

Taking Charge of Headache™
Episode 10: TBI, Headache, and Migraine After Service

Diego Colón:
Hello everybody, and welcome back to Taking Charge of Headache, a part of Operation Brainstorm, the National Headache Foundation's initiative for veteran focused free headache migraine resources. My name is Diego Colón, and I am the associate director of partnerships for the National Headache Foundation. And I'm joined here by my co-host.

Melissa Farmer-Hill:
Hello everyone. I'm Melissa Farmer-Hill, Army veteran, a person living with migraine. I am the founder of the Shero Coffee Club, and I am so glad that I'm here for this veteran focused conversation about taking charge and advocating for your own health.

Diego Colón:
Thank you for being here. We're excited that you're here as well, folks listening at home. Today's topic is something that I hear about a lot when I talk to non-veterans about my job, and I say that I help veterans with their headache and migraine care, I think the first thing that people assume is that I work with veterans living with TBI or traumatic brain injury. This is very true, and I like to tell everyone that ask me this question, yeah, I work with a lot of veterans, or I speak to a lot of veterans living with TBI, living with traumatic brain injury. So, today's episode is on that very topic to kind of understand the nuances of TBI.

Melissa Farmer-Hill:
And because we talk about headache on this show, we're going to talk specifically about the connection between traumatic brain injury (TBI) and headache and migraine, and what happens when those symptoms become part of your everyday life.

Diego Colón:
Some of the things we're going to touch on today is the severity of TBIs and how they can vary, some of the symptoms and how they are different from person to person, how they may appear, and sort of how traumatic brain injury can affect just like your everyday thoughts, your memory, your sleep, your mood, your sensory perception. Daily life is affected by traumatic brain injuries. You can be totally fine on the outside appealingly, but still struggling deeply on the inside. And today's conversation is bringing

us Ashley. Ashley, we're going to talk about how she navigates her TBI. Ashley is a Navy veteran. She works with the Illinois Department of Veterans Affairs. She lives with migraine following her traumatic brain injury and brings her own personal experience. Thank you for being here with us today, Ashley.

Ashley:
Thank you.

Melissa Farmer-Hill:
And we'll also be talking to Dr. Karen Williams, a nurse practitioner, 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. She has a clinical perspective on headache, migraine, TBI, and veteran care. Thank you so much, Dr. Williams, for being here.

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

Melissa Farmer-Hill:
Now, Dr. Williams, what is traumatic brain injury (TBI) and what happens? What are the short- and long-term effects of TBI?

Karen Williams, DNP, FNP-BC:
It's a that's a great question. There are different types of head injuries, traumatic brain injury. Our brain is about 3 pounds, and it sits inside this skull. The brain can slush back and forth or side to side. So, you can have a mild TBI, which doesn't mean the symptoms are mild. That's just the classification. And that is when you may have been knocked out just for a second or two or you're dizzy or your confused. And that can happen from a blow, a jolt to the head, maybe a car accident or getting hit over the head. In our service members, you can get over-pressure blasts or blast directly from the different types of IEDs or those different types of bombs that were going off. You can also have multiple types of ways to have that head injury.

Then you have moderate, which means that you're knocked out for a longer period of time. You may have some sort of bleed. And then you have severe, which means you are in a coma. And they measure this. It's called a Glasgow Coma Scale that they measure those different points. You can also have penetrating. And so, all of them can have different types of symptoms.

With a concussion, sometimes it can affect the eyes. So, you have trouble for your eyes being able to stay focused on the same thing. And so, you may have to go to not only optometry, but physical therapy to work on ways to strengthen those muscles back. You can have a lot of dizziness with that that could be related to the eyes, or it could be just related to the ability to balance, that's in the brain. You can also have memory issues with that. You can have speech issues with that. You can have poor sleep. And of course, different types of headaches with all of that as well. I may not be mentioning everything that you can have. Maybe in the beginning, Ashley said she had nausea and vomiting. Very common after

that. So, looking at all of those symptoms and making sure they're all being addressed is really important.

Those symptoms can persist as well. So hopefully you're getting the rest and the diagnosis right away and then be able to get the rest you need and go back on a graduated scale to doing normal activities. That can be different for everybody. So, some people can recover quickly depending on where they had that head injury. But if you've had multiple ones, like Ashley said, it certainly can take longer. You can have those post-concussion issues that can last a long time.

