INTERVIEW TRANSCRIPT

DISCUSSIONS WITH WORLD-LEADING EXPERTS

You're Not Imagining It: Migraine's Strange Symptoms Explained

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Introduction (00:05): Migraine is a complex puzzle with more commonly known pieces like head pain and nausea and light or sound sensitivity. But many people experience other perplexing symptoms that may have been dismissed or unrecognized as part of their condition.

Introduction (cont.) (00:22): Dr. Jessica Ailani is one of the world's leading experts in treating migraine. She's here to discuss the wide range of migraine symptoms as components of a full-body neurological condition to help us understand what's really happening in the migraine brain and body. Dr. Ailani, welcome back to the Migraine World Summit.

Dr. Ailani (00:43): Thank you so much for having me. It's always a pleasure to be here.

Elizabeth DeStefano (00:45): Well, let's start first with the big picture. You've described migraine as an activation of the entire nervous system. What does that mean?

Dr. Ailani (00:55): It really means that during a migraine attack, the brain and the parts of the brain outside, the peripheral nervous system, they all are turned on. And so you can have symptoms of any part of the brain. People will fixate on migraine being a headache, a headache disorder. But really, the brain is involved in so many other things — vision, hearing, smell, sensation. And your peripheral nervous system is really what carries the signal out to the rest of the body.

Dr. Ailani (01:23): So you can have normal sensation, abnormal sensation. And there are other symptoms like change in your temperature control and regulating heat and cold. And so people will tell us of all these other symptoms during an attack and be very confused about why it's happening. But you have to understand that migraine is a neurological — a brain and peripheral nervous system — disease. So during an attack, all of this is dysfunctioning, so you can have all sorts of symptoms.

Elizabeth DeStefano (01:52): One of our Migraine World Summit viewers, Janis, mentioned extreme fatigue and symptoms like gastroparesis. So when you're describing this in this way, it makes much more sense of symptoms like that that are so far from head pain.

Dr. Ailani (02:08): Right. And I think that having fatigue is a very common symptom during a migraine attack. And I tell my patients, your brain is really busy throwing this giant party — and it's not something that you maybe want to go to — but the brain is busy having it. And there's a huge mess that happens during a party. And the brain is busy throwing the party, cleaning up, and doing all these activities. And so, of course, you're tired. Of course, it's hard to focus and concentrate.

Dr. Ailani (02:34): Of course, it's hard to really do anything you want to do because the brain is busy doing all these other activities — so fatigue, focus and concentration problems, inability to really pay attention to the person in front of you. So someone might tell you that after an attack, they really don't remember things that people were talking to them about. And their family might say, "We had this whole conversation. How come you don't recall that?"

Dr. Ailani (02:57): Well, you were busy having a whole activity going on while someone else was trying to talk to you. So, of course, it's OK that you don't remember that. That's something, "What was wrong with me? What's going on?" Well, you have migraine. That's what's going on. It can totally affect your ability to focus and concentrate during the attack itself.

Dr. Ailani (03:16): And if the attacks are very frequent, you can imagine that in-between time period is so small that your focus and concentration can be affected often. And so I think that these other symptoms — if you think about all the things your brain does and how all of that goes haywire during a migraine attack — it can be much easier to realize it's not just head pain, not just nausea, but all other symptoms that can occur as well.

Elizabeth DeStefano (03:41): Well, our community mentioned so many different symptoms that they weren't sure were part of their migraine. And when it comes to the earliest phase of a migraine attack, they mentioned classic symptoms in prodrome, like neck stiffness or what might feel like sinus issues. But they also talked about things like facial flushing and even voice changes that I feel we hear less about. Could you share a little bit about the most common prodrome symptoms and then some less common symptoms in that earliest phase?

Dr. Ailani (04:14): Sure. So we have actually a recent study that was evaluating the treatment of ubrogepant [Ubrelvy] during prodrome. And during that study, we had some fascinating findings of what were commonly reported prodrome symptoms in that particular study. Now, it's important to note you might have other symptoms; that doesn't mean you don't have prodrome. This was just looking at what was the most common reported in this particular study.

Dr. Ailani (04:39): And we noted in this study that neck pain, nausea, fatigue, light/sound sensitivity, dizziness — these things were coming up as like the top five to 10 things that people noted before the pain of migraine and associated other symptoms would occur. And I'm not totally surprised by that. But what is interesting is to think if you're having some of those prodrome symptoms, and we can sometimes mistake them as a trigger. So you have to realize that it's not the neck that's triggering migraine, but neck pain is part of what might occur during a migraine attack because of where the nerve and the brain are connecting that can trigger or start in a migraine attack.

