

Taking Charge of Headache™
Episode 9: Veterans and the Stigma of Headache and Migraine Disease

Diego Colón:
Welcome back. Hello everyone to Taking Charge of Headache, part of Operation Brainstorm, the National Headache Foundation's veteran focused initiative discussing free headache and migraine resources. My name is Diego Colón. I'm the associate director of partnerships for the National Headache Foundation, and I'm here with my cohost.

Melissa Farmer-Hill:
Hi everyone. My name is Melissa Farmer-Hill. I am an Army veteran and I am a person, someone who is living with migraine. I'm also the founder of Shero Coffee Club, and I am just happy to be here to just bring my own experience and my veteran experience of migraine to the show.

Diego Colón:
We're so excited to get started today on today's topic, is something that I think we deal with a lot in the field. And we're talking about stigma today. What does stigma look like. How does it prevent people from getting care. How can stigma be something that is internalized, by each individual veteran, each individual person.

Melissa Farmer-Hill:
Yeah. And the part about being in the military and serving in the military is that you're always taught to push through the pain. One of our favorite sayings was suck it up and drive on, because you have to stay mission focused and you don't want to let your team down. So, there is a lot of stigma involved with that, so I'm glad I'm here to talk about it with you.

Diego Colón:
Melissa, in your story that you shared with us, you talked about sort of like self-medicating and delaying care. Do you feel like stigma played a part in your journey?

Melissa Farmer-Hill:
Yes, I absolutely believe. I know it does because like the things that I said earlier, you don't want to let your team down. You want to make sure that you're there to carry out the mission, so I self-medicated. I self-medicated it through my entire experience. And then not being properly diagnosed was the wrong thing for self-medication. So, yeah.

Diego Colón:
It's important to really lock in on what we're talking about when we talk about headache and migraine is that it is a neurological disease, neurological disorder, and that seeking care is not a weakness, which is something I think, not just veterans, but human beings in general are trying to work on a little bit more. And I think we need to combat a little bit more. And that stigma can be changed. And in this work, and what I really love about working with veterans is that military personnel are always kind of the first people. They lead the way in a lot of ways. So, them breaking it down first is a great way to help us, who are non-veterans, kind of get the courage as well.

We've got a couple of other advocates here to help us out. Firstly, I'd love to introduce Ashley. Ashley is a Navy veteran, and she works with veterans at the Illinois Department of Veterans Affairs. She lives with migraine related to a traumatic brain injury. She's a veteran advocate, and her personal experience in navigating treatment is going to be something that is going to illuminate this discussion here today. Very excited.

Melissa Farmer-Hill:
And we also have Dr. Karen Williams here today. She is a nurse practitioner, a subject matter expert for Taking Charge of Headache. Dr. Karen Williams is a nationally recognized headache care professional with federal service and leadership roles with the VA's Headache Centers of Excellence, Headache Clinic, and Traumatic Brain Injury Program. And she's going to give us that clinical perspective on headache and migraine and TBI and veteran care and all those things.

Diego Colón:
Ashley and Karen, welcome to the podcast. So happy to have you.

Ashley:
Thank you for having us.

Karen Williams, DNP, FNP-BC:
Glad to be here.

Diego Colón:
Ashley, I want to start with you. Would you mind sharing a version of your story with us?

Ashley:
Absolutely. I'll try to make it as short as possible, but I served in the Navy in 2009, so it was very long time ago. Don't try to add it up and figure out my age or anything like that. Shortly after I got out, I became a police officer. I served eight years with that. And I ended up having to medically retire due to an injury and the also the risk of future concussions, because I did have to other concussions while I was a police officer after my TBI.

So once I had to medically retire, I used my VA benefits, and I went to law school and recently graduated law school. I didn't realize how hard school was going to be going back into it. And so now I'm just enjoying life after law school, working with veterans, trying to be an advocate for as many people in different issues that I can help with.

So, at the time, I didn't really realize how bad like the headaches were. Like you had mentioned before, it's kind of like you just pushed through. I didn't want to take extra time off because then someone else is forced standing your watch or something like that, or you're just kind of, I don't know, you just give off that vibe that your weak. And especially being like one of the few females on a smaller ship, it's just kind of you want to just make sure that you are trying to hold your own with everyone.

