Episode 191: Migraine and Functional Neurologic Disorders (FND)

Lindsay Weitzel:
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.

I am here today with a brand-new guest that we have never had before. This is Dr. Jeffrey Staab. Hello Dr. Staab, how are you doing today?

Jeffrey Staab:
I'm fine. Dr. Weitzel, how are you?

Lindsay Weitzel:
I am great. Thank you so much for being here. Dr. Staab is a professor and chair of the Department of Psychiatry and Psychology at the Mayo Clinic in Rochester, and our topic today is Functional Neurologic Disorders, or FND. And Dr. Staab is a published expert in the area of migraine and functional neurologic disorders. So, I am really excited about this topic.

And I want everyone to understand, I know that Dr Staab understands that we have an audience of people with invisible illness such as migraine and other chronic head pain, who've been exposed to a lot of stigma, medical gaslighting, and basically health care providers who just maybe don't understand them or our disease. And for this reason, the concept of functional neurologic disorders can often seem like another way to categorize the things that happen to us as all in our head.

So, this can be a little bit of a sensitive topic, and I want everyone to listen because our goal here is to elucidate and educate everyone and put everyone's minds at ease. After hearing the stories of a number of people in the migraine community who were diagnosed with FND and seeing some of the confusion that it caused, I sought out Dr. Staab to clarify things for us.

And my first conversation with him may have been one of my most favorite conversations I've ever had. And one of the things he said, I wrote it down. He said you cannot define something by what it isn't unless you know everything and that is not where we are yet in medicine. And he has so many interesting things to say about the relationship between FND and migraine, and I can't wait for everyone to learn from him. So let's get started.

Dr. Staab, I think that the concept of functional neurologic disorder, or FND, can feel really triggering to many of us. And some of this is just due to some of the negative experiences we've had in interactions with healthcare providers. And I'm hoping that what we learn in this podcast obviously just makes everyone feel calmer and more at ease.

So, can you just go ahead and just tell us what FND or functional neurologic disorder is?

02:42
Jeffrey Staab:
So, first let me let me start with why it's called functional. That term actually isn't new. It was first introduced to medicine, well, let's say it was first regularly used in medicine 200 years ago. And at that time what it meant was change in functioning. That's all it meant. It just meant that an organ system had changed its functioning, and therefore that change was responsible for symptoms that people would have, for signs that we could see when we examined people. So, it was a change in functioning as opposed to a breakdown or an injury to the structure.

And that's why we still use the term functional. And so essentially we're kind of coming back to that use of the word functional. And so, looking at a set of symptoms and exam findings that hold together in patterns that we can say are connected to some period of time, either temporarily or permanently, in which the nervous system changes what it's doing, as opposed to having an injury, an infection, a stroke, or something along those lines that damage the structure.

03:55
Lindsay Weitzel:
Okay. So, we're going to spend most of this episode discussing the specifics of FND and migraine, but I think it is important at this point to stop and make sure that everyone understands that FND is a real entity. In other words, it is one of the ways our organ systems can fail us.

04:17
Jeffrey Staab:
Yeah, that's really important. And in fact I really try to emphasize to my teams and especially my junior nurses and doctors, that we have to be careful that we don't use the terms real and not real, because our job is not to sort out real versus real, but what category of real it is. It's all real.

04:35
If a person comes to us and says, I'm having this, then our presumption has to be that they're telling us what their experience is. And our job is to sort out what kind of potential contributors to that experience that is. But let me say a little bit about why that problem has come up. And like you, I've encountered many, many patients, perhaps even most of our patients, who have found themselves in some way or shape or form told that this is perhaps all in your head or something like that.

05:10
So, what happened after that initial concept of change in functioning kind of came into medicine, regular use in medicine, is when once we got to about 100 years or so ago, a little bit more than that.

Some of the things that were in that category of functional that researchers identified where the structural breakdown was, Parkinson's disease is an example of that. So by the time we got to the late 1800s,

Dr. Parkinson had identified the part of the brain that deteriorates. And so there were a couple of other illnesses, in this functional category that kind of got moved over to the structural category.

So people started to doubt that functional was a thing, but rather as something we didn't know.

And at the same time other neurologists, then psychiatrists because the two were the same back then, started to recognize that in some people, at some times, life events could set off a functional presentation. And we have some of those in our language: blinded by fear, paralyzed by fear. Those things happen because human beings have had that experience.

