

Episode 184: How “Caring For Women With Migraine Benefits Everyone”

Lindsay Weitzel: Hello everyone, and welcome to Head Wise, the videocast and podcast of the National Headache Foundation. I'm Doctor Lindsay Weitzel. I am the founder of Migraine Nation, and I have a history of chronic and daily migraine that began at the age of four. I am honored today to tell you that I am here with Doctor Dawn views. Hi Doctor Bruce, thank you again for being here.

How are you?

Dawn Buse Hi, doctor. Myself happy to be here. And hi to everyone who's joining us today.

Lindsay Weitzel: Doctor Buse is a repeat guest that we all love. She is a clinical professor of neurology and a psychologist who specializes in headache. She's super well known in our community, and we are having a very special episode today because Doctor Views, recently was awarded the Women's Health Science Award from the American Headache Society. She has participated in many studies of women with migraine, as well as caring for women with migraine as a headache expert psychologist.

I also recently learned that Doctor Buse is the most published female in headache medicine. Which is really exciting. so welcome to you, doctor views, and congratulations on your award. When you receive this award, you are asked to give a presentation and you get to choose the topic, and you also get to choose the title of your presentation.

The talk you gave was called caring for women with Migraine Benefits everyone. I was lucky enough to be in the audience when you gave this talk, and the entire auditorium was deeply moved, and I truly felt that our audience on head wise,

deserved the chance to hear what was said in this presentation. So I want to thank you for coming and giving everyone the chance to hear this. And that's what we're going to talk about today. so, let's just start. doctor Buse, can you give us a chance to understand, can you explain to us, to our audience just how disabling migraine can be for women, but also for, you know, everyone, not just women?

Dawn Buse: Well, I'm guessing our audience probably knows, but migraine can impact all aspects of life negatively from the smallest daily decision to, you know, taking care of your kids, driving them to school, getting, getting into work on time, to big life choices, whether you're going to have children, getting married, getting divorced, going to graduate school, accepting certain careers, opportunities, everything in between work, school, family, personal leisure, everything big and small, everything that does matter.

Everything that seems little. And in fact, the World Health Organization, has, in fact, in their recent Global Burden of Disease study, found that migraine is the second most prevalent disabling disease globally on the whole planet. And it's actually first for women aged 15 to 49. So, we have the stamp of approval from the World Health Organization that, yes, migraine is truly disabling.

And in fact, I know you've had my colleague Richard Lipton on before. Doctor Lipton will tell you of a time, 30 years ago, 20 years ago, when people did not consider migraine disabling, they thought a disability was something visual. Someone was impaired, they couldn't walk, they couldn't move. That was a disability. And there was a real fight that people had to do.

Researchers, doctors and patient advocates and scientific organizations like the National Society found it. National Headache Foundation, American Headache Society, the American Migraine Foundation all really, really had to make their best efforts to indeed show how disabling migraine can be. But I think our viewers already know.

Lindsay Weitzel: So, what I'd like everyone to understand what you mean. I want to give you a chance to tell them what you mean by the title of this talk that you gave for this award. Talk? Caring for women with migraine benefits everyone. What does that mean to you?

Dawn Buse: Well, I think that we know that women play really integral roles in the fabric of society. And this is not to downplay the important roles that men play. Men are doctors, scientists, researchers, fathers, husbands, all the good things and do very important things. So, I'm not negating their important role. I just want to focus on women for a moment. And we know when it comes to families, communities, workplaces, women are really right there in the fabric.

And when you take a woman out of the equation, let's take her out of the equation for four hours for an afternoon, and because she has migraine or for three whole days because she's had a longer attack, everything kind of falls apart about her. It's like you throw a rock into a pond and there are these ripples. It affects her children, her spouse or partner if she has one, or maybe extended family, or maybe seniors she's caring for, maybe a sick family member. Maybe it affects walking the dog.

And that actually is something that came up in our McAllister study, the Measuring What Matters of Migraine FDA sponsored study, where we did qualitative interviews and people talked about, I have to take care of my pets, how do I walk my dog if I'm out with a migraine? It also impairs workplaces. It impairs all the jobs that women do. Women provide a lot of caretaking roles in their careers and professions as well. They are often teachers, doctors, nurses, healthcare professionals, counselors, support people. They do all sorts of ministry of work and all sorts of work, like being pilots and flight attendants, and so much of the things that keep society running.

So, when you pull women out of that, it leaves a hole that other people try to fill, but it's not easy to fill the shoes of a woman. And so, when I'm saying that caring for a woman with migraine, getting her optimized therapy that maybe avoids attacks altogether and avoids that disability happening altogether, or at least the same extent helps everyone, those ripples help workplaces, communities, family societies. It helps everybody.

