, estrogen, progesterone, testosterone, DHEA, pregnenolone thyroid, and melatonin.

There are articles on melotonin for treatment of neuropathic pain.

Hormone-Based Treatment Approach

There are articles, so I try to have it as scientifically based as I can, but sometimes there isn't a lot of, you know, there's not, they're no articles specifically about DHEA and pregnenolone and burning mouth syndrome.

There is about the DHA and, and pregnant alone and neuropathic pain in general, But there also, There was one article that was really helpful. They looked at menopausal women with burning mouths and without burning mouse syndrome, And they evaluated their thyroid function.

and the women with burning mouth syndrome had more hypothyroid, meaning low functioning thyroid, than the group without burning mouse syndrome. And the really key thing is that when they gave them thyroid medication, their mouth burning improved.

So I try to use, you know, and there are articles in the literature that are kind of like case studies and small studies. And all I can say is I found that it works.

So about 65 to 75% of our patients get their lives back. Does it mean they never have a flare? No, I don't hear anybody. It's ongoing relief. And yeah, well, I'm sure stress kind of plays into it too, you know, and you can't control that all the time and stress, cortisol is a hormone and it throws off other hormones.

So I am sure that's one of the reasons that flares happen. Totally. The interesting thing is so my like patient zero, there was a physical trainer, she was doing great and then she went through a divorce.

And so the divorce, she was on all our hormones and everything, but her burning mouth came back bad. And, um, She actually got relief from alpha lipoic acid, which has been used for diabetic neuropathy.

Um, and it's controversial with burning mouths. It helped her, But I have seen that. So I always ask people like, tell me the story of what was going on.

What was happening in your life when this started? And a lot of time, people will say, I went through an incredibly stressful time of life. So that's really a trigger.

And stress can have somebody who's otherwise been feeling pretty good get their symptoms back again. Most of the time it's like the stress doesn't last forever.

We have some like quick remedy ideas, lozenges and swishes and things that will help when people have a flare. I kind of go back and look at everything and see if there's anything we can augment or improve in their you know, regimen of hormones and medications and supplements.

So hormones are really the foundation. And then there are a number of articles in the literature about nutritional deficiencies and burning mouth syndrome, magnesium deficiency.

CoQ10 deficiency, zinc deficiency and vitamin D, which of course we know vitamin is a hormone really, it's not a vitamin. And I've seen people where we've got their lab testing back and their vitamin deal be like 15 or 12 and I like to have it in the 60 to 80 range.

and they have vitamin D at home and I'll tell them, you know, like load up on high dose for a few days and then go, 50,000 a day for three days. And this has to be done when you've had your lab test done under guidance.

So don't go off and do this on your own people. And, you know, and then be on five to 10,000 a day for anywhere from one to three months, then we recheck.

And some people just with vitamin D have their pain diminish. So that's really critical. Hormones, including vitamin d, correcting nutritional deficiencies.

Then the other thing that I do close to the beginning of treating people is give them low dose naltrexone. We always, I learned about low-dose naltrexone for autoimmune disorders.

But one of my burning mouth patients was taken care of also by a wonderful doctor at Duke University in an academic setting. And he talked to me about Low-Dose Nalterexon for Central Sensitization Pain.

That's pain that's not in the nerves in your tongue. It's Not living there anymore. it's living in you brain. So that has been a help for a number of people.

Stress, Nutrient Deficiencies, and Flare Triggers

Yeah, so we're naturopathic doctors. So we learned about all of these lower dose things and natural treatments in school. That's probably why we learn about burning mouth syndrome, because it's a weird one.

And as NDs, we like weird stuff. But for low-dose naltrexone, and we use it when anybody has a high inflammation picture. So it doesn't just have to be autoimmune.

Like you said, you know it for auto immune diseases. But like if you have a high inflammation picture, we'll often do that for like three to six months to try to get that inflammation down and then kind of go from there to see what else while we're figuring out what's causing all the inflammation to take that out of the equation.

Yeah, so that that's excellent. Yeah. Well, what you learned in nature path at school as part of your curriculum, I had to scramble and learn in weekend courses and night, you know, things after four years of medical school that, well, yeah, but anyhow, we get it.

Trust me. What would you say some of the lessons you've learned from treating people with this disorder? I think the most important thing is hormones are related to chronic pain.

