Gluten Made My Mouth Pain WORSE - BMS and Gluten Transcript

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Introduction to gluten and pain

about today is the effect of diet on pain, specifically the affect of wheat and gluten on paint. This may have bearing for burning mouth syndrome and it also has bearing a number of other chronic conditions.

I'm going to talk to you a little bit about what gluten is and why it's important, about peripheral neuropathy and what the term neuopathy means. Also about celiac disease, which is one aspect of a problem with gluten, and how gluten might affect burning mouth syndrome.

So it was interesting, just as I was putting this talk together last month, A patient messaged me, you know, we have a patient portal through our electronic medical record.

And she was a new patient and she said to me on the portal message, I did have bad mouth pain experience after eating gluten by accident three days ago.

Might tell us something. Indeed, it really does tell something and that something is that gluten can be involved in pain conditions in a whole variety of ways.

And gluten can be involved with the nervous system of which pain is a part in whole a variety ways and first of all the question is what is gluten?

What gluten is and where itu2019s found

Gluten is proteinaceous material that is makes dough real stretchy and allows bread to rise and you know how sourdough bread has those nice big holes in it that are you know, so nice when you toast it up and the edges of the holes get nice and crispy and crunchy.

That's gluten in wheat. It's a protein in Wheat. it's actually composed of a couple of different proteins. One of them is gliadin and that is what appears on lab testing looking for sensitivity to gluten.

We measure gliatin antibodies as well as another protein too. And so gluten is a part of wheat And not only wheat, many other grains have proteins that are similar to gluten.

And so we'll also talk about why it's important for some people to eliminate almost all grains when they're trying to assess whether gluten is affecting their health.

And it turns out that gluten can affect really three major systems in the body. And for many years, and initially celiac disease, which is gluten that affects the intestines and the stomach, it was first discovered 2,000 years ago and nobody knew what was causing these stomach symptoms.

And it really took until the early 1900s, and finally in the 1950s and 1960s to hone down on specifically what the protein was that was creating this kind of intestinal problem.

So this issue has been around with us. Well, documented for 2,000 years and we think it started relatively late in evolutionary terms around 10, 000 years ago when we started eating wheat and when agriculture came about.

So this gluten, this protein material that's in wheat and other grains, can affect three major systems in our bodies.

Celiac disease and the three major systems affected

One, we've talked about our intestinal tract, and I'll tell you a little bit more about that when we talk about with celiac

diseases. Another is the skin, and there is a skin condition called dermatitis herpetiformis.

And just like the name, like herpes, you know, when you get herpies outbreaks, they're little tiny blisters. Dermatitis, herpediformes is confluent little blister that occur at various places on the body and turn out to be due to wheat to a large extent.

And then there are neurological conditions that are due to eating wheat. Some of them quite serious. There is gluten ataxia, which is when gluten attacks the balance and movement part of the brain and creates a problem where somebody has problems with balance, and movements, walking, they have a very kind of swaying gait because they're about to lose their balance as they walk.

So three major systems in the body that are affected. The gut, the skin, and the nerves. And a lot, this is not recognized by the medical profession. I gave this talk last month to our burning mouth, hope for burning-mouth online course membership members.

In fact, one of the people who was on that webinar was diagnosed with celiac disease And celiac disease is an autoimmune disorder caused by wheat, caused gluten, and gliadin.

And it causes an attack on the lining of the intestinal system. What happens is those very important cells that line our intestines that have thousands of little finger projections that help us absorb food and absorb nutrients, get destroyed by gluten in people who have celiac disease.

So it's an autoimmune disorder that's quite serious. It can result in weight loss, malnutrition because there are a number of nutrients that don't get absorbed because those little fingery projections on our lining cells in the intestine are destroyed.

And so mostly the medical profession thinks of celiac disease as an intestinal problem. And it's very difficult to get diagnosed. The person who was on our webinar said she took a really long time to be diagnosed for precisely this reason.

She did not have gastrointestinal symptoms. She had other problems that celiac was causing her, but not GI symptoms. And so it took her doctors a really long time to think that this might be it and test her for it, and find out that she had it.

Peripheral neuropathy and burning mouth syndrome

And I want to focus today on what gluten can do to our nervous system. And one of the problems that gluten causes is called neuropathy. Neuropathie, neuro is nerves, and apathy is something is wrong with those nerves.

Pathology. Specifically, peripheral neuopathy, when we talk about our peripheral nervous systems, It's as if we were a computer that is wired to all work together.