But shortly after my MRI, I started noticing some symptoms like pretty quickly, and they were actually mental health related. And nobody had told me initially that that was something that I could expect or experience from having a pretty bad head injury. And so, it took a lot of time to get like the right answers, find the right doctors, and basically get on a good treatment plan.

Melissa Farmer-Hill:
Wow. I'm glad you pointed out, me being Army and my experience, you being Navy and your experience, the stigma is definitely there. Did you feel cared about or cared for through this experience? Were there challenges while you were going through this?

Ashley:
Yeah. I am a rule follower to a tee. So, when medical told me I was safe to like start watch again or whatever, I honestly did not feel good, I didn't sleep, or I had been throwing up. But I just jumped back into my spot and started back in the rotation because I knew my crew members were having to double up and stuff. So, I was hurting them for lack of better words. And then kind of coming back, I just really, I don't want to say like medical didn't listen to me, but they really didn't give me like a good rundown of what to expect that since I've had this injury, it was more of like, oh, you got the staples removed and stuff like that. It wasn't you might experience mood changes, sleeping, just a variety of things. So, when my mental health symptoms started, I never had them in my life before, and to be honest I didn't know what they were. Like I had anxiety for the first time in my life, but I couldn't really put it into words of what I was feeling.

So yeah, I just feel like. And that was, I mean we're talking some time ago, so they've definitely have revamped a lot of their procedures and whatnot. But I think back then, yeah, I definitely flew under the radar. And I'm lucky that nothing more serious happened while I was at sea because I didn't get any of the screening or testing or anything done.

Diego Colón:
Karen, if I could shift it over to you. When you hear Ashley talk about all of these things in her experience, what do you want veterans to understand about sort of like these symptoms and what it means to be perceived for them?

Karen Williams, DNP, FNP-BC:
Ashley, thank you so much for telling your story, because I hear it and I get frustrated for you. It's definitely something that we have seen a lot. I was working at the Landstuhl Regional Medical Center in the Army Hospital in 2008 to 2013. Yours was in 2009, and we were just figuring out what concussion, what moderate brain injury, what traumatic brain injury. We knew a traumatic brain injury what that look like, but figuring out what mild look liked. Yours was probably mild to moderate if you had some bleed in there.

Ashley:
I lost consciousness, so I forgot what they graded it as.

Karen Williams, DNP, FNP-BC:
If it was more than a few minutes, it was probably moderate. Unfortunately, invisible doesn't mean that it's insignificant. You had some very significant changes that you could feel but nobody else was giving you that feedback on that. And so, it's really important like you did over time being that advocate, because it's really important to get the correct diagnosis, which it sounds like you eventually did. And I'm so sorry it took that long. But getting that validated really matters. And also being able to get that full exam because sometimes those neurological changes aren't seen on the outside. You need to do a detailed exam. And so, from that, thank you again for what you've done. Diego, I hope that answered your questions.

Diego Colón:
Yeah, absolutely. Absolutely. And facilitating the conversation between both of you is incredible for me. I love watching veterans talk to other veterans and being able to facilitate that is what we're all about here at Taking Charge of Headache.

Melissa Farmer-Hill:
Absolutely. And Karen, I have a question for you as well. Like we talked about it earlier, Ashley spoke on it, why can't we just push through or suck it up and drive on? Why can't we afford as veterans, as individuals serving, why can't we afford to have that mentality?

Karen Williams, DNP, FNP-BC:
I saw that happen a lot. And I hear it from both your story Melissa and Ashley yours. And what that does is it takes longer for you to get to treatment so it can become more chronic. And that is something that as a headache specialist, we try to get patients to advocate for themselves as well so that they actually are getting the care that they deserve.

And that's hard because you can't always see it. I worked with a sergeant years ago when I was over working at the Army Hospital in Landstuhl, and he had a traumatic brain injury as a medic. And I would hear him say every now and then, I wish I had lost a limb because people would see that and they would know there was an issue, versus the head injury versus the chronic headaches, those types of things. You may look different, but people start to think you're just trying to get out of your job, or you internalize that stigma that I'm not good enough, maybe I should.

In addition to that, you may start overmedicating. Melissa, you mentioned that. You started treating your own symptoms and you can give yourself worse symptoms when we start that medication overuse. Now we're not dealing with just one type of headache or two, we're dealing with even more. And so, it just can kind of snowball into something that is more severe and takes longer to start getting better with.