Dr. Ailani (05:22): That light sensitivity — it might not be the lights in your office that are triggering a migraine attack — but your brain is so hypersensitive, it might be starting a cycle of migraine so early that the first thing you're noticing is irritability and sensitivity to light. And that can be almost up to a day prior to the actual head pain you experience. So it's not that the light triggered it, but the light was already bothering you because you were already starting to have your migraine attack.

Dr. Ailani (05:49): And so this is where prodrome — if you really start paying very close attention — can alert you to the very, very early-onset symptoms of migraine. But yes, the symptoms of prodrome can be very varied, and other things that people can report that aren't as common are things like changes in urination levels. Who would think that urination has anything to do with migraine?

Dr. Ailani (06:12): But actually, people can notice how frequently they urinate changes, and then after the attack is towards the end — what we call the postdrome — if you don't urinate as much during prodrome, you might urinate a lot more, and you're getting rid of all of that water that you've held onto during prodrome. And it really shows you — remember, the brain is regulating everything. So that change in urination level has a lot to do with the part of the brain that's getting affected during migraine that's regulating urinary flow.

Dr. Ailani (06:41): And flushing is another example. The brain helps regulate our autonomic functioning levels, so people can feel really hot or really cold. They can have this fluctuation in their temperature sensation. It's not common, but it can happen.

Dr. Ailani (6:55): And people can also have changes in their appetite, not because they're nauseous, but just a shift. "I don't feel nauseous or like I'm going to throw up, but just not hungry." Or on the opposite, "I'm very hungry for particular foods, like carbohydrates." And I tell my patients, "Well, hey, your brain is really smart. It knows it has to fuel up because it's already starting to have a migraine attack."

Dr. Ailani (07:17): So you might be craving certain things, then again, thinking that those things were triggering an attack when, in fact, it was the brain already starting to have that part of the brain say, "Hey, we're going to have this giant party. We need our fuel. Let's get those carbohydrates into our system, like chocolates and sugars." And so then you think that, "Hey, that stuff is what caused my headache to happen," when actually that migraine was already going.

Dr. Ailani (07:41): So very unusual symptoms — not the things that you usually hear about when it comes to migraine — but that's because what you're hearing about is the average. What does the average person with migraine experience? Not everybody. So we don't really talk about how varied these symptoms can be because there are so many of them. It's really hard to explain to somebody, "You might have 38 to 48 different types of symptoms. Can you figure out what you're having?"

Dr. Ailani (08:07): You want the person to say to you, "This is what's specific to me. This is what I notice happens every time or most times. And does that make sense?" And so if it's controlled by the brain, that probably makes sense, and we've probably seen it before.

Elizabeth DeStefano (08:24): Very interesting. One of our other Migraine World Summit viewers mentioned becoming extremely productive either the day before or the night before a massive migraine attack. Is that physiologically connected to migraine or us somehow maybe subconsciously being aware of what's in progress and preparing?

Dr. Ailani (08:45): Well, I don't think it's a subconscious thing. I'm laughing because I have definitely heard this before. And a lot of it has to do with buildup of probably the hormones that are needed to fuel that migraine attack. If you really think of it, I think that's why I like my party analogy because it seems funny and at the same time awful because why is the brain enjoying this? But when you're trying to work up towards a party, you've got lots of work to do.

Dr. Ailani (09:14): So you're active and you're busy. And so the brain is probably having a rush of adrenaline and other chemicals involved. And so you're thinking and interpreting that as, "Oh, I have this boost of energy. I'm going to get all this work done." Really, the brain's trying to use that energy to get other things done that are negative for you.

Dr. Ailani (09:32): But it's a way, again, to start to identify by using a calendar: "Every time I get that boost of energy within two days, I get the rest of the symptoms — the head pain, the nausea, the light/sound sensitivity. Maybe I should start to pay attention to that boost of energy and really correlate those two." Sometimes this is very difficult to do, but when you start tracking with calendars, you'll start to see these patterns emerge, and it can really help you understand your disease process much better.

Elizabeth DeStefano (10:01): Let's talk about the strange sensory symptoms that can accompany migraine, some of which can be fairly alarming if we're not accustomed to them or don't know why we have them. Some of our viewers have described phantom smells like smoke or gas that aren't there. Others, like Denise, mentioned strange auditory symptoms. What's happening in the brain that causes those perceptions?

Dr. Ailani (10:28): Yes. So you can, during a migraine attack, activate the parts of the brain that are smelling or hearing things. It is not common for that to happen, but it does. And I will tell you in my training, the one thing I was taught is if someone is having auditory or olfactory hallucination-type aura — so this occurring before a headache itself — that we definitely should do a thorough evaluation and make sure it's not something else.