Our brains and our spinal cord are like the operating system in our computer. All of the wires leading to that central processing unit in the computer are like the nerves all around our bodies.

And those nerves, those wires are what are affected in neuropathy. There are many, many causes of neuopathy, everything from diabetes to a physical injury to hormone imbalances, autoimmune diseases, infections like reactivated viral infections, Lyme disease, and even vascular problems of which, you know, diabetes causes problems with your blood vessels and ultimately cause problems And neuropathy consists of a few different parts.

One is that there may be a loss of signals that normally get passed through and in these situations people will feel numb. Then there can be inappropriate signaling when there really isn't any signaling going on but things are getting transmitted.

because the nerves aren't functioning properly and the kind of an analogy to that would be like static on a phone

line. Nobody's saying anything but noises are coming through and they're not normal noises.

And then the last thing that can happen when signaling is disrupted in neuropathy is an error that distorts the messages. And it would be like watching a wavy picture on your television screen.

You know that there's a picture there, but you know it's not looking normal. We see this with neuopathy, where people do something that should be a light touch, feels very painful or burning.

Lying in bed with the sheets on your feet, you should feel the touch of the sheet. It shouldn't feel like pain on you feet and legs and for some people it does.

So that's distortion of signaling that has happened because the nerves are damaged. Its thought that as many as 20 million people in the United States have some form of peripheral neuropathy.

And we think that burning mouth syndrome is a neuropathy problem. How do we figure this out and what do you we do about it? First there is blood testing and blood-testing can tell a couple of things.

Whether you have antibodies to components of gluten, gliadin antibodies, There is an enzyme, transglutaminase, that has antibodies created to it if your nervous system is affected, if you skin is effected, and if GI tract is effective.

And then there is the genetics of gluten sensitivity and people with celiac disease have particular genetics that predispose them to having celiac disease.

Testing for gluten sensitivity and celiac disease

They may not have the symptoms, but genetics are a tip-off that this could be an issue for somebody. In fact, probably as far as neuropathy goes, neuopathy is, or rather, celiac disease goes.

It's estimated that about 3 million people in the United States have celia disease, but another 18 million have non-celiac gluten sensitivity, and this is actually a medical term, CS, non-celiac gluten sensitivity, NCGS.

And so the tests for celiac don't show anything, but gluten ends up still being an issue. Probably the best way to test for it is to do a gluten elimination.

A gluten elimination is not an easy thing to do. There is gluten in so many different foods. Like I said, there are many grains that have gluten, so not only eliminating wheat, but also eliminating barley, rye, sorghum, millet, teff, Teff is a grain, I don't know if you've ever been to an Ethiopian restaurant and they have a huge tray they serve you and it has a flatbread on it and then they put different types of vegetable and other stews on and you break the flat bread off and eat with your fingers.

That's teff. And so even tef, einkorn which is an ancient wheat, And sometimes even if you're really going on a gluten elimination seriously, you want to eliminate things that aren't even grains like buckwheat, amaranth, and quinoa, which really are technically grasses, not grains, but can contain, again, some of the similar proteins to gluten.

The other problem with a gluten elimination is there is hidden gluten in so many things, like why would they have soy sauce, have gluten, in it? And who would think about it, so you would want to get a glutin-free soy source.

Things like modified texture vegetable protein, and fat can be a gluten protein. Hydrolyzed vegetable proteins, these things are gluten under different names.

dextrin maltose so you need to really look at the labels on everything and probably best not to get anything that is prepared but do everything yourself.

Some artificial colors and like caramel flavoring and color can actually have gluten in it Honey-baked hams can

have wheat starch in the coating on the ham.

So it comes in so many different ways. And then there are alcoholic beverages that contain gluten. Beer is fermented grain. Any malt, malt liquor, is a fermented grains.

You're limited in what you can have as far as alcohol goes. And for people who are very sensitive, even skin products, some skin product, health and beauty aids contain gluten, shampoos contain gluten, Play-Doh has gluten in it if you play with it with your children.

So these are all potential sources of gluten. to really give yourself a good trial to see is this playing a role in your pain.

How to eliminate gluten from the diet

you will want to do a really extensive gluten elimination. We've seen for a number of our burning mouth patients where gluten makes a difference, where somebody went on a gluten-elimination and just with that said, wow, my pain is reduced by 50%. So admittedly, burning-mouth syndrome is a very focused area in terms of neuropathic pain.

There are many other examples of neuro-pathic pains, like the gluten ataxia I was telling you about. And, you know, really doctors need to start thinking about neurological problems and that they may be due to gluten much more frequently than they do.

