

Episode 193: Trigeminal Neuralgia: Symptoms, Causes, and Effective Treatments

Lindsay Weitzel, PhD:

Hello everyone, and welcome to HeadWise, the videocast and podcast of the National Headache Foundation. I'm Dr. Lindsay Weitzel. I'm the founder of Migraine Nation and I have a history of chronic and daily migraine that began at the age of four.

Our guest today is Dr. Deena Kuruvilla. Hi Dr. Kuruvilla, how are you?

Deena Kuruvilla, MD:

Good. How are you doing today?

Lindsay Weitzel, PhD:

I am good. Thank you so much for being here with us today.

Deena Kuruvilla, MD:

Oh my pleasure.

Lindsay Weitzel, PhD:

Dr. Kuruvilla is a board-certified neurologist and headache specialist. She is also the director of the Westport Headache Institute in Connecticut and has authored numerous articles, book chapters, and research publications on things related to headache medicine. I'm super excited to have her with us today. This is the first time we've been lucky enough to have her on our podcast.

Dr. Kuruvilla is going to help us understand trigeminal neuralgia today. What is it, what does it feel like, how is it treated, etc. We have not ever dedicated an entire episode to this topic, so thank you so much for being here.

Let's start so that our audience can get to know you. Why don't you tell them about yourself? Why you love working in headache medicine?

Deena Kuruvilla, MD:

Sure. Well, I'll start off by saying, geographically, I'm in Connecticut, as you said, about an hour north of New York City. And I am kind of a lifelong northeasterner, I would say. My husband says that everything about me is northeastern, whatever that means. But, that's where I'm geographically located. I have a headache practice here.

I was in an academic center at Yale for about eight years and saw general neurology and headache, and I really wanted to branch out and specifically focus on headache at my headache center because there's just such a large population that's affected.

I have experienced migraine myself, so I know how disabling it can be. And among all the neurological conditions, I do have to say that migraine is the most, probably one of the most disabling and the most treatable.

And so it just gives me a ton of satisfaction, number one, to meet new people, because I love talking with people and also to see people get better. And that's just such a positive aspect of my practice, and so that's a little bit about me.

Lindsay Weitzel, PhD:

Oh, great. Well, we're so lucky to have you here. So let's start So even though we have not dedicated an episode to trigeminal neuralgia before, it really does cause a lot of suffering. So let's start talking about how it presents, what it feels like. So how common is it?

Deena Kuruvilla, MD:

Trigeminal neuralgia is actually extremely uncommon. I will say I have maybe 2 or 3 times a week where people may think they have trigeminal neuralgia and they may. It's something that it commonly pops into a person's mind if they're having shooting pain in the face. And that's the most common presentation is this shooting type pain that really goes in specific parts of the face.

So trigeminal nerve is a nerve that runs straight out of the back of the brain. And that nerve has three different branches. The first branch kind of goes over the first part of the face around the eye. The second part goes over the mid face and the upper lip. And the third part goes along the lower lip and the jaw line.

And so most of the time people come in with this shooting pain that comes and goes throughout the day in one of those different areas. Usually it's restricted to one area and it's usually set off by certain things like touching your face, brushing your teeth, brushing your hair for example, depending on where that pain is.

And so when it does happen it can, as you said, be very disabling for people. It can kind of stop you in your tracks.

Lindsay Weitzel, PhD:

Okay. Are there certain groups more at risk?

Deena Kuruvilla, MD:

Definitely. So definitely women are at more risk. People over the age of 50, people who have a history of smoking, people who have a medical history that has high blood pressure, hypertension, those are probably the most susceptible populations.

Going back to your original question, how common is it? I think most of the research shows that around 4 to 13 people may be affected per 100,000 people. So still very uncommon. But those different risk factors may make you more likely to have it.

The other really interesting point that I really wanted to make sure that I don't miss here is that if you have multiple sclerosis, which is another pretty disabling neurological condition, your risk of having trigeminal neuralgia goes up.

Lindsay Weitzel, PhD:

Okay. So let's kind of get into if someone in our audience were experiencing it, what it feels like. How severe is the pain of trigeminal neuralgia usually, compared to some of our, we have certain things in our community like cluster headache, which we know is one of the worst pains known to man. And I'm just wondering where trigeminal neuralgia usually falls in that pain spectrum.

