Episode 186: Burnout From Migraine and Headache Disorders

Lindsay Weitzel

Hello everyone, and welcome to Head Wise, the videocast and podcast of the National Headache Foundation. I'm Doctor Lindsey 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'm excited to be here today with one of our absolute favorite repeat guests, doctor Dawn views. Hi, doctor views, how are you?

Dawn Buse

Hi, doctor. Like so I'm doing well. I'm happy to be here. And hi to everyone watching and listening.

Lindsay Weitzel

So Doctor Vieux is a clinical professor of neurology and a psychologist who specializes in headache. She is so well known, so well respected and loved in our community. We are so lucky that she comes on and talks to us about all things related to taking care of ourselves, related to headache and pain psychology. And I am honored every time I get to talk to her.

So today we are going to talk about a really important topic that, maybe we don't bring up very often, and it is called migraine burnout. Now you can just replace the word migraine with whatever headache disorder you have, because I think all of us have experienced burnout, from our chronic headache or pain condition. And I thought of this because I started feeling a little burnout, a couple of months ago, taking care of myself and my child who has daily migraine.

And it occurred to me that I am sure I am not the only one who has felt this way or is currently feeling this way. And so I talked to Doctor Buse, and I thought we should address this problem. And, we came up with some really awesome questions, some really awesome things to say. So I hope there's something in this episode for everyone.

So doctor views, let's just talk about some reasons, why we might experience burnout as people living with migraine or another headache disorder.

Dawn Buse

Well, like with migraine or another headache disease is, it's a marathon, not a sprint. These are chronic illnesses either a long term, maybe not a lifetime, but decades long chronic illnesses, right? Of course, that is exhausting. Life with migraine or other severe headache disease takes its toll in terms of,

the pain, the discomfort with some of the terrible symptoms that go along with attacks.

Ongoing concerns, like always having photophobia or a cognitive impairment, kind of feeling like you're not as sharp as you used to be.

Our denier. Which is when things hurt on your skin that normally don't hurt. Like wearing a ponytail. Some of those symptoms last all the time. Even when you're not having attacks. So life with migraine itself is not easy.

There's a toll taken on the impact at work, in school. Always trying to play catch up, feeling concerned that others might be judging you, or feeling the stigma of missing out and the missing out on enjoyable things of life. The social activities, the holidays, the vacations, the special days, the fun times that gets stolen away. Just that every the weekends.

All of that gets exhausting. On top of that, if you're seeking medical treatment, that can be exhausting as well. Sometimes we have to struggle with insurers and payers to get the treatments we need. We have to struggle to find the right doctor is the best doctor for us to get those appointments. There might be long waits to get into those appointments.

Once we're there, we have a lot of waits. We might feel like we are kind of moved around through the system, and there are things that we have to do to get to certain treatments to follow the,

the way that that payers have us try multiple treatments of different types of classes before we can try a different type of treatment.

This is all exhausting. This can be just exhausting.

Of course this can be exhausting. This is a lot, and it goes on for a long time. So it kind of has that feeling of being a relentless or vicious long cycle. So it's not surprising given all that whether you're someone with migraine or whether you're caring for someone with migraine, that it's an exhausting process.

Lindsay Weitzel

Right? And I mean, I will, add to that migraine, chronic migraine, particularly, whether you have it, your loved one has it or, you know, God forbid both of you have it. Is like a full time job. And depending on how consistent the pain is, it can really wear you down. And if it's daily, the burnout is going to come fast.

But honestly, even if it's not daily, that concern over when is the next attack going to hit will wear on you?

The stigma is going to wear on you, especially if you are around it every day. If there are work colleagues that you're feeling stigmatized by, or if there's people in your family or feeling stigmatized by, this is going to wear on you.

And we aren't saying this to bring you down or saying this so that you feel validated.

As we move into this conversation, there's also the financial component. If you are having trouble providing for yourself or the, the cost of, of, taking care of yourself or that family member medically because they have, a headache condition is rough.

But you brought up the, the medical appointments and, just as someone who all of the medical appointments I have to go to for myself, and then I'm also taking my child to them. I think that that is part of the reason it the burnout hit me recently, and I was thinking of having this episode. The doctor's

appointments are just incessant, and you know, how on earth am I going to work between both of us being sick and then both of us going to these doctor's appointments?

