Burning Mouth Syndrome: The Menopause Symptom Too Many Women Don’t Know About Transcript

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Introduction to menopause and pain

Estrogen is also somewhat pain dampening. So what happens at menopause is you lose that effect. You lose the pain-dampening effect, and women's testosterone also goes down.

With menopus, as soon as your ovaries stop working, you loose half your testosterone. The other part is made in your adrenal gland. but you lose the ovarian contribution.

And so you have all of these things adding up to more likelihood of pain and all the things that hormones do to keep you feeling good. So just not sleeping because you'd have hot flashes factors importantly in pain.

Have you made it past menopause or are you going through it now? I'm Dr. Pat McShane and on the Women's Health Span Voices podcast, I'll guide you through the menapausal transition and beyond.

Helping you to thrive in this powerful time of your womanhood. Hello and welcome. I'm Dr. Pat McShane, and this is Women's Health Span Voices. And I guess that's common for docs to not have heard of it.

mouth on fire and Dr. Susan is trained in OB-GYN and functional medicine. And she's been more recently spending a lot of her energy on anti-aging hormone replacement therapy and so on.

She can tell us a little bit more about that, but maybe Dr Susan, you could talk to us about how you got into burning mouth syndrome in the first instance.

Sure. It was really serendipity. We were just talking before we actually started recording, and I said I felt like my whole life had led me on this path.

First, going to medical school and deciding to go into OB-GYN.

How Dr. Susan Sklar entered burning mouth syndrome care

Then my children, when they started being pre-adolescent, I wasn't there very much. I was away doing deliveries all the time. You know, I want to be more of a mother, so I'm going to stop the OB, which is unpredictable and keeps you away a lot, and just do GYN.

And with that, i started really taking a deep dive, because most of my patients ended up being perimenopausal and menopauseal women. I thought, "I'm just going learn everything I can learn about osteoporosis and cardiovascular disease and metapausals symptoms, all the things that perimentaposal or menapause women are trying to deal with." And that most OB-GYNs and certainly primary care physicians have not that much experience in their training or in practice, I might add.

Yes, that is a good addition. So I ended up kind of getting burned out on GYN and going into what at that time 20 years ago is called anti-aging longevity medicine, which is really hormone restoration and not just estrogen and progesterone, but looking at testosterone for women, Which is still off label, But has a lot of benefits.

I learned about DHEA, dehydroepiandosterone and pregnenolone, which I knew as part of the steroid hormone metabolism chart that I'd learned in medical school, but I didn't really know what those hormones did.

And one of my very first patients in this new longevity medicine practice was perimenopausal woman. It was almost 20 years ago, and I had this very rudimentary website.

I don't know how many people remember what websites were like. in about 2007, but it was like a one page, no tabs, No clicking around. And I had put up a testimonial on one of my patients, one my early patients.

She was a trainer. she worked at her own gym and she wrote this little testimonials that said after two months on my hormone program, my muscle definition is better because of course she was very aware of her muscle muscularity because she was a trainer.

My energy is better, my mood's better and my burning mouth isn't nearly as bad. And that was up on my website. Honestly, I didn't pay a lot of attention to it.

Like we talked about before the show started, people with burning mouths syndrome hunt endlessly for solutions because nobody generally can help them.

And so I started having people contact me because of what they found on my website, and I was like, oh, wow, I don't know what this is, but I better find out.

So I did, you know, there's about a 40-year literature going back to the 80s. and i did a lot of reading in the like brain research reviews. I'm like what do hormones have to do with pain?

What do like, you know, what is this about? And learned, progesterone helps to heal nerves. They've studied pro gesterones for a traumatic brain injury.

Pregnenolone and DHEA help nerve nerve-to-nerve transmission help inflammation around nerves. And then after about five years, I came across this term, neurosteroids, and I was like, my goodness, think I've hit the jackpot because these hormones are made in your brain.

They are in nerves and they keep nerves functioning properly. So, what I learned about burning mouth syndrome is that 90% of the people that have it are perimenopausal and menopause of women.