Dr. Ailani (10:55): We are concerned about things like epilepsy — seizure phenomenon — because in seizure, we can see that the patients are starting to smell unpleasant sensations before the attack of seizure. And we know that there's a correlation between migraine and epilepsy, that those with migraine could have epilepsy, those with epilepsy are more prone to having migraine.

Dr. Ailani (11:17): And we also know that the aura phenomenon is caused … very similar to what happens in epilepsy with this, what we call cortical spreading depression — the spread of electrical activity. And then the brain is not able to do activity for a period of time after. And because of this, if

a patient describes that kind of symptom to me, one thing I would look at is ordering a test to rule out any kind of abnormality.

Dr. Ailani (11:41): With hearing something that isn't there — if it's always happening prior to an attack — I'd still want to make sure that the person doesn't have something abnormal on brain imaging, and then also doing a thorough evaluation to make sure there are no other times they're hearing things, or is it a specific thing? Is the person talking to you and telling you negative things or telling you to harm yourself? Because other times we worry about auditory symptoms are in certain kind of psychiatric phenomenon. Again, we can still see this with migraine.

Dr. Ailani (12:15): And often with the olfactory symptoms, it tends to be negative — burned smoke, burning meat, never a pleasant thing — which I do wish for that party that the brain was having, it would be like, "I smell bubblegum and cotton candy and nice perfume," which maybe isn't actually so pleasant for our migraine patients. But it is always this very strong, unpleasant, burning, rotting type of smell. So it is interesting how it's almost always described the same. Sometimes gasoline is another one that comes up. We see it in the literature. We see it in our patients as well.

Dr. Ailani (12:52): Whereas for the auditory symptoms, there's not a lot of description on is this a negative experience or is it just random noises that people are hearing? The limited literature out there is [that] there's occasionally you can hear like a loud bang in the middle of the night that can wake a person up and sometimes is associated with a headache disorder, but not much else about like is someone talking to you or saying something negative to you. And I think that's one we do like to do a full workup to make sure there's nothing else going on.

Elizabeth DeStefano (13:23): We're also hearing more and more about brain fog generally in connection to migraine, as well as specific seemingly cognitive issues like trouble finding particular words. What's happening in the brain to cause those types of symptoms?

Dr. Ailani (13:39): Yeah, so it's interesting. I was just speaking to one of my colleagues recently about where we think brain concentration issues are stemming from. Is it a whole-brain phenomenon? Is it coming from the bottom of the brain — the brain stem — being dysfunctional?

Dr. Ailani (13:53): I always equated it to the part of the brain called the thalamus — we call it a relay nucleus, which we know is actively involved during migraine — that that relay nucleus that's supposed to be like the middle person between the bottom of the brain and the top of the brain and taking information traveling through is becoming dysfunctional during migraine. So then it's really hard to pay attention or focus. Other people think it's because the main parts of the brain are not working properly and the signals are getting crossed.

Dr. Ailani (14:21): That's why there are focus and concentration issues. I bet you it's probably all of it. And that's maybe why people have different symptoms. And I think this is a part that we are actively starting to work on, trying to figure out. First of all, what does brain fog mean? It is a word that is commonly used in patients, and they just use that all the time and tell it to us. But I think it actually means different things to different people.

Dr. Ailani (14:46): And probably there are different areas of the brain that are not functioning depending on the feeling the person is presenting with. Like, "I can't concentrate" might be a more cortical or top-of-brain problem than, "I'm having word-finding issues," or, "I just feel like I'm in a fog and I'm lost." That these are all things that actually are probably coming, maybe coming from different parts of the brain.

Dr. Ailani (15:12): Maybe they mean different things to different people and are probably happening at different times during a migraine attack. And I also think those that have episodic migraine — where in between attacks you are completely symptom-free — their experience of trouble with

cognitive issues is very different than someone with chronic migraine — where in between attacks, the time that they're completely symptom-free is very small.

Dr. Ailani (15:38): And I feel like cognitive issues are [a] much higher burden in these people because in between attacks, probably the biggest thing they're going to tell us is, "I'm having constant trouble with focus, concentration, and brain fog, and nothing is working properly when I'm trying to pull it together."

Dr. Ailani (15:55): Not everybody with chronic migraine feels this way, but I do hear it much more often in that patient population of mine than those that have five attacks a month, where in between they're like, "You know, I feel fine. It's just during the attack, I feel like something's not working, and I can't get my words out, and my emails make no sense, and my partner thinks that something's wrong with me because I all of a sudden can't get my words right."

Dr. Ailani (16:19): And so it's probably there's a different process during the chronic portion of the disease where something is in the connection in the brain between the brain and the brain stem, it's just not working properly.