Lindsay Weitzel: I, I don't I don't get emotional on the podcast very often. But this talk, not only did it make me emotional then, but it gets me emotional to just even get started talking about it. I, sitting here trying to work and I have a ten-year-old son with chronic daily migraine upstairs because he cannot go to

school. And it's true, if you take us out of the equation at all there, it's not just us, it's our kids that may also have migraine that aren't being taken care of. It's very difficult. So, thank you so much for communicating this to the audience today. I think this is great. I think everyone's going to love it.

So, throughout your career, you've been involved in so many migraine studies. We have reported a lot of them here on headways. You shared data in your recent award talk from several of these studies that gather data on the impact and burden of migraine, including the Cameo study, the overcome study, and the one you just mentioned, which is my co-host. I know that you also talk with patients in your role as a psychologist.

What are some of the areas that women experience the negative impacts of migraine? Really? I know you went over them specifically, but do you have any right off the top of your head that are going to really have an impact on our audience right now?

Dawn Buse: Well, I think there's some big buckets. So, let's talk about family life. And that may start way back with dating and relationships, establishing a marriage, establishing a family, having children, raising children, and also maybe caring for an aging parent or a sick family member. Extended family, household pets, kind of keeping the household running. All of that is something that can be greatly impacted by migraine, and if a woman is maybe doing all that without support of a partner or extended family, that's really even maybe tougher. So that's I think that's so that's kind of family life realm. There's the work and the school and the financial realm. So younger it might be school and it's such an important time of development.

Migraine starts in adolescence for a lot of people, a time when not only do you need to be learning at school, but you need to have this social development, the time with the peers that kind of enjoyable, but also some of those awkward experiences. Those are all part of growing up, developing, becoming who you are. And so those are important times. And those times can be very impacted by migraine and missing out. So academically, socially developmentally. And then someone can go into career decisions and that can be greatly impacted by migraine. People might make choices based on having migraine. Like maybe I shouldn't go on for an advanced degree, maybe I shouldn't take a more demanding job role, or a travel role, or a role with variable schedules, or a role that's not flexible. And so, migraine may limit people's choices.

And then we know that some percentage of people with migraine, often the most frequent, severe, and non-responsive to treatment, types of disease experience that people have, may not be working at all. They may be occupationally disabled. They may be temporarily or permanently out of the workforce. And we've talked about this before together, you and I. That's something that's not taken lightly by anyone. Not only does it have major financial repercussions, but that's also a major kind of identity and purpose and passion repercussions as well. So those are just some of the ways that we hear women talk about impacts of migraine.

And I'm going to leave one more bucket of the enjoyable things in life. Vacations, holidays, fun. Loud, bright movies, bright beaches, loud parties, concerts, time with children. We do hear people talking about planning for a vacation all year. And then when the vacation comes, they're hit with a migraine

attack, and they spend half of the vacation in their hotel room while the rest of the folks are out doing whatever. So also, that enjoyable social hobbies, leisure part of life.

Lindsay Weitzel: Right. So, let's, trace back a bit and go into some more detail on this data and your experience. And I wanted to start with the impact that these people that you spoke with felt that my or these women particularly, that you spoke with, felt that migraine had on their education and career, especially if they had chronic migraine. What did you find in your research that you can pinpoint for us today on this topic?

Dawn Buse: All of these studies where people have a voice to share their experience of life with migraine. We consistently hear that school was disrupted, achieving college advanced degrees, if that's something that was in their path, was disrupted, that it can be difficult to be consistent at a job. Sometimes they get labeled as being unreliable, especially if there's not a lot of flexibility. And that flexibility often doesn't happen in a lot of jobs. People need to be there at certain hours.

There may not be flexibility in when they can come in, when they can leave, if they can take a little downtime in the day, so there are all sorts of jobs that just may not work well for people with migraine due to these various reasons, due to the occupational environment, what's around them? All sorts of things, whether someone's willing to make accommodations or not.

So, we really hear about migraine limiting people academically in the workplace. We hear a lot about guilt and embarrassment and the struggle that happens with both bosses and coworkers, sometimes with people not being accepting, the person with migraine not being able to participate or to stay or getting something done, on time, that can really be a struggle and can lead to negative feelings. It can lead to poor performance reviews, you know, hopefully, you know, as you and I always advocate, the person with migraine has rights. It is protected. And the American Disabilities Act that you should have accommodations.

So please always remember that if you're getting faced with these kinds of challenges, you're getting not getting accommodations or you're having repercussions, but let's say colleagues, colleagues are different boat. You know, that's more just that someone's giving you a hard time. Or maybe they don't even say anything, but you feel that resentment that you feel, the negative experience.