Deena Kuruvilla, MD:

Right. There is definitely a spectrum of the type of pain that people tell me all the time. Some people describe it as, sadly, a knife being put through their face in that where they have that distribution of pain. Other people describe it as a zap, a quick zap within the face, just a second of a zap. Other people describe it as a burning type of pain that comes and goes, lasts a few seconds.

So there's certainly a giant range of different types of pain that people can perceive. But the type of pain is typically kind of in the middle, moderate to very severe. Because people do often say they have to freeze and stop what they're doing for a second, often have to clench their teeth if especially if it's in the cheek and the jaw distribution and wait for it to pass.

Lindsay Weitzel, PhD:

Okay. So just out of curiosity, is it always kind of a zinging quick pain, or is it ever a constant type pain?

Deena Kuruvilla, MD:

It's typically a zinging type pain. A quick pain that comes and goes that's usually activated with chewing, for example, with touching the face, with brushing the teeth. Even sometimes, I'm

wearing headphones, people have told me they've activated their trigeminal neuralgia with headphones during the workday. It's not typically a continuous type of pain.

Lindsay Weitzel, PhD:

Okay. And then, does it ever affect the entire side of the face, or is it always just the one branch at a time that a person might feel?

Deena Kuruvilla, MD:

Right. Typically, based on the definition, it should affect one branch of the trigeminal nerve. So typically in that eye forehead area mid middle of the face or the lower half of the face. But if somebody is saying that they're having more than one distribution, we have to really, really rethink our diagnosis.

I'll tell you something that I do end up diagnosing in my practice and that's very rare and underdiagnosed, which is something called lower half migraine, where somebody is having pain maybe in just the cheek or those two areas in the lower half of the face covers two branches of that trigeminal nerve. But they also have headaches sometimes, sensitivity to light, loud noise, nausea. They may have some other features with it. So we have to kind of rethink this diagnosis if the pain is more widespread.

Lindsay Weitzel, PhD:

Interesting. Okay. So what do we think could be some of the possible causes of trigeminal neuralgia? Do we know? Does it ever show up spontaneously, or is it usually due to some sort of trauma?

Deena Kuruvilla, MD:

The most common cause is actually a blood vessel, either an artery or a nerve that wraps around the actual nerve and causes some damage locally to the nerve, what we call demyelination or that protective covering of the nerve gets damaged because of the pressing of the blood vessel on the nerve. And that can be an artery or vein, but usually it's an artery that's being pushed up against the nerve. You know that the research shows it's like 80 to 90% of cases. And that's what's known as classical trigeminal neuralgia.

Can other trauma cause it? Oh, certainly. I've seen people who've gotten dental work done, who've had to keep their mouth open for a really long period of time and have had procedures done in the jaw. A condition called postherpetic neuralgia, the herpes zoster virus, can affect one of the nerves that supplies the face, one of the branches of the trigeminal nerve. So there's certainly a broad range of causes, but the most common is that blood vessel pushing on the nerve.

Lindsay Weitzel, PhD:

Okay. So let's get to treatment. So let's say someone is diagnosed, people are pretty sure this is what is wrong, what's causing their pain. Are there certain medications used to treat trigeminal neuralgia?

Deena Kuruvilla, MD:

Absolutely. So the first line treatments that we use, medications we use, are called carbamazepine and oxcarbazepine. These were originally developed as seizure medications but have found to be very helpful for treating and preventing trigeminal neuralgia.

Certainly every person when they get worked up by their doctor for trigeminal neuralgia, that usually includes pictures of the brain with an MRI of the brain and also MRA of the head and the neck, which is looking specifically at the arteries of the head and the neck.

And so we always try to look for if is there something reversible first. And then we start these medications if the pain is intractable, meaning it's really getting out of hand disabling somebody. It's happening frequently. Those are all reasons to start a preventive treatment.

Lindsay Weitzel, PhD:

Okay. Now are there any complementary or integrative medicine approaches that are thought to be effective? I do know that you recently with some other colleagues, I think you published a paper on some of these things that people can do to possibly help their trigeminal neuralgia.