Elizabeth DeStefano (16:32): And I will mention for viewers that are interested in exploring that in more depth, we do have a dedicated interview this year on cognitive impacts with migraine specifically. So let's talk now about pain, but pain that is outside of the head. We heard a lot of comments from viewers about skin becoming very sensitive and painful. Is that related to allodynia, central sensitization, or other components of migraine?

Dr. Ailani (17:00): I think we always relate it to allodynia, and that's when we say the brain's on fire and everything is oversignaling. And so all touch becomes very painful — whether it's in the head, in the shoulders, on the back. But over time, I also wonder about — is that all allodynia? If a person is having this painful skin sensation and the attack is at the end or is completely over, do we ever see this during a prodrome?

Dr. Ailani (17:31): There's so much about this disease process that's unanswered, and clinically we see a number of patients — maybe not the majority, but a number — tell you about this. "I feel very sensitive," maybe before an attack or several days after an attack, but not during an attack. And so I don't know if that's all allodynia. I have patients that are well controlled with their disease, but are experiencing this other times. And I don't think it's a separate thing. I very much think it's related to their migraine. And I'm not really sure why is the brain hyperactive if the head pain isn't happening? Because we tend to equate it with central sensitization during the head pain that's not well treated.

Dr. Ailani (18:13): Again, so much interesting stuff from the science side that we don't have answers to, but very, very frustrating, I think, for the patients who are like, “Well, why is this happening? What can I do about it?” If we're not sure, then how are we supposed to treat it? But I will also say pain outside of the head is not an uncommon thing to occur in someone who has migraine, either during the attack or in between attacks. And the science does show us that if you have other comorbid pain conditions, that your migraine is actually more likely to be active as well.

Dr. Ailani (18:48): And so if I have a person who is seeing me and they have back pain, for example — and the back pain is not going well right now and it's really flaring up and they're undergoing treatment — it's not uncommon that I'll see that their migraine attacks are starting to become more frequent, too. And that's not because of the medication they're using to treat back pain — because many times my patients will try to avoid medication — they're getting procedures. I think it's the brain signaling. Back pain still signals to the brain and the brain is seeing a higher signal of pain.

Dr. Ailani (19:18): And then it's going to interpret that and say, "Well, then I'm going to just have another big party because, hey, one side that wants to party, why not the other side?" So again, it just

keeps building these parties and this trash, the trash gets worse, and then you just keep getting more migraine attacks.

Dr. Ailani (19:32): So sometimes someone can be really well controlled and then things aren't doing as well and you realize, “Well, your other pain condition is not well controlled right now.” And that might be why migraine is worsening. So several reasons for pain elsewhere, but it all comes back to irregularities happening in the brain.

Elizabeth DeStefano (19:51): Can what you've just described there apply also to joint pain or sudden even numbness or weakness? We had some viewers like Janet explain those sorts of symptoms with her migraine experience.

Dr. Ailani (20:07): So one can have numbness or weakness associated with migraine as part of an aura. And aura is interesting. We swear up and down that it's supposed to happen prior to a migraine attack. But I think if you get 10 headache specialists in a room together and you ask us, what do we really believe? We'll look at each other and say, “Well, if it starts even a minute before and it keeps going into an attack, it's probably still aura.”

Dr. Ailani (20:33): But it's hard to say for sure because we've all seen these patients that will get these associated neurological symptoms that aren't always clean-cut. They start before and end before and then you get the head pain itself. So we know that migraine — though it has these phases — they don't always start and stop so distinctly as they do on — if you see any of our diagrams — they really kind of all roll into each other.

Dr. Ailani (20:59): And sometimes you can get numbness and then the headache starts, the numbness keeps going, then the numbness eventually ends, and the headache starts to peak. So it can kind of roll into itself. And what makes us feel more comfortable saying, “Yeah, that numbness and the weakness is migraine-related,” is because it goes away when the attack goes away and it might come back the next time you had an attack or further in the future with another attack.

Dr. Ailani (21:25): There have been rare but reported in the literature cases with weakness where the weakness can last past the attack itself. I think that is a difficult thing to say how much it's migraine-related or there might be other factors in play. Those aren't my patients; I've only seen it in the literature.

Dr. Ailani (21:42): But I do think it's important to bring that up because, again, it's an unusual brain disease and sometimes people don't quite follow textbooks, which I tell all my patients that that's an important thing to remember.

Elizabeth DeStefano (21:56): One of our viewers, Sarah, discussed her pain and described what feels like migraine-like pain, but in her chest and back that feels kind of squeezy, moves around, and is what her neurologist refers to as migraine-like body pain. She said it can even make it feel hard to breathe and that sometimes can actually be worse than her headache symptom.

Elizabeth DeStefano (22:22): Is that something you see often and how do we distinguish between something like that that we feel comfortable being part of our migraine experience — as comfortable as we can be — and something that should serve as a red flag for other concerns?