Melissa Farmer-Hill:
Thank you for sharing that definition, because a lot of people don't know, and I think the examples really help people to get more clarity on exactly what TBI is. Thank you for that.

Ashley, I have a question for you also. Can you tell us about your experience with TBI and when you first realized exactly what you were experiencing?

Ashley:
Yes. So I was at sea, and it was pretty rough waters. So, I was walking up a ladder and I lost my footing and fell backwards down the ladder. I hit my head on one of the railings, required staples. We were at sea, so basically they stop the bleeding and told me to go lay down for a little bit. Because of how long ago it was and just like everything that was happening, I don't really have a memory that sticks out of when I first realized what I was experiencing. Like I knew I had a headache, probably a concussion. But other than that, I really didn't seek any, or I didn't get any other medical care until we got back to land. And it was actually, my like first symptoms were like mental health related. And I've never had them in my life. And I just found myself like depressed and just like having racing thoughts. And I couldn't sleep anymore. And I've always been like really good at sleeping.

Once I was able to correlate those two, it helped put a lot of pieces together, but it takes a while to find the right provider that can explain all the different symptoms and whatnot that can go into having a TBI and how it can affect really any part of your body.

Diego Colón:
Thank you for sharing that Ashley. That is quite the story. Karen, when you hear Ashley describe those experiences in her story. What do you want veterans to understand about what happens after a TBI? And what from Ashley's experience kind of highlights the importance of knowing that?

Karen Williams, DNP, FNP-BC:
Thank you for asking that, Diego. Definitely getting help soon is the right answer. And unfortunately, Ashley did not get the right kind of help that she needed with that first one. So, sucking up those symptoms is not a way for your brain to heal. Our brains are very complicated and we need some time to heal. And you can look healthy from the outside, but still have issues going on inside, especially when you're the one that's kind of confused. You don't know how maybe to explain what's going on, but you can have those changes that others can't see. And again, remembering mild TBI does not mean the symptoms are necessarily mild. That's just the category that it's in.

Diego Colón:
That is important context. Thank you, Karen. Ashley, if I may, what strategies have helped you sort of manage your symptoms day to day? And what do you find that like works really well for you and your recovery? And how have those strategies kind of changed to help you learn more about yourself?

Ashley:
That's a great question. So, I want to say probably 4 or 5 years back, I started going to therapy just because I figured it would help with racing thoughts and everything. And my therapist was huge on, one of the first things she told me was, give yourself some grace. Like, these types of injuries aren't going to heal overnight, and they might last for the rest of your life, which can be a depressing thought to think about. They might cause worse problems in the future and whatnot. So, I think finding the time now to give myself grace when I know that like I really don't feel good and I need to go relax in bed in a dark room for a little bit so I don't get a horrible migraine. And just remembering that healing isn't linear, like it's not going to go, you know, you're not you're not going to keep getting better and better. Like, you might have a good day and then a couple bad days and a good day.

Personally, I found that therapy did, it helps a lot, especially with coping strategies and like reframing, because it can be really hard to sit there and think about, like, I have an eight year old son, and there's times that like, I have to miss some of his events because I can't sit up in bed because I'm that nauseous or I can't be outside, I can't be in the light, like it will kill me. And kind of like once you have your family behind your back on that, and it was hard for to explain to my son, but he eventually, caught on and knew that, like, I was suffering, even though I walk perfectly normal, I was suffering from an injury to my head that we couldn't see.

And making sure that I have a good calendar, my to do lists are so helpful. Having great communication with my medical team as I continue to explore new options, new medications, new products, and just know that like I am not using this as an excuse. This is something serious that happened to me and it could have been much worse. I'm like happy to be alive and mostly functioning. And I just try to like give myself, you know, like you're doing the best you can. And then remember, rest and water. Like, sometimes that's what your brain needs is just a quiet room. We're not doing anything and just some water. So, I try to go down my list and, yeah, reach out to my support groups and stuff like that.

Melissa Farmer-Hill:
Ashley, I'm so glad that you shared that. And I think where you said give yourself some grace is just so incredibly powerful. And as you shared your story and brought your family to it. I want to bring Dr. Williams into this conversation with how important is it for someone that has TBI symptoms to have people around them who understand that recovery isn't something that you can see?