So clearly something is going on with hormones. Like what actually triggers the nerve degeneration and the subsequent pain, I have not been able to figure out in spite of all of my reading and all the time I've spent in the multiple patients I see.

But I seen that hormones make probably three quarters of the people that have it feel significantly better. And it turns out that this is more prevalent than certainly I had thought of.

But again, you kind of know that in a busy OB-GYN or primary care practice, of all the list of things that your doc or practitioner is going to be reviewing, sometimes that one might get to the bottom of the lists behind the blood pressure and the cholesterol and vaginal symptoms and so on.

I've read prevalence, that is what percentage of people get this, as high as 5% in postmenopausal women, which is pretty high. Maybe you could tell us a little bit more about that.

Sure. Well, the estimates go even higher. some as high as 25% of postmenopausal women.

Hormones, neurosteroids, and why burning mouth affects menopausal women

And I think it's probably not quite that high, but certainly post-menapausa women undergo a lot of changes in the oral cavity, just like they undergo, undergo lot changes the vaginal cavity.

It's similar tissue. Those smooth, which should be smooth and well-vascularized, nice and elastic and moist linings become thinned out and dried out. And, you know, women know we have problems with painful sex and other problems, with urinary tract infections.

But in the mouth, the mouse gets drier and things change in mouth. So we don't know how much that's contributing

to burning mouth syndrome in particular.

What I've been able to do, and so treatment with a hormone restoration program is the foundation. And then there can be a lot of other contributing factors.

The Burning Mouth literature, so I did a lot of reading in the neurological literature and neuroimmunology literature. The Burning Mouth literature is really poor.

And so the Cochrane Reviews, which us, you know, physicians, people in the medical profession know is a huge review organization that looks at many, many studies and makes recommendations, unbiased recommendations based on the findings in those studies.

The Cochin Review reviewed 23 Burning mouth studies, and basically said there isn't anything here that's been proven to be really effective. And so I think that's the reason why, number one, doctors don't know what to do and patients just go, it takes almost three years on average to even get a diagnosis.

And then patients get told things like, I know, what's wrong with you. That's good news. The bad news is I have no idea what you need to help you and so it's very discouraging.

So I would say there are two big factors, you know some of which we talked about before, which is that women get written off a lot. perimenopausal and menopause of women really get written off.

And so the people with this problem, you know, they get their mouths examined by the ENT, the oral surgeon and the dentist, it all looks normal. So then they're sent to a psychiatrist where one patient was admitted to psych hospital.

Yes, with any chronic pain, there is depression and anxiety and there aren't about half of burning mouth patients and certainly stress and worsen the perception of the pain and the feelings of pain.

And we know it's really important. I have a lot of patients. This is classic. Somebody who's just entered menopause said, I went through this incredibly stressful time.

One lady told me, she was actually a little earlier in her mid 40s. She said I had a miscarriage and bled for five weeks. Then my brother and his wife at the same time lost a full term baby.

and I was so stressed. That's when it started. And that's the kind of thing that we see where a huge period of tremendous stress combined with hormone decline does something to trigger it.

Or your pain sensitivity, how it's processed in your brain diminishes. And so some more minor pain now becomes much more significant in life. I think you also said an interesting thing prior to that, which is that these folks really do need to rule out dental problems, ENT problems etc.

before we presume that there's you know, only a hormonal and a neurological background to this set of symptoms. So maybe you could talk about that a little bit.

Sure. Well, there are a number of things that can cause mouth pain. And these people with burning mouth, a lot of them have, it's not really lack of saliva, but a feeling that their mouth is dry, and the feeling there's something rough, like bumpy or bubbly or you know what is it looks like a smooth surface and if you put your finger in it feels smooth but when they feel it with their tongue it feel rough.

And then the last one, it altered tastes where everything tastes either salty or metallic or like cardboard, like it doesn't taste. So it seems like there is a whole set of kind of neurological things that go on.

And the thing that's very interesting is women have more chronic pain than men. Testosterone is pain dampening. What you just alluded to, which is that estrogen is also somewhat pain dampening.