Dr. Ailani (22:39): So there is something — and this is a big word — called cardiac cephalalgia. Cephalalgia just means head pain, and it doesn't mean that you have head pain in the heart. Well, actually, it is what it means. It means you have head pain in the heart area, but not in the head. And it actually is a red flag, first, that if you're experiencing chest pain, you should, of course, have this worked up.

Dr. Ailani (23:01): But if the cardiac workup is negative and you have a history of migraine, it actually can be a migraine-like experience that's happening elsewhere. It's in the literature. It is very rare. I have had in my 16-plus-year experience of treating patients with migraine, about three patients that have had this and they repeat experience this. So it's not just a one-time thing. It's happened, we get the workup, the workup is negative, and then it happens again and again.

Dr. Ailani (23:29): And so we know this is part of their migraine-type issues. So if you're having something like this, you absolutely need to see your doctor, or your healthcare provider, I should say, and make sure that you're not having something wrong with your heart. Because out of those patients I've seen, I also have had a patient that we thought it was her migraine and it *was* her heart. And that is not something you want to take lightly. So you want to get that worked up.

Dr. Ailani (23:57): And if it's not the heart, it absolutely could be a way the migraine presents — very fascinating. But then it would be treated like your migraine and can respond to migraine treatment.

Elizabeth DeStefano (24:07): So now to talk a little bit about that later phase of a migraine attack — postdrome. Most of us are familiar with feeling, let's say, less than 100% after the most intense period of a migraine attack, whether that included pain or not. Maybe fluish; sometimes for really bad attacks, I describe it as feeling kind of like I've been recently in a car accident with sort of that whole body impact. Are there other less typical symptoms that accompany [postdrome] in some of the patients that you treat?

Dr. Ailani (24:43): I think probably the most common postdrome symptom is focus, concentration, brain fog-type symptoms. I mean, that is really generally the biggest part. I think that's why it's known as the headache hangover — that just awful, like you described; I like the "flu-like"; that's probably a lot nicer way to say it — that I'm not quite myself, I'm not quite great. I'm trying to think — I haven't really had any other unusual symptoms.

Dr. Ailani (25:09): Dizziness is not uncommon. I kind of feel that that's part of that brain fog, but it really isn't. I think it really should be considered as a separate thing because people can feel off-balance. They can have a room-spinning sensation. It's not as common, but it can definitely come up and that can happen during the postdrome period. Again, the urinary fluctuation, so urinating more frequently or less frequently, depending on how it was during prodrome, it's kind of the opposite.

Dr. Ailani (25:36): And then not depressed, but just like there's a mood change. And I think during the prodrome, people can feel very irritable and during postdrome, they just feel kind of "eh." And I don't know another way to put it.

Elizabeth DeStefano (25:51): Good description.

Dr. Ailani (25:52): Again, I think the "flu-like" is a really good whole picture of how a person's feeling when it's over. And it really does vary depending how severe the attack is. I was also speaking recently to another colleague, and we were talking about how we're starting to get studies about prodrome, but we really need more information about postdrome. Like, how debilitating is it for our patients who have migraine? How much is postdrome a problem? Is postdrome less severe if the acute attack is treated well?

Dr. Ailani (26:23): And I think that is really important as a clinician because many times in clinic, I'm pushing my patients to treat early and they're so fearful because we've talked so much about medication overuse. And so sometimes they're worried and they're counting — should I treat this one or not? But the downside of not treating, I mean, there's always a risk with certain medicines of overuse causing more migraine attacks.

Dr. Ailani (26:45): But if you don't treat your attack, postdrome, I'm convinced, can be very severe. But I don't have any data to back that up because it's not something we've really vested time or energy in evaluating. So I'm very hopeful that in the future we'll have more information there. And also, what are the most common symptoms and what are some of the more unusual things we might see?

Elizabeth DeStefano (27:08): So let's talk now about interictal symptoms — symptoms of migraine that can occur between attacks — starting maybe with some sensory symptoms. A lot of people with migraine — obviously, particularly those with chronic or higher-frequency migraine — mentioned some persistent light and sound sensitivity even between attacks. Is that fairly common?

Dr. Ailani (27:30): Yes, I think with chronic migraine, again, when you're having attacks frequently or some mild to moderate headache most days, we see that changes in appetite are common and they really don't go away. And light sensitivity is always there. Another symptom I will hear from patients is being very sensitive to noise and almost a superhuman power to hear everything. These are the people that can hear conversations next door that no one else can hear.