And then people ultimately their finances are certainly impacted, which makes everything in life harder because you need you need your income to support yourself and your family and whoever you have to support. So, all of those everything can be impacted negatively by life with migraine.

Lindsay Weitzel: Okay. Well, let's move on to what these women said about the impact on their relationships and their families. I find that one particularly difficult. What did they say there?

Dawn Buse: Well, this is an emotional topic. You're a mom. I'm a mom. Yeah. You can imagine how it feels to not be parenting the way that we would like to, that we think we should, or we think that's ideal. A really large percentage of pair. It's still very guilty that they are not being a good enough parent. They

could be a better parent and it's due to migraine and those rates increase with more monthly headache days.

So, from the lowest frequency to the moderate frequency episodic migraine to high frequency episodic migraine to chronic migraine, we see 70 or 80% of respondents saying, I'm not the parent I want to be because of my okay, we see guilt, right? Shame, embarrassment, depression, anxiety, all of the above around parenting, missing out, feeling that they're just not there for their children the way they'd like to be.

We also see that extend to feelings with partners or spouses, or other extended family feeling that you're letting people down, that other people have to step in and help or fill the role, or that relationships kind of get permanently imbalanced. More of a caregiver or caretaker role, or always that this person's always stepping in and this person's not doing enough. And those imbalances can lead to a lot of negative feelings in relationships. So those are all commonly reported experiences.

Lindsay Weitzel: Okay. Well, to get even more specific, this one is actually very difficult for me because I have a child with chronic migraine. He actually has daily migraine. And I also have an adolescence. So that's why this was difficult. You were involved in something called the CaMEO Family Burden study, where you sent separate surveys to adolescent aged children and also partners or spouses of people with migraine, as long as everyone consented and agreed. What are some of the ways that adolescents felt that their parents' migraine impacted them?

Dawn Buse: Well, this is hard for parents to hear. Yeah, the rates of depression and anxiety were higher among those adolescents with parents with migraine, and that's from that's from, a couple different studies, and that always makes us feel guiltier. In the CaMEO study, adolescents did mention things like with a parent with migraine that they would need to be quiet at home, maybe they couldn't have friends over, they would miss some school due to their parents' migraine because the parent maybe couldn't get them to school. They'd be late to school, maybe not having homework done or projects done, or being able to participate in extracurricular after school activities to the same extent, or sports because of other, because their parent might have a harder time, driving and picking them up or being there for them.

So all sorts of, kind of range of things the adolescent would like to do or needs to do being impacted as well as emotionally struggling with feeling worried for their parent, and in some cases feeling, sad that their parents not kind of physically and emotionally there with them at times that they want them there.

Lindsay Weitzel: Yes, I have seen that in both my kids. Luckily, I feel like they're getting to play. I'm getting them to places, but I've definitely seen the emotional impact of me not feeling well, and so that is that is definitely a thing. And it's sad and a kind of tearing up as you talk. So, I'm so glad we're addressing this. I'm sure there's people in our audience that are feeling that, and I think that it's so great that this day and age, we talk about it because when I was younger, no one talked about these things. And I had a father with chronic migraine.

So, how did the partners or spouses of these women say that their lives were affected?

Dawn Buse: So, partners and spouses talked about needing to make shifts in their schedule to kind of pitch in and how that might affect them in their own jobs, their own finances, their worry about covering the finances for the family financially and decisions they would make in the workplace. Like, could they take a traveling job? Could they take a job with more time commitment or certain hours or greater stress or greater flexibility? Partners or spouses did talk about how this affected them in the workplace, as well as emotionally.

They feel worried for their partner, a spouse they feel sad. And then generally there's just kind of missing out. We all know that with migraine, you do miss out on all sorts of moments and events and activities. Partners felt sad about that. They also would sometimes feel this imbalance in the relationship where it started to be like more of a caregiver or a caretaker or than more of an equal relationship. But something that's really important to say is that we also surveyed the people with migraine, and the people with migraine actually estimated the impact to be higher, right? Greater, worse than it was when the teenager or the partner reported.

So, it makes me think that the person with migraine is living with more guilt, worry, and anxiety than the family members are actually feeling. And, you know, as a reminder, children are resilient. Children grow up in all sorts of hardships, globally and over the centuries, and get through it and survive. It often makes them more kind and compassionate and caring individuals.

I know as mothers, we beat ourselves up, or as parents in general. But there's something to remember that children are resilient and that there are some things we can do to ease the burden on the family members. We have a whole topic, a whole podcast topic on how to kind of ease the burden and having backup plans and other things that you can do.