Deena Kuruvilla, MD:

That's right. It just came out last month, I believe. We tried to really look at what does the research say about these natural approaches. Because in reality, in our practices we have most people are probably using some type of natural approach to treat their headache disorder or facial pain disorder.

So we really wanted to know what has evidence and what doesn't. So the conclusion we came to in that particular paper is that things that have been looked at, not in detail or really large randomized trials, which is what we want. But in case series, we call them case series or just small studies. We found that, we looked at vitamin B12, omega three fatty acids. We looked at coenzyme Q10, we looked at acupuncture, cognitive behavioral therapy. The two things that probably have the most evidence are vitamin B12 and acupuncture, interestingly.

So, if somebody asks me what are the best natural approaches to take, the first thing I say is this is something we're adding to mainstream medicine. And the second thing is acupuncture and vitamin B12 are probably the two different things to consider.

Lindsay Weitzel, PhD:

Okay, that sounds great. So are there surgical approaches? Are there people out there who require surgery for trigeminal neuralgia, and are there approaches that sometimes help people?

Deena Kuruvilla, MD:

Certainly. If we find something on the MRI that can be intervened on, then we usually do obtain a consultation with a neurosurgeon. They're the ones that typically do most of the procedures for this condition. Usually if we see that there is an artery or a vein that's kind of pushing on that nerve, specifically the root of the trigeminal nerve, the neurosurgeon is usually able to go in and put a little cushion between the nerve and the blood vessel that's touching it. And that is a pretty good long-term solution for most people if we're able to find that.

There's also a radiation procedure called gamma knife that can be done by a neurosurgeon as well. There's ways to burn the nerve called a rhizotomy. There are some different approaches that can be taken like that.

I will say, though, if the trigeminal neuralgia is a result of trauma, we were talking about earlier, from a procedure that was done, a dental procedure, or a virus like the herpes zoster virus, then most of the time the management really is medication, preventive medication management and getting that under control over time.

Lindsay Weitzel, PhD:

Okay. How often do you feel, I don't know if we have exact numbers on this, but I'm just curious, for the sake of our audience, how often do people with this diagnosis improve?

Deena Kuruvilla, MD:

That's really hard to say. It really depends on the cause. So there's a few different types of trigeminal neuralgia. There's classic trigeminal neuralgia, that 80 to 90% of people where that artery is pushing on the nerve. Those people are very treatable because they can go to our friendly neighborhood neurosurgeon and have that little cushion put in between the area that's affected. They're very treatable.

Then we have trigeminal neuralgia we call secondary trigeminal neuralgia which is caused by another condition. For example like the herpes zoster virus causing postherpetic neuralgia, to a tumor and things of that nature. That's also getting to the root of the cause to treat what's going on.

The third type is called idiopathic. When somebody starts developing trigeminal neuralgia for unclear reasons, we can't find a cause for it. And those folks are much more difficult to treat. And it does take a much longer time to see improvement.

Lindsay Weitzel, PhD:

Okay. And I don't think we defined for the audience, herpes zoster, when you're referring to that virus, that is the virus that causes shingles and chickenpox and that can get into our nerves. Correct?

Deena Kuruvilla, MD:

Yes. That's correct.

Lindsay Weitzel, PhD:

Okay. So is there anything else that you think our audience should know about trigeminal neuralgia?

Deena Kuruvilla, MD:

Well trigeminal neuralgia often gets the most airtime because it does tend to be one of the most common nerve problems that we see, nerve pain disorders we see. But there are other what we call cranial nerves or those nerves that come from the brain that can also cause pain in neuralgia.

And I'll just mention intermedius neuralgia where somebody can have focused pain in the ear. And glossopharyngeal neuralgia, which is when somebody has pain that kind of shooting out of the neck. So nerves are a tricky thing. They're all over the body. And any nerve at any particular time can be irritated and cause that type of shooting pain or burning pain or those different types of pain.

Lindsay Weitzel, PhD:

Okay. Well, thank you so much. That was very interesting. I hope everyone learned something from that information. And thank you for being here. And thank you everyone for listening and to this episode of Head Wise. Please tune in again to our next episode. Bye bye everyone.

Deena Kuruvilla, MD:

Thank you.

Lindsay Weitzel, PhD:

Thank you.