Dr. Ailani (27:57): They're also very smell-sensitive. They know what's cooking in the kitchen, even if they're five doors down from the kitchen. They can tell you what you ate from lunch just on the smell off your clothing. And they think it's really strange. But I always tell them, "It's your superpower. You know what things you don't like. You know what things you like. You can sense it before it's going to happen because it's actually the way your brain's protecting yourself."

Dr. Ailani (28:20): These are things that the brain doesn't like for you, so it keeps you away from them. So you can sense it before it's even happening. Of course, this is not a great way to live your life day to day, especially in a place where, you know, we're in open-concept mode all the time — the kitchen, the living room, everything's all open to each other. So it can make it really difficult to live like that.

Dr. Ailani (28:40): But I think there might be a reason the brain has done this in evolution to really keep the migraine person in a safer place. But it is very interesting, the hypersensitive smell, the hypersensitive sight, the hypersensitive awareness of everything going on. And I think we see that a lot more in our patients who have less frequent time between attacks.

Elizabeth DeStefano (29:03): What about between attacks, things that feel like they're related to the ear, maybe one-sided earache or even jolts or stabs of pain?

Dr. Ailani (29:13): I think that sometimes those that have frequent attacks, the one thing we should be doing is evaluating their TMJ [temporomandibular joint disorder], evaluating them for bruxism. I do think a lot of our patients that might have ear symptoms, I will often find that they might actually have some jaw issues going on. And we forget that the jaw actually can help control our inner ear. And so you can get popping in between, you can get ear ringing.

Dr. Ailani (29:41): And if they're having jabs and jolts, you also wonder how much they're activating the area and the nerve is getting irritated. And so they're having little bits of pain. We also know those with migraine are more prone to getting stabbing headaches. And so that to me is a way of saying, "Hey, your migraine maybe isn't the best controlled, so you might be getting stabbing pain."

Dr. Ailani (30:01): But again, if they're getting jabs and jolts or stabs, we want to make sure that the brain looks OK. That to me is a sign or a time that I think, "Hey, when was your last MRI [magnetic resonance imaging]? Let's do another eval and make sure there's nothing else going on that might be triggering or causing this before I give you a diagnosis of primary stabbing headache." But again, looking at the jaw is, I think, very important. Looking at a bite. It's not anything I'm going to treat. That's not my area, but I can at least see if I pick it up. Recommend some physical therapy. Recommend they see [an] oral maxillary facial person and talk a little bit more about TMD

[temporomandibular disorder] and TMJ and what they can do to start to work on that and if that could improve their migraine disease.

Elizabeth DeStefano (30:44): Others in our community have mentioned vision-related symptoms like blurriness in between attacks that they feel relates to their migraine. How might that be?

Dr. Ailani (30:55): Yeah, I think vision is the most common associated symptom we see in aura. Visual aura is about 90% of those that have aura are having visual symptoms. Probably what I hear the most in clinical practice is about vision changes, but it's always hard for people to describe what are those changes.

Dr. Ailani (31:13): And it ends up being described as blurred vision, which I always want them to get a good evaluation by an eye doctor because is it blurred vision? Are you hitting a certain age [where] you need readers? Are you using your glasses properly? Do you have strabismus that might be getting worse? And that's when the eyes are not aligning properly and we aren't seeing in the general population. But as we get older, that weakness in the eye alignment can get worse. And again, if you have migraine, you're going to be very sensitive to any kind of changes that are happening to your body. So you might be picking up a change in your vision.

Dr. Ailani (31:48): And if you're not seeing someone who's checking for all this, they're not going to pick it up. And they can sometimes brush it off and say, "Everything was fine. Your eye exam's OK." But if they're not testing the movement of the eyes properly, they might not pick that up.

Dr. Ailani (32:01): Another very common thing we're seeing that runs along with migraine, especially in women, is dry eye. And dry eyes can definitely cause a blurring of the vision, especially certain times of day. And so that's another thing that sometimes we'll talk about. If you're having blurred vision in between migraine attacks, it might be something that relates to migraine but isn't caused by migraine. And then again, if they're having constant daily pain and they're having some blurred vision, that's been hard to say. If all those other things have been ruled out, is it that the brain — the eye part of the brain — is always active?

Dr. Ailani (32:37): And so we're having some vision changes that are occurring. And you're having changes in your pupil size at different times. And that's causing the patient to experience blurring. Or there's just a lot of noise in that part of the brain. And that is causing the person to have symptoms that make them feel like their vision is blurring. Most of the time, we can end up relating it to some other issue going on like dry eye or strabismus. Fatigue — that comes up a lot.

Dr. Ailani (33:04): But if not, and the person does have daily headache, it might be this is just some unusual manifestation of their migraine because of activity in the brain itself. And then just quieting that down with good preventive treatment can be very helpful.