There have been studies done on people with celiac. There is a clinic in England where they study celiac patients and found that not all of them have gastrointestinal issues.

Not all have neurological issues, but in general, the people that were on a gluten-free way of eating in generally had less pain. And so that kind of sums up what I have to say about gluten and its association with pain.

I think it's underrated. And being on a gluten-free diet is something you can do yourself. There are a lot of materials online that are helpful in terms of what contains gluten, and how to eliminate it.

And I'm not saying it's an easy thing to do, I've done it myself. I was thought to have ulcerative colitis, must have been 30 years ago, and it was really affecting my health very severely.

The medications they gave me weren't really working. And, believe it or not, a little article in my local Long Beach newspaper that talked about people with stomach problems should maybe try eliminating gluten.

And all of my signs of ulcerative colitis went away and I had, you know, was getting colonoscopies done periodically because people with ulcersative Colitis have increased risk of colon cancer.

So they were, I was under observation and. The medical profession doesn't catch on to these things very quickly. And my doctor, who's a friend of mine, because I'm a physician, she's one of my colleagues and friends, said, wow, everything's looking good.

What are you doing? And I said well, I am on this gluten-free diet. It's really working for me. She literally patted me on the shoulder and said that's good, keep it up.

I knew she had no idea what I was talking about. So, you know, even if you can't get your doctor willing to prescribe lab tests for you, this is something you could do yourself and look at what the benefits are on your health.

For a lot of people, sometimes unexpected things happen, like they do a gluten elimination to see if it makes pain better and they discover their skin condition improves.

And these are even people without dermatitis or pediformis. just having various kind of scaly rashes that they can't

figure out. Or their joint pain may get better, which is an unexpected benefit because really gluten, whether you are celiac or officially diagnosed as non-celiac gluten sensitivity, gluten is inflammatory and gluten destroys the tight junctions between the cells that are lining your intestine.

And this has been shown even in people who feel perfectly healthy and don't have any symptoms. It is destroying those tight junctions. So even though you may feel fine and think gluten doesn't apply to you, it is working under the surface inside your intestinal lining to damage it.

So I hope that convinces you to at least consider a gluten elimination. Let's see, I know we had one question from somebody which I'm happy to answer.

Personal experience and practical takeaways

Is there a test for gluten sensitivity or allergy? So it's a really good question. Testing for real allergies is a particular immunologic pathway called the immunoglobulin E and it is responsible for what we call immediate hypersensitivity reactions.

Somebody is allergic to peanuts, they eat peanuts. It could be life threatening. They may break out in hives, their lips get swollen, They start to have wheezing and difficulty breathing.

That, and it happens very quickly within a half hour. that's an immediate hypersensitivity reaction. Most people do not have those reactions to foods, and usually if they do, they know it because they've had these severe reactions right after eating the food, so it's very easy to pinpoint what's giving you that reaction.

There is testing for wheat allergies. Allergy doctors do skin prick testing where they will make a little scratch in your skin and put a drop of the allergen on it whether it's wheat or birch trees or you know grasses and things like that and look and see if your skinturns red which is an immediate hypersensitivity reaction.

So that's one way to get tested for wheat. There also is a lot of blood testing that we do. so there's a wheat IgE immunoglobulin E blood test There is a celiac panel which has anti, or what are called, deaminated gliadin antibodies, which is the best way to tell if you have celiac.

There are tissue transglutaminase, the enzyme I mentioned, and seeing if have antibodies to tissue-transgluaminases that can help tell you are having GI problems due to gluten.

And then there is the genetic testing for celiac. So a number of different ways to test for it. And the question is, I heard you have to be gluten free for three months for to completely out of your body.

It may be quite a while until the white blood cells that are like fighting soldiers that create these antibodies really shrink back and don't produce this gluten reaction.

So it could be that long. And one of the questions that comes up is if somebody has been eating gluten-free, they may in fact not show up with gluten sensitivity or on blood testing.

And so this is often a dilemma for us with somebody who has been eating gluten-free and wants to know officially, you know, are they celiac or gluten intolerance?

And we can certainly do the genetic testing on them. But I always hesitate if somebody has been successful eating gluten-free and feels better that way, telling them they need to start eating glutton again and feel bad for a few weeks before we do their testing.

So that's one of the dilemmas in going gluten free before you get tested. If you're able to get your doctor to test you, that probably is optimal, and then go glutenfree, see how you feel.