And so what happened, unfortunately, to the term and the concept of functional is it got all wrapped up into psychosomatic, psychogenic, not neurological, not medical. And that's where this idea of not real comes from. Because if we can't tie it to the body, then it's not real. Then somehow or another, it's something else. And that's how I was trained.

That's how most people who are practicing across any specialty, across any discipline in the medical field were trained. And that is if we cannot identify a structural problem, we can't identify an abnormal lab test or MRI or other kind of thing, then this is a functional, psychosomatic, all in your head, go see a psychiatrist and figure out why you're stressed kind of a problem.

And what we are now understanding, is that those things can happen but don't always happen. And so that's I think where the challenges is, is that we're sort of changing back to that idea that functional shifts can occur sometimes triggered by stress, sometimes not. But that's the dilemma of sort of the changing concepts of functional that a lot of patients get caught up in.

07:43
Lindsay Weitzel:
So, in my conversations with you, I realized that the best way to understand what FND is may be to perhaps hear a short history of how it came about. Can you explain that to us a little bit?

07:58
Jeffrey Staab:
Yeah. As we talked about, the idea was change in functioning. And we can look in medical writings even back to ancient times and see some of these patterns. So see patterns of tremor, descriptions of people having tremors, descriptions of people having blindness, having gait problems, that had patterns that we can see even to today.

So I think the first thing is to realize that very careful clinicians, doctors, scientists, and others, have seen functional patterns for as long as people have written in medicine.

And in more recent times this idea about a change in functioning, took a bit of a detour into it's all psychological and now kind of back to changes in functioning can come from psychological stressors.

09:04
Yes. We haven't abandoned idea, but not for everybody. Sometimes it can be a medical event. Sometimes it can be a side effect of a medication. Sometimes it can be other kind of circumstances that can cause that change in the way that the body's functioning and that settled into that kind of a new pattern.

09:23
Lindsay Weitzel:
Okay. All right. So it doesn't have to be a really stressful event that causes a functional neurological disorder to occur.

09:31
Jeffrey Staab:
Correct. Sometimes yes, but we have to say, we have to make that connection. We can't just assume that it's there. We have to actually find that it's there. And if we don't find that it's there, then we have to look for what other potential connections there might be.

09:48
Lindsay Weitzel:
Okay. So there are so many symptoms that can be associated with a migraine attack.
I mean, having had it my entire life. I am still occasionally surprised on the rare occasion by something new that shows up. So we have some very typical symptoms, like head pain, photophobia, and phonophobia. Then we have some less common symptoms, like tremor, weakness or paralysis, zoning out, and vestibular symptoms.

So can you talk to us a little bit about how migraine is known to lead to some unusual symptoms and how over time this has led to some sub diagnoses like hemiplegic migraine or ophthalmic migraine and some other symptoms are diagnosed as FND.

10:33
Jeffrey Staab:
So I think most people who have headache disorders know that there's no clear test for it. That the way that we in medicine diagnose any of the headache disorders is what are the set of symptoms that cluster together, that allow us to say this is a migraine, this is another type of a headache. And those have been developed over the years by consensus, by having experts get together from time to time and set out the sets of symptoms that run together.

11:02
And over the years, some of those subtypes of migraine that you talked about, Dr. Weitzel, have been identified as subtypes, the hemiplegic migraine, the vestibular migraine being the most recent of those. But what that still leaves is some changes in sensation, changes in movement, changes in cognition, attention, awareness that don't necessarily fit into any of the check boxes.

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And when that occurs, then the question for experienced migraine doctors is, is this thing mostly within the realm of the migraine and so I know as an experienced neurologist, that experienced neurologists know, sometimes migraine can do odd things. Or is there something about the way that those symptoms have developed that suggest that it's not within the realm of what realm we understand is migraine.

12:04
So what's an example of that? An example of that would be, say, a symptom that lasts for many, many, many hours, kind of waxes and wanes and is not necessarily connected to something that suggests that a migraine is going on.

So, not with much photophobia or phonophobia, for example, but really is looking kind of at the pattern and recognizing that some things have just been defined as in, and some things have been not defined as in. And that's where those things that are not defined as in become a matter of kind of careful evaluation.