Diego Colón:
Yeah. I've been to a lot of events and spoken to veterans, just like around the country, and I think that is something that is very common. People are just sort of like I do whatever I need to just kind of make it through the day. And I always like to gently remind them like that I'm glad that you're finding something that is helping you get through the day, but long term that might not be so great, especially after service.

And I want to ask Ashley really quick, that military mindset of pushing through the pain and sort of walking it off, that has got to be something that follows you outside of service and into civilian life. How did that affect you entering the workplace?

Ashley:
Looking back, I think it was probably one of my biggest barriers. But at the time, I didn't realize it because I went right from military into police officer work or law enforcement work. And I again was one of the very few females. So, like if I had a really bad headache or something like I would wear sunglasses, take my medication, and just like try to make it work through the shift. I didn't want to be the one to call in or anything like that. I just felt like a lot of extra pressure because of, I don't want to say just being a female, but I didn't want to be seen as, like, oh, we have this new girl, she can't hold her own type of thing.

And right then and there, I just started to come out and let my bosses and friends who I was comfortable with like let them know that I've had this fall in the military and it's affected me in many ways. And sometimes people realize that just talking to me, like if I repeat something or something like that. I just try to be like open about it. And I don't want to say like joke, but sometimes you're going to tell me twice or three times or four times.

And then when I started law school, it was really frustrating because I had always been used to being a good student, didn't really have to like put a lot of work in to see good grades. And I know law school is difficult, but even with accommodations, it was hard, very hard just dealing with, because I hate the saying like when you think too hard, your head starts to hurt. Like that's true for me. So, knowing when to walk away from studying or homework or something like that. And kind of like if anyone had said anything to me, I kind of was like, okay, well, this happened to me. I don't have control over how I feel right now. You know, just being more bold I guess in the workplace too and saying this is not safe for me to be like on the street driving in a squad car right now. I can't even open my eyes to the light type of thing. I think it helped and it was a big barrier because I should've let myself, I don't want to say relax a little bit more, but like ease up and listen more to what my body was telling me.

Diego Colón:
I think there is a follow up question there. Is there anything you did to help? I heard you talk about sort of like finding humor for yourself. I heard you talk about sort of like eventually coming forward to talk to your supervisors about it. Is there anything that helped you to combat the stigma at work and home? What ultimately helped you get the treatment plan in the workplace accommodations to help you out?

Ashley:
I would say as a police officer, within I want to say six months of starting, I suffered another concussion where I lost consciousness. And from there I obviously had to be off of work because they were very careful with their protocol and like rehab and stuff like that through their private doctors. So that was an easy door to kind of open to be like, all right, I already had this one really bad one. Now I had this one. Things are not looking good in my favor of like I wouldn't say like getting better, but I'm probably going to have more issues going forward. And just keeping that line of communication open and saying, I just had this second concussion. I have to be careful. And knowing in my head too, I need to think about things before I do them, like is this a safe situation for me to be at alone, or should I wait for a partner or something like that. So yeah, it's I guess, I don't know, like it could go either way.

Melissa Farmer-Hill:
Karen, I have a question for you. And one of the things you said earlier, I'm so glad that you mentioned it, because migraine and headache are things, wounds that we can't see. And I think it's so important that you brought that out, so thank you. But my question to you is how important is it for someone with headache or migraine to have a provider who actually listens to them and works with them to get the right treatment?

Karen Williams, DNP, FNP-BC:
That's a great question Melissa. And I would say it's a team approach. And so, the patient needs to be able to talk with the provider, feel comfortable, and talk to them about all the symptoms that they are having, in addition to what treatments they've tried, whether they be over-the-counter treatments or those types of things. So again, it's that partnership. And if you're not feeling comfortable with what the provider is saying, then it makes it harder for you to be able to be honest and just come forward with all of the symptoms. So that's really important.

The other thing too is it's individual. And so, what works for one person may not work for another. I used to tell my patients, if you had a twin who was exactly like you and you came in and you said, this is exactly what works for them, I would go, okay, let's try that with you. But otherwise, I can't. It is so individualized and it may mean that we need to do more than one treatment, should definitely be on an abortive or something that stops the current pain and also the other symptoms that go with the migraine, but then possibly a preventative. And some of that may be looking at ways to reduce areas that increase the possibility of that migraine in a work situation like Ashley talked about with the bright lights.