So, if people out there are feeling that way, you're not alone. And also, we're losing loved ones and support system a lot because we have this invisible illness. So, here we just we wanted to throw out we brainstormed a lot of these reasons that, so many of us start to feel burnt out. So, doctor views, this is something that you are going to have way more input on than me.

What are the signs of burnout?

Dawn Buse

Well, the idea of burnout originally came in the 70s. It was coined, and it related to work, the workplace, and there were a couple aspects of burnout. One was not caring anymore. So maybe you are struggling with trying to make something right, trying to do time, trying to take care of something. And you get to a point. We just say, I throw up my hand, I don't care.

So that kind of loss of that connection, the loss of the passion for it, the loss of the caring. That's one of the signs of burnout. Just kind of giving up and feeling apathetic about something.

Feeling hopeless and helpless. Now, these are hallmarks of depression. They're also hallmarks of burnout. So you've got this relentless stressor that no matter what you do, it feels like you're not, you're not accomplishing what you want to accomplish.

You're not getting past the stressor. You're not getting the results you want. That can be really exhausting. And that can lead to feeling that you are helpless to make the changes that you want to see, or hopeless that things will get better in the future. And,

depersonalization. So starting to lose, listening to others, empathy for others, just kind of becoming so overwhelmed that you kind of get a little bit of a harder shell about yourself.

These are all symptoms of burnout. They are similar to depression. They're similar to symptoms of depression. But the burnout is really related to a situation as well as the more general depression is often more general. Now, you might say that we know that depression is comorbid with migraine, and that people with migraine are more likely to have depression, that rates of depression increase with monthly headache day frequency and headache severity.

So, there's obviously relationship between migraine and depression. But the difference with the burnout is really the exhaustion. Frustration, about specific aspects of living with migraine. And we mentioned several. You mentioned financially it may be affecting you, your work and your income, your ability to go to work, your ability to, take promotions or different types of jobs that might bring in more income or your ability to work at all. And then the direct cost of medical care. Plus, you mentioned all the time out of work to go to medical appointments.

The frustration with trying to get to the right treatments for you, be they medication, be they kind of CBT or biofeedback, be the neurostimulation. They can all be difficult to get access to. So here you are trying to care for your care for migraine and trying to do the right things.

And it feels like these walls keep getting thrown up. You're just like thwarted on getting to the outcomes that you need or even getting diagnoses, getting answers that you need. And it's not surprising that after trying, trying, trying, eventually you just want to give up. And that is burnout.

Lindsay Weitzel

Right? And it and it I think that my experience of what I felt was burnout. It frustration was the biggest word for me. It's when you feel like it's just you're not it's it's like beating your head against a wall and you're not actually accomplishing anything. Except taking care of this disease that maybe isn't really getting better. You know, at that particular time, you might be in a space where you feel like you're you're just the same every day.

And that that's a that's a frustrating space to be in. And someone who's, doesn't really have a memory without, experiencing migraine. You that space will occur and it's okay. You know, we move through it as people with migraine, we move through it. So, we discussed that it is similar to depression. And how do we know if we're experiencing burnout instead of depression or overwhelm?

Can we speak to that at all?

Dawn Buse

Depression has some other psychological and physical symptoms,

that may not occur with burnout. So with depression there is the feeling of feeling down, sad, or depressed. By. Many of the days, much of the day. Then there's also this anhedonia. So anhedonia is the idea hedonism meaning pleasure and meaning, not the idea that you are not getting pleasure. I think you used to. So maybe, you know, enjoy your hobbies anymore, or social activities or things you used to enjoy. That's often a sign of depression, and that might be different than the burnout, which is more focused on a specific situation. Right?

In depression, you might also have a loss of appetite, or you may eat too much comfort eating, kind of overeating and gaining weight. You may have very little energy, or you may feel very agitated and fidgety and restless. So there are some other symptoms of depression. Depression often affects sleep. It affects mood. It affects the general kind of quality of life.