Lindsay Weitzel: Getting care about caretakers. Get us exactly giving them very specific ways that they can help, even if it's young, young children giving them a way you can help. You know, if you could bring mommy a cold washcloth right now and whisper really quietly a story that would make mommy feel better. Well, hopefully it makes you feel better. But even if it doesn't, now, you've given this child a sense of, here's something I can do to help mom.

Dawn Buse: Exactly. Child. Feel better, feel less worried. If your child's feeling better and less worried, you're going to feel less guilty. So there are things that you can do both in parenting as well as in partner relationships, to try to keep them more on an even keel. Like what you said, caring for our caregiver. So always right, I know. Remember to maybe when people are feeling a little bit better about giving some extra attention and gratitude and right time to the caregiver, to the partner.

Lindsay Weitzel: Right? My son used to when from the time he was very little, he had some sensory. He had a dragon made of Legos that he was sure had migraine, and he would wrap it in a blanket and bring it to me, and he thought it was good luck when you had a migraine. And I don't know why it made him feel better so that even little, little kids can do little things that make them feel better. So I think that's a

great way to help. I think it makes them better when you kind of expect, as the person with migraine, you expect the help that makes people feel better, right?

So moving on to stigma, which is just such an important topic, you and your colleagues have been studying migraine-related stigma as well, and you published a study where some of the data was collected in New York City headache clinics, as well as the overcome study, which was just published in neurology, to my understanding, this week, I think. Is that correct?

This week, when we're recording, probably not the week that it's actually being released, but it was very recent. Believe us, believe us on that. Can you tell us a little bit about the implications of, of stigma for people with migraine because, and don't let your eyes glaze over because it's so much more than what you're what people think this is. This is actually impacting our health. So I love I love this data. Go ahead.

Dawn Buse: Right. Okay. So stigma is there's a bunch of versions. One type is a self stigma. That's where you think I'm really not worthy. You feel guilty. You feel embarrassed. You feel ashamed of your own self, in your own actions due to having migraine. And lots of people will feel that it's pretty common.

And so when you have to cancel attending an event or you can't fulfill a responsibility at work, or you don't parent the way you want to, you feel personally ashamed and guilty about that because you have migraine. That's a self stigma. There's also an external stigma. It's how others view people with a certain disease or condition. And so that would be people in the general society saying, oh, people with migraine, they're faking it, they're lazy, they're using it to get out of work. It's kind of an external stigma. And so we looked at a couple different types of stigma.

And first we did this in headache clinics, led by Betsy saying, and Richard Lifton and myself and others in the clinic. And we found that having higher rates of stigma, experiencing this self stigma was associated with more depression or anxiety, more catastrophizing, more disability. And then we looked at these same kinds of questions in the overcome study, which was a mailed or an emailed survey to more than 59,000 people with migraine in the US, the largest migraine survey ever conducted.

And we asked people how they felt others viewed them. So it's kind of an internal view of others' perceptions of you. And we asked questions, do they think that others view them as using migraine to get out of things? So a secondary gain or that others don't understand how painful and disabling migraine can be and others minimize it and we found so many results that we expected a couple that were surprising.

So certainly higher stigma was related to more disability. So more missed work, school, family, social leisure. You know, you wonder which way that goes. Is it because someone feels stigma that they don't engage in all those things? Or is it that the more they have to miss, the more stigmatized they start to feel right? Also, it was associated with interattack burden. That's what people feel between attacks. How much do they worry about the next attack? How much do they change or cancel plans or not make plans in the first place because they're worried about that attack?

So the more interattack burden they felt, the higher stigma they felt like, and we don't know which one comes first or which is the chicken or the egg care, but it makes sense and worse.

General quality of life with stigma. So, this all makes sense now. All of these things get worse with monthly headache days. So those were things we expected. But there was a finding that really surprised us. We expect that life gets harder with monthly headache days increasing. Certainly, in that life with 25 or 30 headache days is a lot more challenging than life with two monthly headache days.

But we actually found that no matter what the number of monthly headache days, people with stigma had worse quality of life, whether they had 30 headache days or two headache days, compared to some without stigma. So someone with two headache days a month with high stigma, actually globally, has a worse experience with international burden on quality of life than someone with 30 headache days with no stigma, some with daily headache, but doesn't believe it's their fault, that doesn't feel less than that, doesn't feel guilty, has a better quality of life than someone with only a couple headache days per month who carries this burden within them.