So what happens at menopause is you lose that effect. You lose the pain-dampening effect, and women's testosterone also goes down. With menopus, as soon as your ovaries stop working, you loose half your testosterone, the other parts made in your adrenal glands.

but you lose the ovarian contribution and so you have all of these things adding up to more likelihood of pain and all the things that hormones do to keep you feeling good so just not sleeping because you factors importantly in pain.

Low energy, because your DHEA and testosterone are lower, your thyroid is low, makes it more difficult to sustain yourself in the face of pain, so there is a whole set of hormonal things that go on, and in literature, what I've done is go through two little studies about thyroid and burning mouth, one of them said that they had a control group of Menopausal women without burning mouth syndrome and a group with burning mouse syndrome, and the group was burning now syndrome had more low thyroid function.

And when they replaced their thyroid hormone and got them up to normal function, the burning mouths got better. You know, there are these like little case series.

There was a little K series from Dr.

Diagnosis, rule-outs, and common contributing factors

Lawrence Afrin, who's the well-known hematologist oncologist in the functional medicine arena who had two little cases studies about mast cell activation and burning mouth syndrome.

So mast cells are cells that they line our entire oral cavity and GI system and they're on our skin. They're up our nasal passages and then our lungs.

And it's what makes, you know our eyes burn and our nose run when we have allergic reactions, and some burning mouth is associated with overactivity of those cells.

And then there was another report I read where maybe it is a reactivation of a herpes infection, like, you know, oral herpies, cold sores or shingles.

It gets reactivity. You don't necessarily have a visible outbreak. And it can cause pain. And so there are, there's not like good, large studies, randomized controlled trials that, you know, we want to depend on, but there was like these little case reports and what I've kind of done is try to put them together.

You know there reports on nutritional deficiencies. The Mayo Clinic put one out. People with burning mouse syndrome have, anyone with neuropathy has lower B vitamins, lower zinc, low iron, lowered CoQ10, and lower magnesium.

So we check for all of those things. And if they're not optimal, we replace them mainly through supplements. That's kind of like how I've gotten my treatment protocol with like reading an article here and an articles there.

Nothing really overarching, just kind like cobble it together basically. What percentage of women who don't have any other cause except sort of primary burning mouth syndrome can be helped by the replacement or reestablishing their hormonal environment?

I think about two-thirds. And what's very ironic is in this 40-year scientific literature, I've read this stuff since the 80s, There have been about four or five studies about estrogen and burning mouth syndrome, and they all show about two thirds of people improve if they're put on estrogen.

One of the studies was from Europe, estrogen, progesterone, testosterone kind of combo medication. Two-thirds of those people did better too, and nobody carried it forward to try to treat any large number of women.

And so these are like four studies over the last 40 years. And I'm not the only one that showed it worked. Maybe you should do a series of your own patients, have somebody go back through your records.

How does your approach differ from a conventional medical approach? Well, the conventional medical system views burning mouth syndrome as, you know, once they've ruled out, and you asked me what other things get ruled, out you want to rule out oral lichen planus, which may be an autoimmune disorder.

You want a rule-out definite auto immune disorders like Sjogren's and lupus that can give you mouth pain and dry mouth. you wanna ruleout yeast in the oral cavity.

Gastroesophageal reflux can give you oral burning. Something called laryngopharyngeal reflex, which is, you know, in a different area of the throat, but it's also reflex of, acid gastric contents.

And so, and you want to rule out people get aphids ulcers, with your little ulcerations in the mouth. So you want to rule out all of those things. And usually by the time people have come to see me, they have seen the dentist, the oral surgeon, air, nose and throat doctor, and they've had a thorough exam and had those.

Either ruled out or already treated. Well, lucky that they find you, I think. Right. So I would say about probably 65%, maybe two thirds of people. get better on a hormone restoration program, which means estrogen, progesterone, testosterone, DHEA, pregnenolone.

Also thyroid. We know that melatonin helps neuropathic pain, so that's kind of the basic. That's a pretty standard anti-aging medicine, you know, kind-of regimen.