12:41
Lindsay Weitzel:
So, I think one thing perhaps that it would be good to clarify at this time is, is the pain as associated with migraine itself, could that be considered a functional neurologic disorder? Because I do think, I have noticed that when some people write in the groups or they talk about, having come home and been diagnosed, with one of their symptoms as being a fad, they get a little worried or confused if their entire, migraine disorder has been diagnosed as such, so is the pain associated with this diagnosis?

13:19
Jeffrey Staab:
So pain is in and of itself right now is we've looking at kind of defining FND. Pain as a single symptom is really not within the world of FND. I think, my suspicion is, that what sometimes happens is that when someone goes to their doctor and says, I'm having these attacks of head pain, and I've got all of this other stuff that comes with it. And the overall impression is that it doesn't really fit into the check boxes. Then they can be told that, well, this is all functional or this is all psychosomatic.

14:00:07
And I think that, you know, that I don't doubt that people have had that experience because I've certainly seen patients who have. But your point, the pain specifically,

right now is we know that it can run with people who have FND, but in and of itself, isn't considered to be an FND symptom.

14:21
Lindsay Weitzel:
Okay. So, I love this part, and it might be a long answer, but I think people are going to find it super interesting if they're interested in this topic. In one of your publications, you give four possible relationships that you feel should be investigated for the possible association between migraine and FND symptoms.

Can we talk about these four hypotheses?

14:47
Jeffrey Staab:
Sure. Let me give the viewers/listeners a little bit of a background on that research study that you just mentioned. So where that came from was observations that we had that there were people who came and had a variety of different neurologic symptoms. So episodes of neurologic symptoms that were always connected with a clear cut migraine headache. But the symptoms were these ones that are sort of the outliers, the not in the checkboxes of the subtypes of migraine that have been clearly defined. And so we would ask them how often do you have these spells of symptom. And they would say you know however often. And we said, do you always have a migraine with them?

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And they say yes. Do you ever have them without a migraine? No. And so when we saw that there was this sort of 1 to 1 connection, we started to ask the question, was migraine potentially then the trigger for these, this other substat or cluster of symptoms. And that's where this research study came from.

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And it turns out we weren't the first ones to do that, that people going back 100 years have from time to time made this kind of similar observation.

But let's talk about how, why might they be connected. And if we say on the one hand it could be just chance. Migraine is pretty common. Actually it's very common. FND is pretty common too, much more common than people really understand. Two common things might by coincidence run together. Now, we don't think that's a great explanation because it just happens too often.

16:19
That there's more to it than just oh you're sort of kind of have a dual whammy.

At the other end of things, it could be that there are certain symptoms that represent a subtype of migraine that hasn't yet clearly been defined. Meaning until vestibular migraine was defined,

many neurologists knew that dizziness, vertigo could sometimes happen with migraine, but they didn't have a subtype for it.

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So perhaps there are some of these symptoms that right now lie outside of a formal definition that really very much are part of a migrainous process and not anything else.

So, I think the more potentially challenging connections are kind of two possibilities in between those end points.
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And so one would be that the migraine attack becomes the trigger, that it's not a psychological stressor, but it is the stressor of a migraine attack. The pain, the other symptoms that run with it,
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that then sets off kind of behavioral extension of this event. And so migraine can happen, maybe cause some weakness or numbness or tingling on one side of the body. And then from that we get additional symptoms. We get like a tremor that extends to both sides of the body, or we get zoning out that stays for a long time,

17:57
things that start to feel a little bit again outside of the box of the migraine. So again, that pattern which the migraine sets it off.

And another possibility might be and so, so I'm sorry that that one is the migraine is its thing. The FND is its thing. But one triggers the other.

18:17
And the third possibility is that there is a shared vulnerability. That in certain people there is a vulnerability to both migraine attacks and FND symptoms. And that common triggers can set those off and those can be common triggers like poor sleep, conflicts with family members, certain situations or places. And so that what happens is you have two connected problems with similar triggers.
18:51
So again, purely by chance. Yeah, probably in some people. But there's more to it than that. 100% migraine possibly for some people that we haven't sorted out. And then these two possibilities of overlapping connections in between.

19:08
Lindsay Weitzel:
Right. And I think, the first time we spoke, we were talking about is there even a possibility that it could be a combination of all those things too? Is that a possibility?