And I that we're probably going to see more of this. One of my kind of heroes is a doctor named Forrest Tennant, and he treats a very, way worse than burning mouth syndrome condition called adhesive arachnoiditis.

which is a pain condition that occurs because the cauda equina, which are nerves that hang down at the bottom of your spinal cord, get glued to the covering of the spinal chord, and it's an incredible pain-producing condition.

And he was the first place I read about using DHEA and pregnenolone. He actually has written a book that he put on Amazon And he mentioned me in it, I didn't even know he was going to do that, talking about all the ways that hormones act on in chronic pain conditions.

And there are definite pathways, the three pain pathways that estrogen works on. And so you can see that for each of the different hormones, testosterone is a pain dampener.

Men have much less chronic pain than women. We think it's because their testosterone level is like a hundred times higher than woman's, but testosterone it is an important component of what we do because of its pain-dampening effect.

So I think, you know, one of things that I personally am trying to get out into the medical community is how hormones can help chronic pains. I'd also like to add that hormones are, especially estradiol is anti-inflammatory and a lot of pain is from inflammation.

And so if you dampen that in that pathway as well, it's going to reduce your pain. For sure.

Lessons Learned and Why Practitioners Should Care

And I guess the other lesson is, I don't know what's going to change this, but what we said about women not getting listened to, women getting written off.

I recently wrote a blog post in terms of sexual dysfunction. Women actually have more sexual disfunction than men. There is only one FDA approved medication for sexual dysfunction in women, only got approved in December last year.

And it has a ton of side effects and it's incredibly expensive. It's called Addie. And there are, you know, 11 different things that men can do. And in addition, seven different forms of testosterone they can be on.

So, it's like, who's taken seriously? Where has the research gone? I read recently that for every dollar of research, only five cents goes to research on women.

Which is ridiculous since we make up more of the population. That's right. So anyhow, those are my big kind of points. I kind know the answer to this question, but I want you to elaborate for our listeners.

A lot of practitioners don't know about it. Why should practitioners be interested in this condition that they probably never even heard of? Well, for one thing, I mean, it is an example of how functional medicine, naturopathic medicine works to correct things when you correct some of the underlying dysfunctions rather than just giving a pharmaceutical.

And doctors, I must say, aren't going to run across it very often. But most doctors when they do, you know, have had patients say well, my doctor told me I have good news for you.

I know what you have, but I had no idea what to do about it. So I think the more I can get the word out there, the better. And it's estimated, it depends on whose statistics you look at, and it is anywhere from 3 to 20% of menopausal women have burning mouth syndrome.

It's millions of women worldwide. Is there any last minute things that you want to add to let our listeners know about this topic before we let you go?

Yeah. Well, people search incessantly. The people with burning mouth syndrome are on their computers and on the internet more than any other group of patients I've ever seen in my 40-year career.

And all I can say is that if you have a problem and you know you a have problem, keep searching. Do not believe people who say it's all in your head or you had nothing happening here.

You need to keep looking because there are solutions out there. Yes. I love it. What a beautiful way to end. So thank you so much for being on our podcast today.

It has been a joy talking to you about this very interesting and topic that needs more Yeah. I mean, I probably haven't really thought about it since med school.

So. Yeah, clearly there's a lot of women out there that need this. Thank you so much for coming on. And thank you for having me. It has been great.

Final Advice for Patients and Closing Remarks

Well, this has another episode of Hormone Heroines and we will see you next time. Bye! You know how us women are always just pushing through it and then when we go to find help we're often not taken seriously or told, oh, that's just far to be in a woman.

Yeah, we've lived through prioritizing everybody else and our own health falls to the wayside. That's why we started blossoming longevity. By women or women.

We created programs that meet women where they are, addressing the root causes and all of the struggles that come with every stage of life. Like our vitality program.

It reconnects you with your youth and your life so that you can thrive through the years. And with Clarity, we go beyond the skin to restore your health, clear your complexion so you feel radiant from the inside out.

With our Silhouette program, we help you reclaim your strength, optimize your metabolism, and your body composition so that you can feel great in your own body again.

And with Harmony, We help rebalance your hormones to heal from within so you feel vibrant and ready to take on the world. That is why it's time to stop saddling and start flourishing.

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And write a review. That helps more people find their way back to balance. See you next week.