



MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD-LEADING EXPERTS

TRANSCRIPT



STAYING HOPEFUL: TREATMENT BURNOUT IN CHRONIC DISEASE

DAWN C. BUSE, PhD



Introduction (00:05): There are areas that really enhance resilience: having that social support, working on your own health and well-being, staying connected, advocating, learning, growing, pushing for yourself, as well as getting out of yourself, as well — thinking about advocating for others, thinking about a passion that is outside of life with migraine, or helping other people besides yourself. And sometimes when we get so focused on caring for ourselves and we're going through such a hard time, it can be a real breath of fresh air to think about helping others.

Elizabeth DeStefano (00:43): Living with a chronic disease like migraine means a lot of different things, as we all know. And one of those things can be burnout, of sorts — whether that's because a highly anticipated new medication doesn't pan out, a previously successful one stops working, we've been fighting for insurance coverage, or we're incapacitated by frequency or severity of migraine. When we're worn out, we can feel our hope and drive to be well flicker. To help us navigate through treatment failure and avoid burnout is Dr. Dawn Buse. Dr. Buse, welcome back to the Migraine World Summit.

Dr. Buse (01:19): Thank you, Elizabeth. And hello to everyone watching. I'm honored to be part of the Migraine World Summit again.

Elizabeth DeStefano (01:27): Well, Dr. Buse, to start, what is a treatment failure?

Dr. Buse (01:32): So, payers or physicians or guidelines will use this idea of treatment failure to say how we choose treatment options for people living with migraine. And so when it comes to, for example, getting one of the newer classes of medications — for example, one of the CGRP-targeted monoclonal antibodies — a payer, your insurance, may say: "Well, before you go to that, you will need to have tried and failed two previous traditional oral preventive therapies," or "three previous traditional oral preventive therapies," or "one traditional oral plus one onabotulinumtoxinA," which is Botox. They may say this, and this is how they have set up their, kind of, stepping through the therapies. And a lot of that probably has to do with cost. The traditional oral therapies are all generic now. So that's a lower cost as opposed to the onabotulinumtoxinA or the newer CGRP-targeted monoclonal antibodies, which have a higher cost to the payers.

Dr. Buse (02:35): Now, I don't love this term "treatment failure" because I do not want this to sound like you failed in any way. I think that even though it's more of a mouthful, we should say: "This treatment failed you." The failure can be for two reasons. It can be efficacy. It doesn't work well enough; you're not getting enough reduction or prevention of migraine days. Or it can be tolerability — the side effects are just not tolerable. And if you've had experiences with any previous treatments, you probably know about side effects from some of them, which just didn't work for you. But what happens is that the traditional orals are traditionally tried for two to three months before we say that was a treatment failure — or it failed you, as I like to say.

Dr. Buse (03:24): So, imagine you go through one of those, and then you get back to your neurologist, your primary care, you get another appointment with your doctor. You try the next one. Now you've got another couple, three months. You probably had a month or two in between those visits. For many, many people — and for decades — the traditional oral preventives did help both in a good amount of prevention reduction of number of headache attacks and were either tolerable or tolerable enough. So, people made that choice like: "Ugh, yeah, I am feeling this side effect, but it's worth it for having the reduction of number of attacks." So people kind of lowered their expectations a little bit and made these trade-offs with themselves and their doctor about what they would accept. But as we had more treatment



options come into the space ... And this is true both for the preventive therapies, as well as the acute therapies — we now have also new classes and new types of acute therapies in the mix, and those also by insurers have this kind of stepping up through the various treatment options.

Dr. Buse (04:34): So, a guidance came from the American Headache Society who, in 2021, put out a consensus statement, which included the American Headache Society, authors, the board of directors, and other stakeholders, including patient advocates, including payers — a lot of people in the world of migraine read it, gave their input, and came to the best guidance that they could figure out that would both be helpful to patients and doctors, as well as be something that was realistic for payers, because it needed to be realistic. Otherwise, they may not be willing to follow it. That's something you can read for yourself. It's available for free, right on the American Headache Society website. It is the 2021 consensus statement on new therapies. And it actually includes all therapies — it includes the whole world of migraine treatment in one article. You can read it for free and then you'll have an idea actually of why and how your doctor's making some decisions. And you can even take it to your doctor and say: "Look, here's the guidance that came from the American Headache Society."

Elizabeth DeStefano (05:42): A good tip for a lot of us to empower us and really be more knowledgeable about what some of the options are and the guidelines out there. What sort of tolls, psychologically, does a treatment failing us often have on those living with migraine?