So that's a really big deal. Yes, that makes me really want to work on eliminating the stigma individuals are feeling so that everything can feel a little bit more in their control. A little lighter, a little better quality of life can feel better. And the burden, the worry between attacks can really do well. They hopefully also work on getting optimized treatment for them. At the same time, we also found that part of this puzzle piece, part of this puzzle, one more piece is that people with higher stigma were not seeking care. They were not as likely to see a doctor to get a diagnosis and to get medical treatment. And as we know, the migraine-specific medications are by prescription.

So that means you have to get to a doctor, and you have to get that prescription. So, we found that that stigma is a barrier to care seeking. And maybe those two findings go together. So maybe it is that people who have more stigma aren't getting care, and therefore their quality of life in general is worse. Right? But it gives us two ways. Now we can intervene. One, we need to hit stigma head-on. How can we address stigma? And two, we need to get people to talk to their doctor about migraine and make sure they have optimized treatment. So now we have two action items, and I really like ways forward. Rather than just talking about the problem, what can we do about it?

Lindsay Weitzel: Right. I'm glad you move forward with that because my next question, you keep answering my questions before I can ask them, because you're so good at talking about this, but I want to ask you so that everyone can really end on a positive note here.

What can we do with all of this information? How can we improve for ourselves as women, for other women, etc.? What can we do? We've already covered talking to our doctors, realizing it's not our fault, helping other people realize it's not their fault. I think that even those of us who work in the community are prone to self-stigma. Maybe not always going to our doctor as often as people might think we do. I think that if we really, really were honest with ourselves, stigma affects those of us who even work in the community. I think it's going to be a bigger and bigger topic as the years go on. So, what can we do?

Dawn Buse: Well, you mentioned some of the big ones. Let's get everyone to talk to their doctor about migraine and try to get optimized treatment, being medication, non-medication, probably a combination of all those things. We need to get everyone to try the treatments that they'd like to try and see if we can get to better outcomes for them.

But there's also things instead of always putting the burden on the shoulders of the person with migraine, there's things society should be doing. We need to be supporting women with infrastructure, including basic necessities, affordable childcare, affordable education opportunities, affordable healthcare, the basics, affordable medication, access to medication, affordable healthy food. We need to think about accommodations in the workplace and we do have those rights in the United States to workplace accommodations.

So, if you haven't asked for accommodations, that's something you might want to think about. There are some great talks that Lindsey has done on accommodations. You could also look on the National Headache Foundation American Migraine Foundation website and think about accommodations. And there might be ways that your job can modify so that you can still keep doing the job that you do. And it might be things like telecommuting, flexible or asynchronous work hours, childcare, some more flexibility in your schedule.

So, if you need it close your door. And if you have a door, if you have a room, if you have a place, you can go and either take a medication or get some water, lay down, close your eyes, rest and maybe not leave work for the whole day. But part of the day there may be accommodations at the workplace, and then also maybe accommodations in school as well. And a lot of times, we need to advocate for our kids with migraine. We may need to talk to the school nurse, the principal, even the superintendent. It's good to start with a medical letter from the doctor, the pediatrician, the neurologist, primary care doctor, outlining what some of the accommodations may be. A place for the child to lay down, the ability to leave the room right away to get treatment, the ability to have treatment available at school, the ability to keep water with her or him all day so they can stay hydrated, maybe the need to have an extra healthy snack break so they don't go as long without eating.

So, some of those accommodations at school, some of the accommodations in the workplace, supporting women with all the general infrastructure that can help women care for everybody else, so often a societal level, we need disability reform. And that's something that our patient advocate groups are working towards. The Headache and Migraine Policy Forum is working on that. Doctor Bob Shapiro has been tirelessly working on that. Lindsey, I think you've participated in headache on the Hill before.

Lindsay Weitzel: Yes. Many times.

Dawn Buse: Yep. There are all sorts of advocacy. The other thing that we need to do that by participating in headache in the Hill, you're supporting additional funding for migraine research. That's really important, reducing stigma, and having access to behavioral and psychological therapies and support when needed. But then the other great way to reduce stigma is just education support, like this podcast, like your work, like things that the National Headache Foundation, the American Migraine Foundation do, and kind of continuing to support each other because as women, we take a lot on we tend to feel quite guilty for letting anyone down. And we actually need to remember that we need to care for ourselves first so that we can care for all of those people around us.

Lindsay Weitzel: Yes. Put your oxygen mask on first is one of the best bits of parenting advice for everyone, but especially for people. Families with migraine, I feel like. So, I'm glad you said that. Thank

you so much for sharing this information with our audience. I'm so glad they got to see it here. It was so amazing to be in the room when you gave this talk. And just thank you for being here. And thank everyone for watching today. Please join us again on our next episode of Head Wise. But I.