That may be a little bit more unique to depression. And depression is pretty global. You kind of feel it all of the time where it's really feeling kind of this medical burnout or burnout about life with migraine or any kind of chronic condition if either you or get access to a treatment and it worked really well, I would expect that that would lift for you.

Or if you were just to focus on something else, you had a vacation coming up or something, you were really excited about something you enjoy, and you kind of just took your focus off of that topic for a little bit and really let yourself kind of sink into this other, this other activity or this other, event that you can forget about that burned out a little bit.

So burnout is very situation specific, whereas depression is more global.

Lindsay Weitzel

Okay. So let's just I want to address really quick because I do run into this so often. Can burnout be one of the reasons or causes of people with migraine, and other headache, disorders and diseases that they stop seeking treatment or seeking help for themselves?

Dawn Buse

Oh, absolutely. Absolutely. It may feel sometimes like the system is, is set up to be such a fortress that, you know, you can't get the appointments with the specialists that you need or the doctor you need.

You can't get to the treatments you need, be it, something that that payers or insurances don't cover or support or you have to go through this process of trying multiple treatments and, and failing them so they know they don't work well enough for you.

We can't tolerate them. The side effects are a problem, and you feel like a guinea pig of three months of this one, three months at that one, three months of that one, knowing that they may not work for you.

This is very exhausting. You know, we're talking about burnout with migraine. This could be with any medical condition.

You talked about all the appointments, the time, the time away from your regular life at time from work, the scheduling, the hours on the phone, with insurances, with the hospital. It, as you said, can become a another job. And the amount of time, the amount of frustration,

can be very overwhelming. And it's easy at that point to say I give up.

I, I can't even try, with migraine, if you give up now, it might be okay to take a little break for a bit,

to take a little time off that might be fine. You know, it might be a time you've got a vacation or summer vacation or winter holidays. You think I'm just gonna put this on the backburner for a couple weeks and come back to it?

You know, that's not always easy when you're hit with migraine attacks, which are painful and have really, really debilitating associated symptoms. So it's not like we can just forget about it,

because it might rear its head whether we want it or, you know, rear its head anyway, even if we're drinking a little break from pursuing treatment or pursuing, the different avenues of getting help,

but if you feel like you've hit a wall, maybe take a little time off, or maybe just figure it's time to pivot, it's time to think about something different. Is it a different provider? Is it is it,

is it reaching out to some of the advocacy groups for migraine? Is it is it, listening to podcasts, learning new information? Is it trying different treatments other than medication? You're trying nutraceuticals, trying neurostimulation, trying behavioral therapy, cognitive therapy.

Back. What can you do to switch it up?

How can we switch it up a little bit?

Right now, naturally, migraine waxes and wanes. That's what we know from research. It naturally without any, any involvement of of treatment or with treatment. You get better periods and you get worse periods.

That happens every month. For some women, it happens seasonally. For many people, it happens over the course of years. It happens over the course of decades. So migraine is fluctuating.

Now, some listeners may have daily migraine. They may have continuous pain. I know, Lindsay, you have continuous pain. And that is a particularly exhausting way to live because when you have continuous pain, you can't even really hope for that next break. And I don't know that your pain raise in the lower.

Does it wax and wane or is it always for sure?

Lindsay Weitzel

Yeah it does. And I can say, and

I know the reason I say this is maybe there's someone out there or you may give someone hope or, you know, someone can relate to it. But I had for your in pain like almost indescribable migraine plus an additional burning head pain that was a different diagnosis up until the age of 30.

And then I got considerably better, but I get considerably. I'm so much better, but I still have daily pain, and I can say that even

after getting considerably better and being so grateful, daily pain, it wears on you and you will experience burnout. And so, I mean, don't be hard on yourself if you're burnt out and and you know how you said to take a vacation,

you know, a mental.

Dawn Buse

Make it a real vacation or a mental vacation, is there? Anyway, now, you can't really take a vacation away from your pain. That pain comes with pain. So, I mean, what do you do to cope with this?

Lindsay Weitzel

Well, what I would say the biggest thing that came to my mind is don't disappear. Because what I keep running into is people who just stop seeking treatment altogether, and then they don't even know about the new medicines that have come out that they could be trying. And that to me is so worrisome. So never do that, never totally disappear because there are new.