Dr. Buse (06:00): I would expect a range of emotions and probably more than one emotion. And sometimes that idea, that kind of coming down hard on yourself, is a really common feeling in migraine and in other medical diseases. We call that self-stigma, and we've been doing more and more research in this area. And it's very common among people living with migraine and other diseases — even though, you know, from Migraine World Summit and everything else you've read — this is a biologic disease with a genetic predisposition that has to do with neurochemicals in your brain.

Elizabeth DeStefano (06:36): An important reminder. When we are constantly working on our health — as can be the case in living with something, certainly, like chronic migraine — sometimes it can feel like the fight in us is burning out or fizzling a little bit. What is that burnout as it relates to someone living with a chronic disease? And what guidance, really, do you have to us about how maybe to manage it?

Dr. Buse (07:01): That's something that someone living with migraine or another chronic disease — or even an acute disease, a new illness — can certainly feel. It's exhausting. It is overwhelming. It takes over everything. And as we know, migraine is unpredictable, painful, sometimes relentless, potentially disabling to every aspect of your life — big and small. How could that not be emotionally exhausting? And so, when we think about exhaustion, we think about your resources. There's a really important concept called "learned helplessness," where Martin Seligman, a wonderful, brilliant psychologist, put animals into a situation where they — I'm sorry, this is gonna be hard to hear — they received a shock, and they couldn't get away. And then he lifted the gate and gave them a shock again. And after they received that shock so many times and couldn't get away, even though the gate was lifted now, they didn't try to get away.

Dr. Buse (08:01): So, the idea is you learn after being knocked down so many times, so many times, so many times, that you have this belief: There's nothing you can do to get out of it or make it better. So, sorry this is such a bleak conversation, but I wanted to explain psychologically



what can happen when you get beat down and hit down and disappointed so many times. And that can happen when living with migraine or another chronic disease. Now there is an opposite to that. And I know we're gonna talk about that in a moment. And we're gonna talk about how do you bring in resilience, how do you keep going, how do you, kind of, rise above this relentless experience of life with a chronic illness?

Elizabeth DeStefano (08:48): Well, before we do move onto that, what can you tell us about what impact that these sorts of feelings — that learned helplessness — can potentially have on health outcomes in managing migraine?

Dr. Buse (09:02): Learned helplessness is directly tied to depression and anxiety. It is a driver, a cause, and entirely associated with both depression and anxiety. When you're feeling either of those, it is much harder to cope with all the things that you need to do to live well with and manage your life with migraine. In addition, as we know, both depression and anxiety are comorbidities of migraine, meaning they come on kind of naturally along with migraine for a variety of reasons: They share some of the same neurotransmitters in the brain; they share some of the same genetic predisposition. So, someone living with migraine already has a propensity to also have this comorbidity of depression and anxiety. You add either one of those and it's just harder to cope with all the things that life with migraine throws at you.

Elizabeth DeStefano (09:59): A lot of what you've described that can go along with this concept of learned helplessness can also be very similar to actual symptoms of migraine itself. Is there any way to assess the difference there, make a distinction?

Dr. Buse (10:18): That's a great question that we talk a lot about in migraine research is: What symptoms are depression? What symptoms is migraine? For example, if you were to look up the criteria for depression in the *Diagnostic and Statistical Manual of Mental Disorders*, it includes things like low energy, loss of interest or pleasure in doing things, undereating or overeating — lot of things that are part of a migraine attack, as well. So, this is always challenging on how we measure and separate. And in a lot of cases, we just don't separate. We just know that they kind of travel together, but we can see the good news is that treating either one has benefits on the other.

Elizabeth DeStefano (11:04): Once we recognize this burnout of sorts as it relates to treatment or management of our migraine, what can we do to get ourselves in a better place? And how can we handle better those responses to a treatment failing us?

Dr. Buse (11:21): How are you resilient? There are quite a few things, but there are about half a dozen that really matter. One is a sense of social connection, social support. It may be within your migraine community. It may be without your migraine community. It may be spiritual, it may be friends, may be family, may be colleagues. Wherever you find it, it's a great benefit. The next one is taking good care of yourself physically. It's the sleep and the exercise or movement and the healthy nutrition and staying hydrated — and all of those things matter. The next thing that matters is having a passion or purpose in life. And one thing that can happen when living with any disease or illness is a lot of the areas of your life start to float away, and your life becomes a smaller and smaller circle of this disease, until some people feel like their main identity is being a patient. And their main purpose and things that they do is going to appointments and learning about and talking about their disease.



