NHF InSights Episode 1: Impact of Migraine on Daily Life

Hope O’Brien: Welcome. My name is Doctor Hope O'Brien. I'm a neurologist and headache specialist based out of Cincinnati, Ohio. And you're listening to the inaugural episode of the National Headache Foundation called NHF InSights.

The NHF InSights Podcast opens discussions with industry partners on the latest research findings and treatments about living with migraine and other headaches. This episode discusses some incredibly insightful information from a survey recently conducted by the National Headache Foundation, with support by Pfizer. Our hope is to raise awareness of how migraine impact productivity and daily responsibilities, specifically how it differs between men and women and some of the societal perceptions that exist about migraine.

I'm excited to be joined by our special guest, Doctor Nicole Schaffer. Doctor Schaffer, would you mind introducing yourself?

Nicole Shaffer: Thank you, Doctor O'Brien, I am so glad to be here. What an important topic to be discussing. I am Doctor Nicole Schaefer. I am a doctoral prepared nurse practitioner who's been practicing for over 29 years. I have dual roles. I practice as Pfizer's global medical director for their employee health programs, and I also practice externally as a family practice nurse practitioner.

Hope O’Brien: Awesome. Thank you so much. So, we're going to sort of focus, as I mentioned before, around the survey that was done in August of 2023, that the National Headache Foundation did in partnership with Pfizer, that was conducted among individuals with migraine that focused on characterizing patients and their unmet needs, regarding acute treatment. So, the survey included individuals living in the US that was diagnosed with migraine by healthcare providers for the past two or more years.

And currently they're under the care of, again, a health care provider. The respondents had mentioned that they had at least ten migraine days per month, seven of those days where they actually wake up with migraine. Now, we know that migraine can, impact individuals, not just, themselves, but from an emotional and social, state of mind. We know that patients, will complain or say that they feel like individuals that don't have migraine don't understand what it feels like to have migraine, and there might be the stigma behind that.

So first I want to just ask you to share your experience and what it's like to live with migraine. And what led you to getting a diagnosis?

Nicole Shaffer: Sure. So, in 2010, I had been a year post diagnosis of breast cancer and was having significant headaches and losing my balance and just not feeling well fairly frequently.

And so of course, when I went to the health care provider for evaluation, the first concern was they thought that I could have had brain metastasis from breast cancer. So put me through a whole lot of testing and evaluation and the scare of it being brain cancer.

Luckily, that was not the case. But then it was a journey of finding the right treatments, finding the right care to be able to manage what ended up being migraines, and learning what my triggers were for those migraines so that I could look for ways to avoid them. And again, it's finding the ways to be able to get the right treatment because it's not an exact science.

It's something may work a little different for each person. So, it takes time and patience.

Hope O'Brien: And, you know, I hear that a lot in my clinic in terms of, you know, waiting to figure out what's going on and getting that right diagnosis. How long did that take from the time you started having symptoms to you then finally getting the diagnosis? Oh, this isn't, you know, a metastasis. This is actually migraine.

Nicole Shaffer: It was well over six months. So, it was follow it up following up with neurologists. It was following up with my primary care provider. And as the tests go on, because each one of these appointments takes time. So, it's not like you go from one appointment to them saying, oh, well, we're going to refer you somewhere else so you can see them tomorrow.

Each one in their practice is very busy. So, you are next on the list. And so, the timing was a good six months. I would say one of the challenges, though, is just how to function on that daily basis with those headaches. And at that point, I still had three very small children and was working full time.

Hope O'Brien: Can you just share a little bit more in terms of what it was like dealing with migraine and having to obviously continue with your career and raise a family and kind of balancing all of that despite having this disabling disease.

Nicole Shaffer: It was quite exhausting because I think when you say that you have a headache or you say that you have a migraine, just like the survey and study showed, people don't get it in general, that it's like, oh yeah, you've got a headache. I've had a headache before, but it's the ability to push through and function is exhausting both physically and emotionally.

So, it's trying to be able to keep your mind focused when your mind, the last thing it wants to do is focus and trying to keep your energy level high, and to be able to do all the things that you would normally do. So definitely not functioning at my peak and yet still trying to make sense of it and keep things going for the family and my job.

Hope O'Brien: So, for those of you who are not aware, migraine is not just a headache, but it's a complex neurological disease that is physically disabling, and it can also have a negative impact on an individual's emotions, mental state, and social interactions. Many of my patients have shared their stories of how migraine has reduced their ability to function and enjoy important moments in life.

And in fact, the survey showed that 25% of respondents were unable to perform daily activities due to their migraine attacks and said they felt a significant impact on their productivity. And this was particularly true amongst Black women and Black respondents as a whole. So, tell me this, Doctor Nikki, have you had, individuals around you talk negatively about migraine or have you experienced migraine stigma?

And how is this different when talking about, you know, that, when you were diagnosed with cancer and that kind of conditions that you dealt with.