Elizabeth DeStefano (33:21): So it sounds like regardless, these are important symptoms to bring up with your provider to determine whether this is part of migraine, whether migraine is worsening those symptoms, or those symptoms are worsening migraine. And also, if it might be something separate that that inherently sensitive migraine brain is detecting and needs to be treated separately as a vision-related issue.

Dr. Ailani (33:42): Absolutely. I mean, I encourage my patients, they're always like, "I don't know if this has anything to do with you." I'm like, "That's OK. Just tell it to me and I will figure it out." And most of the time, many of the things that our patients are talking about are common issues faced by people with migraine.

Dr. Ailani (33:57): It might not be something I can handle in my office, but we generally know where our patients should be going and who to talk to and what to say because migraine runs along

with so many other disorders. It's not uncommon that we are seeing people that have joint issues, that have vision issues, that have back and neck issues, that have autoimmune problems, that have blood sugar and high blood pressure issues.

Dr. Ailani (34:22): And we really like, as a headache specialist, you end up being the person that can help navigate some of these conversations, but also questions to ask. Another one is orthostatic hypotension. We're seeing it quite often where patients [are] having lots of variations in blood pressures. And this can cause all sorts of unusual symptoms. And the person's like, "This must be all migraine." We're like, "Well, actually, it's related that people with migraine tend to have this, but it's not the migraine."

Dr. Ailani (34:50): But there is something you can do about it. And there is a way to get tested about this. So I think it's great to bring it up to someone you trust in your … whoever's taking care of you in your healthcare community. If you're seeing a headache specialist, there's a good chance they're going to have heard this before. So it's a good idea to bring it up.

Dr. Ailani (35:07): And they can, if it's not something that they know how to treat, they can definitely refer you to see someone who would know a lot more about the underlying condition.

Elizabeth DeStefano (35:17): So as all of the community questions on this topic we received show, there can be so many things that we experience that we never knew were part of migraine and are, or we can run the risk of thinking that everything we experience is a symptom of migraine when it may be or could be a comorbidity or could be unrelated to migraine. So that brings us to a very important question our community has, particularly about what could be the most serious of those symptoms that might not be migraine. How do we know when we should seek emergency care for something that might fall into that category?

Dr. Ailani (35:55): Yeah, I think that's actually the most important thing to think about, you know, “When do I go to the emergency room?” I actually love it when my patient asks me that because I would think the same thing. I would be worried. When do I worry? When do I not worry? I have to say also, as a physician, I get symptoms all the time and I'm actually not always sure if I should worry, when I should not. So it really can be sometimes very confusing.

Dr. Ailani (36:17): And generally we tell the patient, if you have a symptom of aura that you've had before and it's always the same, don't be so concerned about it. But if you're having an aura, like you always see bright flashing spots in your vision and then get a headache, but now those bright flashing spots are going on [for] more than an hour. Or this time, they're not spots, but like it looks like the vision is peeling down and there's like bright fireworks everywhere. Something is different.

Dr. Ailani (36:45): You want to seek care for that. You're having weakness for the first time and that's something urgent. You want to go into the emergency room and make sure you're not having a stroke. You've never had trouble speaking before and now when you're speaking it's all jumbled and no one understands what you're saying. Go to the emergency room, get an evaluation. There's always a chance that your neurological symptom could be a stroke, and that's not something we can easily assess in the clinic. We need urgent imaging for that and that's when it's important.

Dr. Ailani (37:16): If you're having a symptom you've had before and it's just ongoing and being bothersome, come into the clinic and that's when we want to talk about it, do an exam, see if there's something different or if this actually is part of the migraine picture or part of something else, and we can refer you to see someone about. And I always tell my patients in the end, if you're not sure, just send a message to your doctor.

Dr. Ailani (37:37): In this day and age, there are so many ways you can reach your clinician. And I keep saying “doctor” and I apologize about that. Really, whoever is taking care of you, you can

message them on their patient portal. You can call the office. Sometimes we'll have patients just walk in because they don't know how to get a hold of us and ask the question of the front desk. And really, if you're not sure, it's better to ask than to not say anything.

Dr. Ailani (38:00): And then we get concerned later that, "Oh, I wish you had told me this because this is something I'm worried about." If you're not sure, ask. If you're weak for the first time, numb for the first time, can't speak properly for the first time, go to the emergency room. If your symptoms are lasting more than an hour and they are always less than an hour, go to the emergency room. These are all the times that you should be concerned.

Elizabeth DeStefano (38:23): And it sounds like, as you touched on before, if someone is experiencing something that feels like it could be cardiac — related to their heart — that hasn't been determined to be one of those very rare instances of a migraine-related symptom, that that could be as well a time.