Dr. Buse (12:29): And so, trying to keep that sense of self that goes beyond the smaller kind of circle that can happen when you're living with a chronic illness is really important. And he has a really neat website, Dr. Martin Seligman, called Authentic Happiness. All of his validated instruments he's put on there. So you can go on and take, for free, questions about your resilience, your strength, your heartiness, things to work on, areas to improve. It's a really neat place to start looking at doing a little bit of self-assessment in this area and exploring it a little bit more. And his model of well-being is called PERMA™ [Positive Emotion, Engagement, Relationships, Meaning, and Accomplishment] model. And it talks about things like the purpose, the connection, your sense of self, all of these things. How do you keep living life, even though you are living with this chronic unpredictable, painful, debilitating disease.

Elizabeth DeStefano (13:28): So, I want to recap there a few very, very important areas you gave us to make sure that we're focused on — not just in the moment, but long term, almost as part of our comprehensive migraine management plan — social connection, attention to physiological conditions — you know, sleep, eating and so forth — and purpose and identity outside of our disease. And making sure that we're thinking of all of those as part of an overall care plan.

Dr. Buse (14:00): That's really important, Elizabeth. Thank you for summarizing. And one note I need to say is that whatever those things were for you before, they might be different now. It might be a new sense of social support, new people, new connections. It might be a different sense of purpose. You may not be doing the same career or job that you used to do. You may not feel like you're able to right now. You may need to think about putting your purpose and your passion elsewhere: be it a different type of career, be it a volunteer opportunity, be it something you do from home — something that you fit into what you're able to do right now. So, some of these may be changing from what they used to be. And it's OK to feel grief about that, to feel anger, to feel sadness. But we do need to let go [of] what you are not doing or can't do right now and look for other ways to meet those important areas of your life.

Elizabeth DeStefano (15:04): This is a great time to talk about hope. Personally, I struggle with how to truly accept migraine yet also continue to strive to minimize its impact on my life as much as possible. And the intersection of these two can be a little tricky — at least for me, a lot of the time. What thoughts do you have on how to balance acceptance of the disease with the drive to continually improve your condition?

Dr. Buse (15:32): So, the idea of keeping hope is really essential. We talked about that learned optimism, being really connected to feeling a sense of well-being in life. And there's a lot of ways to keep hope. And those are ... might include ... Obviously you're watching the Migraine World Summit, so you're staying connected, you're learning about what's new, what's coming down the pike, you're hearing from other people about what they've been through. All of that is really helpful. You're keeping informed, and that's one part of self-advocacy. That's really great. Keeping good communication with your health care professional. You know, half of the people living with migraine, in the United States at least, have actually not been diagnosed or even talked to a health care professional about their migraine. So, if you're in that camp, the first step is to get in to talk to a health care professional. If you're in a camp where you've already tried a lot of treatments, then you may be talking to your health care professional about : What else? What can I add on? What's new? What can I try?

Dr. Buse (16:37): And I would say stay open to not only medication treatments, but nonmedication treatments; be they behavioral, like biofeedback, cognitive behavioral therapy



[CBT], relaxation therapy, the mindfulness therapies, neurostimulation — there's various types of neurostimulation that are available — as well as the lifestyle pieces, which can really help with feeling well and living well. Those sleep, nutrition, exercise, social connection are so important. So that's the hope piece. But like you said, Elizabeth, we need to balance that with the realization, the reality, that this is a genetic predisposition of a biologic disease that is not curable. It's manageable, but it's not curable. We know more, we're understanding more, and we have more to offer all the time. But at the same time, I also want to say: Don't wait on that to live your life. Live your life today, in whatever way that is. With whatever limitations you might have. Start to think about, what can you do differently? What can you bring into your life? What can you modify or pivot so that you still have these areas that matter, even if it's different than what it used to be or what you would envision your life to be?

Elizabeth DeStefano (18:04): You mentioned resilience. Is resilience something that we are born with? Are there ways to cultivate it, to make it grow in our lives?