If that doesn't do the trick, we add low-dose naltrexone which some of this pain is peripheral, meaning it's in the nerves around the mouth. Some of the pain has gotten, because of certain neurological feedback loops, now exist up in the brain or in spinal cord and requires a different kind of treatment.

And so, low dials naltrexone, which is naltrexon is an opioid antidote. So if somebody has overdosed and you give them naltrexone, it will block the opioid receptors.

The opioid won't get on those receptors and suppress breathing, which is how people die with opioid overdoses. And when you use naltrexon, that's when it's used for overdosis, its 50 milligrams usually at a dose.

Narcan, right. Right, and so low dose naltrexone is anywhere from one and a half milligrams to four and half kilograms and there's ultra low-dose also and when you use that instead of blocking the opioid receptors it actually stimulates them and we have our own opioids our bodies and our brains make and it releases those opioids and that is very anti-inflammatory.

So using low-dose naltrexone along with hormones helps. And then there's another, you know, like 10% of people where we correct either addressing their mast cells with antihistamines or the combination of also correcting their nutritional deficiencies.

They may have copper that's too high and zinc that is too low. You know women that are on long-term birth control pills can have very high copper levels and that can contribute and they can low B12 and folate levels.

Hormone restoration, thyroid, mast cells, and supplements

that can all contribute to neurological symptoms and chronic pain. So those are some of the other things that we look at. How about inflammation? Almost everything that I've been talking about recently is made worse by an inflammatory, a pro-inflammatory diet.

And is that the case with this disorder as well? Yeah, it's very interesting. So I've had some people get a whole lot better just with cutting out sugar, which is very inflammatory.

You've probably had the experience of women with hot flashes who cut out and their hot flash has got better. Gluten can be a contributor. We sometimes try people on a gluten-free diet.

And sometimes if we have to go further, we also do dairy- free, gluten free sugar free. Mostly the problem is a lot of these patients are very nutritionally deprived.

So when your mouth hurts, the only things you want to eat are soft, cool things. People are eating a lots of ice cream, white bread, rice, and you can't hold them.

They'd like to eats salad again. One of my first patients, You know, her big thing how she knew she had gotten better was she was able to have vinaigrette dressing on her salad and really enjoyed it.

So it's not that people don't want to eat well. It's just they're limited by the pain in their mouths. Smoothies come to mind. You can put the kale and the fruits and vegetables into the smoothie.

You've told us a big pathway of approaches for a chronic pain syndrome, basically. And this has applications not only for mouth pain, but I imagine for other kinds of pain that are covered to some extent in functional medicine.

And how would you describe the crossover that you might expect between the approach that we've had with this disorder and other chronic pain disorders?

Well, one of the things that I'm trying to do is to speak at as many chronic pain organizations as I can. The only other person I know, and he's written a book about hormones and chronic is a doctor named Dr.

Forrest Henik. And he treats a very difficult pain condition called adhesive arachnoiditis. There are filaments that hang down below our spinal cord. And those filaments can become adherent through inflammation to the covering over the spinal cord.

And it's called, you know, the arachnoid membrane and it is called adhesive aracnoides because they become inherent and is a horrible chronic pain condition.

It affects people's bowels and bladder in addition to being horrible pain. He has used DHEA and pregnenolone and wrote a nice book about what hormones can do for chronic pain.

So I'm trying to get the word out. I attended the International Association for the Study of Pain a few years ago, their national meeting in Portugal, and went around trying if anybody was interested in finding out about hormones and pain and mostly not.

So I'm going to try again either to get a poster session or something like that because I think this may be something that the entire chronic pain arena in medicine may missing out on.

Yeah, anesthesiologists often are involved in chronic pain treatment. They do a lot of injections and certainly assessment of things. So that's another group you might tap into.

Send your abstract off to them as well. What would you say are the lessons that you've learned from treating this very tough and very grateful, I'm sure, group of women?

Well, one lesson I've learned is that in spite of the fact I asked people, I never know how bad it is for them. And somebody a couple of weeks ago said, "I'm really glad I found you because I was about to end it all." So never underestimate how severe it for somebody, even if they look okay.