Karen Williams, DNP, FNP-BC:
Right. And, Ashley, I think all of the different coping mechanisms that you have done are exactly what needs to be done. You have the support of your family, which is really helpful in order to get that education out there and your medical team. But you also understand yourself you can't do it alone.

And that's really important to have all of that in place. So, I would say Ashley's progress is a prime example of what works when you are able to get that extra support that you need.

Diego Colón:
Thank you so much, Karen. Ashley, as you mentioned, you continue to work, you continue to advocate for yourself, and you've built a life. You had a son. All while sort of managing the effects of this traumatic brain injury. What did it take to find a treatment approach that worked for you parallel to sort of like living your life, parallel to like the journey of life?

Ashley:
I've always been a huge advocate for mental health, and I think that's like forefront for some of these issues. Like, yes. I'm not saying that some people don't experience like a horrible headache or have a horrible migraine that's completely debilitating, but also the effects of mental illness that comes with that can be like a comorbidity I think it's called of a TBI.

So, once you navigate that and you kind of are able to really accept the path that you're on, it's much easier to deal with like the problems and know that you have the support of my family. And I do feel, I have the mom guilt, but my son, he knows when I'm not feeling good or he knows mom's laying in bed, is she okay, that type of stuff. So, I think like just getting that out there and just showing that like taking these steps is going is not going to fix the problem, but hopefully it can mitigate some of the circumstances to where I would go, like worst case scenario.

Diego Colón:
Yeah. Thank you for sharing that, Ashley. We have had conversations in the past before with not just veterans, but spouses who talk about sort of like how their children become part of their routine, how their children sort of adapt and understand their role when mommy or daddy has a headache or has a migraine. So, Karen, I'd like to ask you, how important is that kind of support? And not just in the home but from a provider. And how do we encourage someone trying to manage their traumatic brain injury and headache to advocate for the kind of support that someone is getting from their child, from their provider?

Karen Williams, DNP, FNP-BC:
Yes, definitely. So having good communication with the provider, which it sounds like Ashley has with her provider team, and it may be more than one person that's there. And again, Ashley brought up mental health. So important, especially when there are changes in mood, those types of things to help work with the different issues that are going on and work through maybe that cognitive behavioral therapy, that part. Not only can that help reduce the different types of headaches, but it also can help you function better. The other thing is, again, it's individualized treatment. So, what works for one may not work for the other. And having a supportive workplace is really important with accommodations, if they're needed. It can be really helpful and a way to get you back into the game and be utilized to the best of your ability, which gives you a sense of purpose as well, and that it's not just that I have this and I can no longer do anything. Ashley, I think is a great example of someone who said, okay, these are the changes that have occurred. This is how we're going to work through them. And that's really important

to advocate for that and know that you can still function. It may just be in a little different way or need some accommodations.

Melissa Farmer-Hill:
Thank you for that, Dr. Williams. Now Ashley, I have a question for you. Your story is incredible and thank you for sharing. But what would you tell another veteran who is struggling right now to find what works for them?

Ashley:
I wouldn't start the conversation with this, but it can be very difficult to kind of figure out exactly what works for you. But my first piece of advice would be don't give up. There's so many great resources out there that either the VA can connect you to your local VA department, Illinois Department of Veterans Affairs. The amount of support it's crazy that we're not aware of it as much. Like they come out to different resource fairs. You get connected to them. But you really have to like kind of go out of your way to find them. So just going to a veterans' resource fair. I mean, that's how I met Diego. And like we kind of like started talking about everything.

And also, just keep advocating for yourself. Like, it does not matter if 2 or 3 doctors tell you that it's all in your head and that you're crazy, and/or that it'll go away. Because you know what you're feeling. You've lived with your body your entire life, so you know when something's not right. And I hope that someone would always be able to find a community or support group. Like, feel free to look me up on LinkedIn. And I'm happy to either connect you with the resources or just be a friend to talk to on those hard days. Because I'm not saying that I don't have those days where I am in bed crying, because it is kind of hard to think about that I'm going to be managing these symptoms for the rest of my life. And I tried to reframe it in the best way, but it gets the best of me sometimes.