Dr. Buse (18:15): Yes, yes. It would be both. That some people have different personality styles — we're all born with a bit of certain personality styles. But it can absolutely be learned and cultivated. And Jon Kabat-Zinn has this great quote — he's a psychologist who brought mindfulness into chronic pain decades ago — and he says: "You can't stop the waves from coming, but you can learn how to surf." I think of resilience as all the strategies that are your surfboard. What helps you kind of get on top of these ... these waves that keep coming? What helps you stay resilient and top of it? And as I mentioned, there are areas that really enhance resilience: having that social support, working on your own health and well-being, staying connected, advocating, learning, growing, pushing for yourself, as well as getting out of yourself, as well — thinking about advocating for others, thinking about a passion that is outside of life with migraine, or helping other people besides yourself. And sometimes when we get so focused on caring for ourselves and we're going through such a hard time, it can be a real breath of fresh air to think about helping others.

Elizabeth DeStefano (19:35): I know a lot of people who work with and volunteer for Migraine World Summit say that very thing about what draws them to this work — being part of helping others who live with something they know is so tough and the satisfaction they find in stepping outside of themselves to do that.

Dr. Buse (19:52): Exactly, exactly. And there are more and more opportunities in the migraine community to connect today than ever before. A lot of it can be virtual, right from the comfort of your own home or wherever you are.

Elizabeth DeStefano (20:06): There's obviously no drug that we can take forever that makes us more resilient. You mentioned mindfulness, and there are some behavioral therapies or approaches that can, and also have some evidence in reducing migraine. Can you share some examples of these?

Dr. Buse (20:22): Oh, absolutely, Elizabeth. There are five therapies with evidence for migraine prevention and migraine management as well as helpful for resilience training. And you can read more about all these also in that American Headache Society 2021 consensus statement, because they are all mentioned in there, as well. So, it's lovely that they're mentioned in there right alongside the medications. And the big three with oodles of evidence include cognitive behavioral therapy, biofeedback, and relaxation training. And those may be done together. They may be done separately. Some of those you would need to talk to a psychologist — at least



traditionally, you would go see a psychologist, maybe a physical or occupational therapist for biofeedback training, or maybe a mental health therapist for some of these. But there are more and more options these days, as well, to do things on apps and to do things remotely and over the web, which kind of help for someone living with migraine who may have challenges getting into regular office appointments or challenges finding a provider. So those are the three that are very traditional with good evidence: cognitive behavioral therapy, biofeedback, and relaxation training.

Dr. Buse (21:38): And then we had two other types of therapies that had very strong evidence in other types of conditions and that more and more evidence has been growing for migraine management. And that includes mindfulness-based therapies and acceptance and commitment therapy [ACT]. The mindfulness-based therapies could include something that's kind of a combination of mindfulness and cognitive behavioral therapy, and it's called mindfulness-based cognitive therapy, MBCT. Or there's a mindfulness-based stress reduction, which I mentioned Jon Kabat-Zinn — when I mentioned the wonderful quote about you can't stop the waves from coming, but you can learn how to surf — and the mindfulness-based stress reduction therapy is what Jon Kabat-Zinn first piloted about 40 years ago now for chronic pain and has since expanded into a behavioral therapy for migraine, as well.

Dr. Buse (22:31): So where to start with some of these? Sometimes people say: "Well, which one should I start with? Where should start?" They are all going to teach slightly different things, but also overlapping approaches. And what I would say is to look for a provider — you can start with finding a psychologist — and find someone who is comfortable with cognitive behavioral therapy. And if you can find someone who has biofeedback equipment — it's just a really neat experience to get hooked up to biofeedback equipment and actually see your body in action under stress and under pain. We can see that fight-or-flight response happen and then learn how to kind of calm and relax the nervous system. And I like to think about this as exercise for the nervous system. And this is really resilience training. As you get hit with a stressor — you get hit with a painful attack — how do you kind of bring everything back to a healthy balance? So, these are five different ways with evidence that you can start to not only improve migraine management, but also enhance your resilience.

Elizabeth DeStefano (23:40): Living in fear of the next disruptive migraine attack is common, whether because of concerns about how we might not be able to show up for people in our lives or for events in our lives, or the risks of becoming impaired if we experience an attack at a certain time. What might be important, perhaps along the lines of behavioral therapies, in managing this type of "anticipatory anxiety," as one of our viewers, Garry, refers to it?