This is the most exciting time for people with my brain. And so you don't want to disappear. Because there's, you know, there's new things coming out for us to try. But what do I do for myself? I, try a new form of meditation or try tai chi, or I find an empowering movie that's going to inspire me.

I find something that's going to inspire me. I think that's the most important thing. Or I have this little skill that I call zoom out because I feel like when we are getting burnt out or stressed out or frustrated, we tend to zoom in with this tiny lens on the world and, and, and things are not good right that moment.

But if you zoom out on your life and on the world, it's a much easier perspective to get through what you're going through. And that's one of my favorite skills. And that's my simple term for it, is zoom out. So those are some of the things I do. But I think one of the most important things is for sure take a break from that doctor, get a new one or something, but don't disappear because there's always new things coming out.

I agree, and I think that is one of the anecdotes. Antidotes to burnout is staying hopeful, and we have seen developments in migraine in the past ten years like we've never seen in the previous 2000,

Dawn Buse

years, that there are so much, so many developments and treatments in medication treatments, in non medication treatments, in our knowledge, there's so many options to try now that I do want to encourage people to not give up entirely.

Even if you do take a little break, take some time off because you're getting burnt out from seeking care, trying to get that care.

Don't give up. And and maybe it's time to switch it up with a different provider or a different health system. You're going through some different advocacy options or trying some entirely different types of treatment.

You know, maybe you've never added on biofeedback recording, behavioral therapy or neurostimulation or nutraceuticals or changed your try to improve your sleep or tried to start exercising, you know, whatever it may be. Now, that's not to put the blame on anybody, because we know migraine is a kind of genetic neurochemical experience. This is not your fault. You haven't caused it by not doing X, Y and Z, or by doing A, B, and C, so we're not saying that at all.

But when you feel like you're in a rut and nothing's working, take a little break, take a breath, regroup, and then think about trying something different.

Lindsay Weitzel

Right, right. And focus on those things that are not medically part of your life, that are fun for friends and etc. and it's interesting how it all starts to fall together again. And that's kind of how we get through those rough, burnt out times, in my opinion at least.

Dawn Buse

Yeah, shifting your focus, focus on something else for a bit. Also, focusing on, situations outside of ourselves can be really helpful. It sounds very counterintuitive to think if you are suffering and you're in distress, that going to volunteer to do some work,

with being an animal shelter or being refugee, you know, be it making a Thanksgiving or holiday meal for a family in need, whatever it is.

You would think, oh, I really need to focus on taking care of myself right now. But there's something very empowering and kind of going outside of ourselves for a moment and focusing on others that can be very fulfilling.

Lindsay Weitzel

It's very true. And I think even just listening to podcasts like this, going into the groups and knowing that there's other people that experienced burnout, is hugely empowering and important. So thank you so much for doing this with us. Doctor views. This is I think this is going to be important to so many people.

Is there anything else you'd like to add before we go today?

Dawn Buse

Well, I love what you said. If you are experiencing burnout or any of the feelings we talked about, you are not alone. This is very common, if not surprising. In fact, if as a human being, you didn't feel a little bit overwhelmed, helpless, and helpless by kind of fighting this uphill battle for a long period of time, that would almost be surprising.

I think it's actually normal to have some of these feelings, and if you do reach out to other people, you read some of the the chat through the National Hate Foundation, American Migrant Foundation. You kind of listen to what other people are saying. You'll find that not only you're not alone where and there's a lot of people in this big boat all together and there's something very empowering about that.

So, migrant, it's not your fault. Other severe headache diseases are not your fault. And, And yet we want to give you as many tools as we can to keep you moving forward and seeking better outcomes. And there are really a lot of therapeutic options that we mix and match and create the perfect best combination for you that we really expect that many, many people can experience a great degree of improvement.

And so if you haven't experienced benefits, don't give up. Keep trying.

Lindsay Weitzel

Right. Well thank you so much doctor Abuse. And thank you everyone for tuning in today to head wise, the weekly Videocast and podcast of the National Headache Foundation, and join us again next week. Buh bye.