So, if you're in an office setting, being able to set your computer to nighttime can be helpful. But also, maybe if you've got fluorescent lights overhead, getting some sort of shading to help with that, or getting special glasses that can help with reducing that bright light. Maybe noise will set you off, or

smells. Often, fragrant flowers or candles or perfumes or tobacco or those types of things, they can really set a person with migraines, whether you've had it from a head injury or just regular migraines. The migraine brain is definitely a brain that is more sensitive and likes to stay on a schedule. And I don't know Ashley if you had to work different shifts, but that's also another area of accommodation that may need to be looked at, is getting people on one solid shift, hopefully during the day, so that they can have a continuous schedule.

And hydration, again, as a police officer, you probably can't always get the fluids in that you need or get your breaks so that you can eat a balanced diet, those types of things. So those are all things to look at with the type of work situation that you're in. But again, talking with your provider about that, who could possibly write those accommodations for you and give it more validity so that it's not just you saying hey, I need this. It's actually, no, this is medically necessary for me to be able to continue to do what I would like to do as an employee.

Diego Colón:
Incredible advice. Thank you so much for that. Ashley, hearing all that great advice, I think it's a great idea for me to ask you, as somebody who has lived through this, as somebody who has worked through this, gotten the care they need, gotten to a place in their work where they got the accommodations that they love and is helping on their treatment plan, what would you say to a veteran to help them internally combat the stigma that they're facing, at all intersections of their life, in their veteran-ness, in their gender, in their race, however? What do you say to them to encourage them to push through?

Ashley:
My biggest piece of advice is find a workplace that is 100% supportive of your medical history, your medical illness, your mental illness, if you have anything along those lines. And just kind of feel out if they're going to be supportive because you don't, I don't know what I will feel like tomorrow or this afternoon. So, I think that's like the biggest part. And then also being vocal about your limitations. I think there's a fine line between like sucking it up and saying like I don't want to do this today. So, you need to just find out exactly like how much brain power or thinking is going to go into this. Am I going to be able to do it? Am I going to see this project through today, or is it better off putting it off till tomorrow when I'm feeling better?

I like to just tell people off the bat of like my head injuries. Because I just feel like if they see it up front, then they kind of know a little bit like backstory of like what I'm talking about or probably if I like forget something. Maybe I shared too much information, but so far it's worked well with me. And then make connections in like support groups because it is really hard to deal with and we're such a small population of people. I mean, I know there's many people that experience headaches and migraines, but within the veteran community, that's an even smaller piece. And there are support groups out there.

And then lastly, just know your rights within your workplace, know your rules and policies and where you can advocate and when. It took me a while. I mean, we had talked about this at the conference, to find a job that had really supportive leaders. My previous job actually denied my VA accommodations and terminated me because of my migraines. So, yeah, it was a lot. It was a lot to go through because obviously that didn't help how I was feeling mentally and whatnot. So, I am very fortunate that I found a place to work that they are awesome, like very supportive.

Melissa Farmer-Hill:
Ashley, thank you so much for those nuggets. I mean, I definitely know. Thank you for your story and your transparency and just being willing to share it with us. I think a lot of veterans who are listening probably saw themselves in what you described. I know some of the things that you had gone through, some of the things that I've gone through, I mean, that shared veteran experience. But thank you so much. What you had to say today was so valuable.

Diego Colón:
Absolutely. Karen, I'd like to take a step back and talk about sort of like why these experiences are so common. Why is this part of the culture? What can we do to combat it? And how do we get veterans to lead the charge on that?

Karen Williams, DNP, FNP-BC:
That's a good question. I think Ashley answered a lot of that when she talked about the self-advocacy and making sure your work environment understands what's going on. Some of that self-stigma or the internalized stigma, I think is important for people with migraines, especially if they've had concussions, those types of things, is something that they need to have addressed, whether that be with somebody from mental health, maybe psychology or social work. But it's definitely part of the issue with the migraines is I am not able to do this because of the migraines, and therefore I'm a bad person. Or but you also have that external stigma or what they call in one of the articles that was written is the enacted as far as people think that you're trying to get something or get out of something because of the migraine.