Dr. Buse (24:09): Well, well said, Garry. This is incredibly common. As you said, Elizabeth, why wouldn't it be? We're all intelligent. We know that we've had these attacks in the past that are painful, debilitating. They just might come out of the blue. Or you might know they're coming and they disrupt all sorts of important things in life. Why would you not be worried and dreading when this is going to happen again? It is absolutely logical to have this anxiety. Unfortunately, that anxiety itself can be uncomfortable, stressful, make it hard to sleep, make it hard to make plans, make you doubt yourself, kind of have that anxiety feeling in your body. So, the anxiety itself now becomes an additional unpleasant experience as well as that attack that may be coming in the future. And so we can call that "anticipatory anxiety," "interictal anxiety," and it is really important to notice if that's becoming more of a challenge for you, if it's becoming more present and something you're experiencing — and thinking about how to



manage that anxiety: maybe through some self-talk; maybe through some relaxation, some breathing, some meditation; also through planning — Who can I count on? Who can I ask?

Dr. Buse (25:30): The more you have your plan B in place, the more you can kind of start to feel a little bit more relaxed knowing: Yes, it's gonna be painful and unpleasant and take time out of your life and steal time and experiences, but if you've got that plan B in place, that's going to help a little bit. And one thing that I often remind people living with migraine is it's OK to ask for help. It's OK to accept help — beyond OK. If I had that prescription pad again, I would write you a prescription that says: Ask for help and accept help. Just say thank you. Because you know what? When you let someone else help you, you make them feel better, too. Now they're doing something. They wanted to do something to help, and now they're being helpful. So, ask for help, accept it, and make that plan B. And that's gonna also start to help reduce a little bit of that anxiety about what's gonna happen with the next attack.

Elizabeth DeStefano (26:30): One of our viewers, Ann, put an important idea beautifully by stating: "Showing up daily for my health in a compassionate way isn't always easy, but it's the only thing that works." Why can it be so hard to show ourselves compassion with migraine that we'd actually probably be very likely to show others?

Dr. Buse (26:51): There is a reason in the brain that all these things are happening. It's not your fault. And yet people with migraine often feel embarrassed, ashamed, and try to hide that. So, I would love for everyone to think about being as compassionate and kind and gentle with yourself as you would be with a friend, as you would be with a family member, as you would be with your child, as you would even be to your pet. Try to bring some of that kindness to yourself and give yourself some grace, and realize you are living with and doing your best with a painful, relentless, potentially debilitating disease with attacks that come out of the blue and give yourself some grace.

Elizabeth DeStefano (27:38): Thank you for that. Is there anything else that you'd like to share with those of us with migraine who may be facing failures in treatment or potential burnout in managing this condition?

Dr. Buse (27:53): I understand why you're feeling this way. This is not an easy path. It's a long road for many people. It can be a decade until diagnosis, and it can be another decade until they find treatment that works. So it's a long path. At the same time, this is one of the best times ever in history with what we know, what we're learning, and all the treatments available. And if what's available now still hasn't helped enough, hang in there. There are more scientific discoveries happening every day. And there are more treatments and more management options on the way. So, stay hopeful. But at the same time, don't put your life on hold, try and live and experience your life to the best that you can right now with where you are and what you have.

Elizabeth DeStefano (28:50): Where can we learn more about you, Dr. Buse, and the work that you do?

Dr. Buse (28:55): I have a website — it's just my name: dawnbuse.com. And that's a good place for seeing some of the articles and some of the research I do. I'm really fortunate: I get to participate in wonderful large-scale research learning about life with migraine. That's also a place if you're looking for a psychologist, looking for a headache expert: Go on the tab under "Resources" and you can see links right to the scientific societies for biofeedback, for cognitive



behavioral therapy. And that's also a place where I offer free relaxation exercises, breathing exercises, guided visual imagery. So that's a good place. And the other place, if you feel like it, is you're always welcome to come read any of the science yourself directly. And that might be interesting from time to time. You might want to do that. To do that, go to the website PubMed, P-U-B-M-E-D. You don't need any special log in or anything. Everyone is welcome to go right to PubMed and just search — search for a symptom, search for a medication, search for "photophobia," sensitivity to light, or "interictal burden," and read for yourself firsthand, in the scientific language that we write in, what's going on and what's new. That might be kind of an interesting thing that some people might enjoy reading there. And you can even take that information with you to your health care professional and keep them updated with what's new, also.

Elizabeth DeStefano (30:30): Thank you so much, Dr. Buse, for again joining us on Migraine World Summit and for all of the incredible information that you have covered here today. We appreciate you.

Dr. Buse (30:40): Thank you, Elizabeth. I appreciate the Migraine World Summit for all the wonderful support and education that you bring into the world. And I appreciate and value and respect everyone listening today.