Dr. Ailani (38:37): Yeah. So if you're having chest pain for the first time and no one's told you, "That's OK, we did everything and it's normal." Yes. You want to go to the emergency room and get that evaluated. Shortness of breath — another reason to go in and get an evaluation in the emergency room. Anything you're very concerned about and you're having difficulty and you think you're not going to be able to keep going — I'm not able to walk straight, I'm really dizzy and I keep falling over. These are all things that can't be dealt with in a clinical setting. You want to go to the emergency room for treatment.

Elizabeth DeStefano (39:12): So for the person listening who just had some sort of a light-bulb moment — realizing that a symptom that they've experienced that has always felt sort of unusual or unexplained to them is actually a biological part of their migraine. What is your most hopeful message?

Dr. Ailani (39:29): We can probably take care of it. There are lots of great treatment options out there for migraine. If you've been seen over a decade ago and thought nothing was helpful, definitely go back into clinical practice because there are lots of new treatment options out there, including things like neuromodulation. So if you don't think medications are a great idea for you, there are devices that we can prescribe that can be helpful to treat symptoms as well.

Dr. Ailani (39:55): So I think that it's important to keep up to date with what's happening in the field because there's so much and there are so many new things coming out. And while we tend to study pain the most, we're always hopeful that some of our treatments are effective on all the symptoms of migraine.

Elizabeth DeStefano (40:12): What future research excites you most as [it] relates to treating migraine as a systemic condition?

Dr. Ailani (40:20): I think that some of our targeted therapies looking at the proteins involved in migraine — like CGRP [calcitonin gene-related peptide] and PACAP [pituitary adenylate cyclase-activating peptide] — they're very interesting because these studies are also looking at other symptoms of migraine, particularly cognition. And some of the endpoints built into the studies are looking at cognitive change.

Dr. Ailani (40:39): We're really trying to bring the idea of what patients are telling us in clinical practice about this brain fog and better understand what that's looking like in a clinical trial and how if a patient responds to treatment, does that brain fog and concentration focus difficulty get better as well? Our anti-CGRP drugs have been around a long time, but some of the later studies, like phase 4 trials, are starting to go back and add some of these screeners in. So I'm hopeful we're going to get a

better sense of how they work in patients that are having concentration and focus issues related to migraine.

Dr. Ailani (41:18): And our anti-PACAP trials are ongoing. So if they're positive trials, we might have some data on some of these endpoints as well. I'm always hopeful in the neuromodulation section because there are so many new devices that are being studied. They don't always have the ability to study all of these endpoints. They tend to be very small companies looking at devices. But I'm hopeful that one of these devices will come out in the next year or so.

Dr. Ailani (41:43): I think that adding to our nonmedication options is really important for our patients. They appreciate having a nonmedication to use in their toolkit of treatments. And sometimes medicines add to symptoms of migraine, so having a nonmedication option can be really helpful.

Elizabeth DeStefano (42:01): And I'm glad you brought that up, Dr. Ailani. We have a dedicated interview on neuromodulation this year that I'd encourage people to check out to further explore those options.

Elizabeth DeStefano (42:12): Well, Dr. Ailani, this has been incredibly interesting and valuable information. I think it's very validating to learn that not only those symptoms we hear most often about, but this whole variety of symptoms really can be a part of migraine, which is so variable from person to person and even potentially attack to attack. So we appreciate you sharing that with us as we really embrace this understanding that migraine is a full-body condition. Where can those listening learn more about you and the work that you do?

Dr. Ailani (42:45): Well, I'm not on social media as I'm a pretty nonsocial person at times, but you can always learn more about us at our MedStar Georgetown website, which just Google "MedStar Georgetown" and you'll find us anytime. And then you can always find me at an American Headache Society meeting. And we welcome all people to come to our meetings and I'm pretty active in our society.

Dr. Ailani (43:08): So if you ever want to chat more or learn more about the disease state and what we're up to in the field, come to one of our meetings or watch us on demand.

Elizabeth DeStefano (43:16): And are there any resources on this topic or migraine in general that you would like to recommend to anyone listening?

Dr. Ailani (43:24): So I think there are lots of great resources out there on migraine. I think American Migraine Foundation has some great articles. The Migraine World Summit itself has some great resources as well. And so I will always advise my patients, look for these vetted websites that have great articles. There are many that are meant for patient-facing information, so you don't necessarily feel overwhelmed by what's coming at you.

Dr. Ailani (43:50): And you can always speak to your clinician if you want more information. They can guide you to some great resources specific to what topic you're interested in learning more about and what you're questioning about.

Elizabeth DeStefano (44:03): Dr. Ailani, thank you so much for joining us again on the Migraine World Summit.

Dr. Ailani (44:07): It was my pleasure. Thank you.