19:24
Jeffrey Staab:

Sure. And let me give you examples from actual patients that we've seen. So, there are times in which the people's history starts with a clear 1 to 1 association. Every attack of FND symptoms comes with an attack of migraine. Sometimes a migraine can come first. Sometimes the FND comes first. But they always run together.

19:48
And then what happens is that the attacks of the FND symptoms kind of take on a life of their own. And so then they're not always connected to the migraine. And we know that that can happen because any pattern that the body develops can kind of get settled in.
And so sometimes we can see that there is an evolution of the illness over time.
And then that makes it a little bit more challenging to sort out, because by the time somebody shows up, there might not be that initial 1 to 1 connection which was a little bit more obvious at the beginning.

20:25
Lindsay Weitzel:
Okay. I love the whole hypotheses and everything. I hope that that elucidated some things for people. It's a little bit long to listen to, but it is just to me it's very eye opening.

So the next thing that I think might be one of the most important things, possibly that we could cover today is management strategies. For some of these symptoms, if people are experiencing some symptoms that are like this, what can they do? What is the treatment?

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Jeffrey Staab:
Yeah. So the practical thing first is to recognize that all of what we just talked about is not yet settled. So, my team is not the first to raise these questions and we won't be the last to raise these questions.
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So but in the meantime people need treatment before we get a chance to figure this all out. And so what I ask people and ask the neurologists that I work with to do is to say, is a migraine present. Is a migraine disorder present, yes or no? And if so then it requires treatment.

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Whether it's with daily medicine, behavior or lifestyle changes as needed, medicine, whichever is the best strategy for the migraine attacks.
Let's make sure that that's part of the treatment plan. And then from my side of things I say okay. How tightly connected are these FND symptoms to the migraine. Are there other things in this person's life, present or past, that can also be contributing a risk factor.

22:02
Or the that those FND symptoms do present and make sure that that's part of the treatment plan too. And not get caught up in the unknowns of how are these two connected. But rather to

agree if they're both present, the treatment plan needs to address both and let's make sure that that happens.

22:23
Lindsay Weitzel:
Okay. So you had mentioned yesterday some things people could do and you used the example, if you felt like you were zoning out. People who kind of and by zoning out, I think you even went into more specifics. And I know people, sometimes experience this. If you're if you're experiencing a bad migraine, you sometimes, we'll go into a zoning out episode where you can't answer when people are talking to, etc..

I think that was the example you gave, and you said that there were, specific things that people could do to focus and not zone out. Was there an example you could give?

23:04
Jeffrey Staab:
Sure. And, so, this is where it's easy to get caught up into, well, as is the thing that I'm experiencing directly related to the migraine, or might it be a functional neurologic symptom. And sometimes with an example like that, it's hard to tell.
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As you said really intense pain causes us to kind of shut down and not really want to respond even if we can't hear or see what else is going on.

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But if you say to a neurologist, I can hear and see what's going on around me but I just can't respond, that's a classic functional neurologic symptom. And that's what we've been taught. And that's true. But if you take that absent the intense pain experience, then it can be classified clearly as functional. So, without debating where the symptoms may be coming from, there are certain things that you can try to see if you can cut down the intensity and the duration of the symptom, and that is to do the opposite of what the symptom is doing.

So if it feels like this attack that you're having is causing you to kind of shut down, zone out, try doing something simple to zone in. Two examples that I have people do is to draw the lines on one time of their hand with a finger from the other hand, just to look and do that. Or some people have a little phrase that they want to say to themself over and over again if they concentrate on that.

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So not something that's complicated to concentrate on, but just something that really allows you to zone in.

So, if the spell feels like it's zoning out then zone in. And it's best to try to do that at the very beginning because once you're in the middle of a major attack, very hard to counteract the intensity of the symptoms there.

25:00
But as they start to develop instead of zoning out zone in, something simple. Or if there's a little sort of quiver or tremor that starts in one hand, to try and make nice smooth graceful movements of that hand. So usually a tremor is kind of herky jerky.

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And instead of allowing the spell to kind of take over the movement control system and make herky jerky movements, you purposefully, say, no, I'm going to override that with graceful, smooth movements. Again at the beginning that can help. Once you're in the middle of the spell and there's lots of different herky jerky kind of things going on, really difficult to counteract it. But the idea is to think is what is the spell doing? And is there something that's the opposite of that that I can try to do in order to kind of counteract it?