The other thing that people don't realize besides the things we talked about how women get written off and perimenopausal women getting written of is people with chronic pain, are so consumed by it, they kind of lose who they are.

They lose their passions in life. they don't socialize. If it's in your mouth, how much socializing do we do around eating? They don t go out to dinner.

And so another patient said, you know, her big thing how she knew things were better was she had Thanksgiving with her family for the first time in years.

Diet, chronic pain, and patient lessons

because she never knew how she was going to feel and she couldn't eat this and couldn' eat that and people think you're just being a pill and you know so you don't understand how much somebody's suffering and that's one thing and don' underestimate the impact it has on people's lives it's absolutely huge and so Those have been really the big lessons I've learned is listen to people.

I learned so much from patients. What kind of rescue mouth washes work? Well, I had people tell me and then it works for other people, you know, so we doctors and practitioners really need to listen.

Are there group chats for this group of people? Do they find each other? They find each other and I haven't been on them because it really like ends up looking like self-promotion.

But some of my staff has gone on some them or if we have a talk and want to let people know about it, they a lot are very discouraging because people can't find answers.

And the most discourage ones is there are ones on Reddit of young people with burning mouth syndrome. They're much harder to treat. They're not in hormone decline.

I'm not honestly sure, you know, for a lot what to do for them. And so there are groups, I am not sure how helpful they are. So one of the things that we're doing once we fully, and have enough of a, you know, kind of cohort of people, we're going to start having regular monthly meetings for people with burning mouth syndrome.

And we have a health coach that will help to answer questions and guide people through, and then I'll get on periodically to ask her questions also, because people need a lot of support.

Switching gears a little bit, tell us about some of the other projects that we were discussing before we got to be recording here today. Sure. So I wrote a book called A Hope for Burning Mouth, developing your personalized treatment plan so that you can enjoy life again, and that's available on Amazon under Hope For Burning And I have an online course that's got nine modules and 72 lessons.

And it can help you understand all the different things that I've learned about hormones and mast cells and all of the contributors to Burning Mouth. How to find a practitioner a lot.

It's naturopathic doctors if there's a practice in your state. how to handle friends and family because a lot they don't understand and you look perfectly okay and so what's the problem?

And so you don' t get the support that you could get from them. So it's an online course and those things are all available on my website which is SusanSklarMD.com.

and I also developed a supplement, so I was trying to figure out what to do because everybody couldn't come to see me as a patient. And I took two of the steroid hormones, and people get nervous when you say steroids because they think about bodybuilders abusing hormones.

Resources, remote care, and closing remarks

But this is a class of hormones that's really important for our health, And took 2 of them, DHEA and prigmenolone, that are available in supplement form in this country.

and put them together in a supplement with some B vitamins and lipoic acid, which is an antioxidant that can help neuropathic pain. And about two thirds of the people that use the supplement feel better also.

So that's available on my website as well. I try to have a variety of things to help people learn about what's going on, maybe provide them with relief.

For some people, the supplements is all they need. Wow. Cool, very good. And do you see patients remotely or only in your office physically? No, I actually only see patients remotely.

I no longer have a physical office and I'm licensed in four states. So I am licensed California, Texas, New York, and Florida. Well, those are big ones.

Yeah. It covers a fair number of the country. And then I also see people in other states, if they have practitioners that will order their tests and order medications, then they can provide them guidance.

So, you know, even if you're in a state where I'm not licensed, we can give you guidance. That's great. Anything else that you want to tell our audience in our last couple of minutes here?

Or we've covered so much. I think we have gone over everything. You know I already said what my main takeaway is that we need to listen to people. And people need to speak out, not be afraid to speaking out.

That's the other side of us listening. Yeah. Well, this has been amazing information and novel, unique, and I'm very glad that you were able to join us today.

Thank you so much for having me on. I'm always happy to spread the word. And to our audience, if this is the kind of information that you like, please like and share this with your friends so we can reach more women to have the healthiest lifespan that they can have.

Thank everybody. Take care and see you soon. If this episode spoke to you, Please share it with a friend ready to take charge of her health. and please leave a review.

It helps more people to find us.