So just knowing that it doesn't matter if someone dismisses your symptoms, mood, or condition. It's how you feel. And you need to just find a right medical team that's going to work with you and make you feel heard. And then also remember that medicine keeps advancing. So, I may have a grim outlook, right? Not grim, but I might have that outlook like, oh man, I'm like always going to be dealing with these, like a bad headache. I don't know that maybe in two years there could be like a super pill that comes out and cures everything. Who knows? Our medicine is advancing so quickly, so I wouldn't get down on yourself. If you have a bad day, I like to say it's a self-care day. Make the best of it, do your favorite things and relax. And give yourself that grace. Like, that's what I mean. I live by that saying. And I tell my son too. He's only eight. But I'm like, if you're having a bad day and you need just time to yourself like take it. Life is hard no matter what age you are.

Diego Colón:
That is so real. That is so real.

Melissa Farmer-Hill:
It is. I was going to say, Ashley, that was great advice. And I chuckled because you said, when they have events and things like that, that's how I found National Headache Foundation through a military event.

And like you said, there's such a wealth of information out there, but you have to advocate for yourself. And, you know, we want to world without headache, right?

Diego Colón:
Yeah. Well, that's what we're trying to imagine for sure.

Melissa Farmer-Hill:
Imagine a world without headache and the medical advancements that are happening. So yes. Thank you so much for sharing your story. I think it's incredible.

Diego Colón:
I'm so grateful for all for both of you. And I agree. Sometimes when I talk about the resource fairs or attending and meeting people at the resource fairs, it seems cheesy, but I'm like, the real resources is the people I met along the way.

Karen, if I if I may, getting into a little bit more of the clinical side, why are headache and migraine attacks so common in a diagnosis of traumatic brain injury? And how are the treatments the same? How are the treatments different? How should someone look at them?

Karen Williams, DNP, FNP-BC:
Those are great, great questions. So definitely we do not have a certain way to treat a post-traumatic headache. Right now, the guidance is to treat it according to what symptoms it looks like. And most often there is a component of migraine in there. So, there is the nausea, the vomiting, the light sensitivity, the dizziness, the brain fog, all of those things in addition to the actual concussion itself. And usually about 80% of those with concussion have a headache. It hopefully resolves, but it may not. And then you go to treatments for that characteristic that those headaches have. Some look more like tension headache, and we may treat those different than the migraine.

But there's also a component of neck issues that can happen. And it sounds like with Ashley, hitting the back of her head probably made her neck go forward. And that may be another area that we need to look at. So that would be a cervical issue. But also, you can have nerves in the back of the head. This is one of my little pet peeves when people don't push on the back of the head. We have a set of nerves back here called occipital nerves. They give a sensation to the front of our head. And when we whack back there, we really irritate those nerves. And that can give you that bad headache in addition to the migraine itself. So, doing certain treatments back there, such as occipital blocks or working with physical therapy to relieve back there is helpful, maybe ice or heat as well.

There are a lot of different treatments that are out there that we use for post-traumatic headache, some of the newer migraine medications, but also some of the neuromodulation devices that are out there. And as always cognitive behavioral therapy can be helpful to understand what triggers or things are contributing to the headache that we can resolve. Maybe we can get rid of that. And as Ashley said, drinking lots of water, staying hydrated is very important, getting the right amount of sleep and a proper diet. So those are all things that can help in treating it.

But then if there's other symptoms that you have, such as the difficulties with words moving on the page, then there's an issue with the eyes in coordinating together. And so, getting special help for that is helpful. It's called ocular motor dysfunction. And we see that a fair amount in post-concussive patients. And as I mentioned before there's different strategies to help with that. But if you used to be a person who read total novels, but now you're down to like reading one page and then you're starting to get a headache, possibly there's something going on with the ability for your eyes to stay focused on the same thing at the same time.

Melissa Farmer-Hill:
For the veteran who's listening and thinking, that sounds like me, when would you recommend Dr. Williams that they see their healthcare provider?

Karen Williams, DNP, FNP-BC:
After an incident you should be seen by somebody. If you were dazed or confused, you need to be evaluated by somebody. That does not mean you need to go right to the emergency room, maybe the urgent care, but you do need to be evaluated. And that does not mean you need necessarily imaging. It depends on other types of issues, say you're on a blood thinner or those type of things, or you're having these symptoms that are getting worse. Maybe you were very conscious when you came in, but now they're starting to see that you're not staying awake, you're having more issues. Those are signs that you need more imaging. But getting that help right away is important.