Again, they can't see it. They can't see all of the issues that go with it. I mean, the headache phase is one part, but you can have that brain fog, you can have that nausea, you can have that hangover effect that it will bring you for a whole week. And making sure that people understand I'm not making this up, these are true symptoms. I need your help with it. And sometimes it's the family members who are the worst at supporting you because they're like, yeah, yeah, another one. And so, making sure that the family gets the education they need or that the healthcare provider gets the education they need.

And there are some wonderful sites that can help with that. One of the main sites I found was Health.mil. And it talks about TBI and there's education for both the patient, the family and I guess three, and the provider as well. So that is really important. But minimizing the symptoms is not a good way to do that. You need to be able to get the care that you deserve because you're not alone. Sometimes, especially in the military, somebody else needs it more. And that is not the case when you are trying to do your job. You need that care just as much as somebody else as well. So, advocating for that's really important.

Diego Colón:
Thank you so much, Karen. I really appreciate that. I've got one final question for you before we sign off on this episode. If someone, I think Ashley talked about this a little bit, but if someone out there is listening to this podcast and they see themselves or they hear themselves in this conversation, what's the first step you want them to take?

Karen Williams, DNP, FNP-BC:
If they're a person that has those migraines or different headaches or things that are keeping them from doing their job, keeping a calendar is really helpful. And documenting the days that you don't have a headache because you may have more than one type of headache. In addition to that, advocating for yourself and finding the proper help because you do deserve the care. You are not alone. And as Ashley said, it's a smaller unit within the veteran community, but it's still there and it's becoming very well known. You just have to find the right source in order to be able to get that help that you deserve, and so that you can get back to the quality of life that you deserve as well.

Melissa Farmer-Hill:
So I think there's some things that we definitely need to take into consideration.

Diego Colón:
Oh yeah. The takeaways.

Melissa Farmer-Hill:
Yeah. The takeaways. Ask yourself this. Am I minimizing my symptoms? Am I telling myself to just push through? I think we talked about that in detail today. Am I afraid of being judged? You know, in the military, most people are A-type personalities. And we don't want to be judged except for being awesome. But being awesome is taking care of yourself. Consider that.

Diego Colón:
Absolutely right.

Melissa Farmer-Hill:
Also, am I comparing my pain to someone else's? I think Karen, she laid it out for us today. Every individual, even if you were twins, there're different diagnosis for everyone, so it's a case-by-case basis. And then am I avoiding care because I don't think I deserve it? And that is big, especially just from my personal experience as a veteran. Transitioning from active duty to veteran status, I thought it was only for people without limbs and things like that. I thought that they needed to care more than I do, so I can relate. This was a powerful episode.

Diego Colón:
It's such a false narrative to have that belief of like, there's only so much care to go around, like it's pie, right? Like there's only so many slices of doctor to go around. Requesting accommodations, Ashley touched on this a lot, is not weakness. It's super important for your journey. Finding providers, a team, Karen and Ashley both mentioned finding providers and a team, is deeply important to being successful in your care. Taking care of yourself allows you to show up for the people in your life, allows you to show up for loved ones, and allows you to show up at the workplace. It allows you to show up for yourself in the mirror.

Melissa Farmer-Hill:
And you know, Diego, like you said, seeking care is definitely not weakness. It's one of, I think, the strongest decisions that a veteran can make. So don't stop advocating. I think every episode we push that. Don't stop advocating for yourself. And you don't have to navigate this journey alone. I found National Headache Foundation you guys, and they are here to definitely help us as veterans through this journey.

Diego Colón:
If you're learning about stigma off this, or if you're having a more self-aware understanding of your own stigma, let this be the day that changes. It can change the second you decide to make a change and you deserve that care. You deserve that treatment.

Melissa Farmer-Hill:
But before we go, a special thank you to Dr. Karen Williams and Ashley for joining us today and sharing their expertise and their experiences. We truly appreciate you for being part of today's conversation. And be sure you guys to visit OperationBrainstorm.org. You got to go there. Go there right now. And don't forget to use the promo code OPB2026 for 10% off your next purchase of your order at SheroCoffee.com.

Diego Colón:
Yes, as we sign off, remember taking charge of headache starts when you're treating your health with the same commitment that you've given before, because taking charge of headache is part of the mission. Thanks so much.

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