The behavioral terms are called habit reversal or competitive inhibition. So our muscles can do a lot of things, but only one at a time. You pick one that you stay in control of, it's hard for the spell to break into that.

26:12
Lindsay Weitzel:
Okay. I, I'm glad that we said that because it just. And everything that you say, I think because it's so new in our, community, I think it's very helpful to help people understand what's going on, what can be done. And you even mentioned, that it in really high episodes of pain versus when it's not associated with high episodes of pain. And I think that was very interesting that you set it apart.

So thank you for doing that. So is there anything else you'd like to add to this topic today before we go?

26:47
Jeffrey Staab:
Well, I think that, there is something else that I try to help patients understand, and that is that what we're talking about today is changing concepts of FND and the relationship of FND to other medical conditions.

it's going to take a while for us to make the change to this sort of broader concept that functional neurologic signs and symptoms can have multiple triggers and have multiple pathways by which they're connected to, problems other than life stressors. So, what the practical that is that what you really need to get through these kinds of things, is a clinician who is able to say, okay, I'll treat your migraine.

And yes, I've seen migraine do strange thing. I don't know if all of the things that you're doing are connected to your migraine, but let's give it a go.

And if that's the openness that any of the clinicians you're working with can have and that you're willing to say, and I'm going to take on the responsibility of looking at not just my diet and sleep and other kind of things, but what is happening around me and who I'm with and where I am when these things happen and see if there's something of those psychological, environmental kind of things that fall into a pattern.
28:26
I think if you're willing to do those things, somebody who's kind of open to the kind of curious about the variations that you're that you're talking about with them and that you maintain a curiosity about how it playing out, that you can come to a meeting of the minds and have a good outcome.

28:45
Lindsay Weitzel:
Right. I think you said something. This is another thing you said yesterday that I wrote down that I thought was just awesome. You called migraine a structural functional disorder, a cellular process that sets off an entire nonstructural process. And I thought that was an amazing message to get across. And so as we close, I'm wondering if you have a message you could say to any people out there, who might be watching this because they, were told that they had a functional neurologic disorder, and they may have already felt like their migraine was already all in their head and it was their fault, etc..

And so they're feeling a little worse. What would you say to that person?

29:36
Jeffrey Staab:
Well, so that concept that you just talked about, I'm not going to take, I don't want to take ownership of that. It's an accurate one, but I really want to give the credit for that to the people that have really brought that up and that is some really, really, accomplished researchers trying to understand migraine.

29:55
And so what, what a number of different neurologists and neuroscientists who study migraine have said is that we're starting to identify where in the nervous cells are some changes in structure, changes of receptors, changes of other cellular components that are different in a person with migraine than somebody without migraine, and that under certain circumstances, the kind of triggers we know, that and interact with those cellular structural changes to set off a chain of events that changes temporarily the function of the brain.

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We know some of those changes in function that are connected with aura, for example, you know that when people you know, can read about, you know, cortical spreading depression, that's something you can read about easily in terms of migraine aura. So that's not a structural breakdown in the brain. That's a change in functioning that comes and lasts for half an hour to an hour and stop.

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So that's why these days, you know these experts in the neurophysiology of migraine say we're seeing where there are some subcellular structural changes. And then we know that the migraine attack is associated with an entire change in processing in the brain. Change in functioning. But that doesn't mean that it's all in your head except that's where your brain is, but otherwise not the all in your head idea.

31:19
But then that's why there's at least some possibility that those changes in functioning can extend well beyond what we currently consider migraine into other neurological psychological symptoms that can be associated with the attack. So I think that the message at the end is, we'll get better at this.

And we'll understand all the nuances of the brain come together. But in the meantime, the idea that there might be two sides to this coin, and that looking at both and how they come together is really the way forward and in trying to control symptoms.

Lindsay Weitzel:
Okay. Well, thank you so much. I think you are such an interesting person to listen to. Your view on this topic I think for our community is really amazing. And I just want to thank you for coming on today, and I want to thank everyone who listened. And please tune in again for our next episode of HeadWise. Bye bye.

Jeffrey Staab:
Bye bye.