When the headaches persist, making sure that maybe you're getting something that helps prevent them, but also treating them. If you're having a change in your symptoms, maybe you're having more issues with concentration, you're not sleeping well, those are other things. And symptoms that are interfering with work or your quality of life, especially if you have family members that you're trying to help or take care of, whether it be children or other family members, and you're not able to do all that you used to be able to do. So, seeking the help early is really important so that these symptoms don't become more severe.

Diego Colón:
Karen, if I might ask, when I talk to veterans at events and they talk to me about sort of like their treatments, I feel them kind of circling this idea of getting back to normal, which in a lot of instances of medicine and a lot of instances of health, like when you are sick, you do something to get better, to bring you back to normal. What do you want veterans to understand about recovery in dealing with a traumatic brain injury and headache and migraine? Is there a point where someone should feel like they're supposed to live in this back to normal place?

Karen Williams, DNP, FNP-BC:
That's a good question. That is individualized. I will say for some people they recover completely. Those headaches resolve. Their symptoms resolve. It depends again on the extent of the head injury itself. But in addition to that, there may be a new normal. And that is something that can be a little hard to deal with. And that's not only in head injury. That can be in anything. You know, there's people who fracture an arm and it heals, right? You put a cast on it, it heals and you do some physical therapy, you

restrengthen, and you're back. But there's others who now require surgery, and it may be a little weaker now, or they can't do all the things they used to do. And so how do you deal with that?

Again, going back to mental health or talking with other people saying, what is that new normal? And that pattern can be different for everybody. As Ashley had said, it's not linear. Everybody can be a little bit different. You can take two steps forward and one step back depending on what else is going on.

I did want to bring up just a couple of places that you can get more education for that are really helpful. Military wise there's one called Health.mil, and they have a whole section on TBI, resources for not only the providers, the service members, but also the family members and caregivers if you're like that. A couple of other sites, there's the Brain Injury Institute, and there is the CDC, all have information on that and would be quality places to look to get extra help for those other questions that maybe we didn't answer today or they need reinforcements.

Diego Colón:
That is all great information, Karen. Incredible resources and honestly, a smooth place for me to transition into talking about Operation Brainstorm, because if you have been to these sites that Karen recommended and you are noticing some similarities in your TBI and you're also feeling some headache or migraine symptoms, definitely check out OperationBrainstorm.org. Get one of those headache diaries that we got on there. We have apps on there. Keep track of your symptoms, monitor them, see what changes. And schedule yourself a dedicated appointment. When I say dedicated appointment, it means you are going into your healthcare provider to talk about your headache, to talk about your migraine specifically, how it's been affecting your life, whether it's work, sleep, any other daily activities. And you can ask about treatment options. And you can also find some treatment options available on Operation Brainstorm. Some of the resources there are very helpful, as well as the stories of folks who are on that website as well that shared their stories with us and shared how they got treatment and how they got the accommodations for their headache and migraine.

Melissa Farmer-Hill:
And here's something that you should also remember. You may not be able to see a brain injury, but it doesn't make it any less real. And one important thing for you to also remember is you don't have to do it alone.

Diego Colón:
Absolutely. Getting a traumatic brain injury might be a chapter in your story, but it's not the whole book. If you're living with a headache or migraine, cognitive changes, other symptoms of TBI, you deserve to be heard. You deserve to get that treatment. Make sure that you do. Make sure that you advocate for yourself.

Melissa Farmer-Hill:
Ashley, we want to thank you. We really appreciate your honesty and your willingness to talk about something that so many veterans experience but may not always feel comfortable in discussing. And Dr. Karen Williams again thank you for joining us and helping us better understand traumatic brain injury (TBI) and its connection to headache and migraine.

And thank you for joining us here at Taking Charge of Headache. And remember, your symptoms are real. Your health matters. And you don't have to navigate this alone. And don't forget to use promo code OPB2026 for 10% off on your purchase at the Shero Coffee Club store at sherocoffee.com.

Diego Colón:
Thanks for spending time with us here today. And until next time, keep advocating for yourself. Keep getting the treatment that you need because taking charge of headache is part of the mission. Thank you.

Thank you for watching. Taking Charge of Headache™, a podcast brought to you by Operation Brainstorm™, an initiative to support veterans living with headache and migraine through education, resources and community, by the National Headache Foundation in collaboration with Shero Coffee Club.

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