Nicole Shaffer: So, when you're diagnosed with cancer, everybody comes running to assist you. What can we do to help? Oh, my goodness. That's a horrible diagnosis where migraines again people tend to believe it's just a headache. What's the big deal. But they don't realize all of the other stigma and sorry stimuli that that impact how you're feeling. If I'm sensitive to light, if I can't see when the headache set, it's worse.

If I can't function, it's way more than just a headache. So, it's not, you know, suck it up and keep going. It's really, I've got to be able to take care of this. And so, it's a very different perspective from people in general. And I see this with my patients in family practice too, where they're very frustrated.

They've not been able to find an answer or a response to why they're having these headaches. It often gets pushed off to it's something else. It's menopause related. It's just a symptom of menopause. And it's downplayed versus getting to the root cause to be able to find a way to treat it, to make the quality of life better.

Hope O'Brien: you are right on the money with that one. In a survey, women reported experiencing higher social isolation, stigma, distress, anxiety, and lower health related quality of life, all attributed to migraine. And the survey also found that 68% of women experience the social isolation from others who don't understand migraine, and women are also more likely to interpret a lack of empathy from people without migraine.

So, if you could, talk a little bit about, your interactions with patients and, you know, kind of what you've heard from them in terms of, you know, feelings of isolation or how migraines had, you know, this negative impact on them.

Nicole Shaffer: So, I think the one big piece is that they do feel so isolated because no one believes that this is real. And so, they then in turn start questioning, am I making this up? Why do I feel so bad? Something has to be going on. And a lot of people, both women and men, tend to give up. They've tried to be their own advocate, at least temporarily.

They don't get any answers, or they don't get relief. So, they may even have. And a health care provider that believes they have migraines may have tried one method of treatment and it didn't work. So, in the person suffering with migraines mind, it's like, okay, well that failed. Now I'm on my own to figure this out. So, it's really trying to encourage those that are experiencing migraines, how to continue to push through until they get the answers and the treatment that they need.

So, you know, if you equate it to other medical conditions, whether it be cancer or whether it be having a heart attack, you're going to keep trying to get the answer until you're treated with everything that needs to be treated. But I think with headaches, because there is that thought that it's just a headache or I should be able to deal with this and we try to downplay it.

We don't we don't stand up for ourselves and really advocate for getting that full treatment.

Hope O'Brien: Yeah. I think it's, an exciting time to be a headache specialist because, you know, now we've got, you know, treatments out there that we didn't have, you know, ten years ago that are effective, with minimal side effects. And so, it's wonderful to see patients, you know, who had this disabling disease now come in and say I'm better.

And so, one of the reasons why I, I advocate for patients advocating for themselves, that if they're not satisfied with where they are in terms of their quality of life and, you know, missing out on, you know, not just work, but on special events with family or social events, weddings, graduations, that kind of thing, you know, because it can really make a difference.

What do you tell your patients, you know, who come in and say, you know, I've been struggling with this for so long. You know, I'm really hesitant about trying another treatment out there because of my past experience. How do you sort I get past that, that barrier and unmet need of making sure that patients are adequately treated.

Nicole Shaffer: I explained to them that there are many different options and that it is a trial and error. Unfortunately, that what works for one person may not work for another. And just because one didn't work, let's take that step again and let's try a different method. And it's really just getting them to trust you that we can work through this together, and that you're looking out for their best interest, that you really are there to help partner with them to find resolution.

And I remember my early days of being in family practice, when the chronic migraine patients would be in 3 or 4 times a week to get shots, usually some form of narcotic shot, and usually also something for the nausea to just make the pain go away. And so oftentimes you would see these patients on the schedule, and somebody roll their eyes and say, oh here they come again.

And yet there wasn't any discussion at that point of how are we getting to the root cause and fixing this and helping them with their quality of life. These folks were not having a good quality of life at all. Sitting in a dark room carrying, a basin in case they threw up, with them, that was not the quality of life they wanted.

Hope O'Brien: I agree with you. And I think one of the things that I try to point out, to patients is making sure that they understand their condition, that this is a disease that has, you know, roots in the brain. And, you know, how does that then, transfer into the symptoms that they're experiencing. And when they understand that, oh, this is not something that's my fault.

This is not something that I can control. You know, because they oftentimes with guilty that they have this and they hide, you know, and don't really talk about the fact that they have this condition. And I think, you know, with, you know, social media out there and a lot of different opinions out there about, you know, what migraine is, or you know, what these strong headaches are.

I think, and something to be said that oftentimes we hear migraine put in a negative light. You know, if you're watching, you know, different TV shows, you hear, oh, I have a headache. Or, you know, it's always putting a negative light. and so I think it's important that as patients, we, we do bring up this discussion and talk about it and say that, you know, this is a condition like any other disease process that needs to be, you know, diagnosed first of all, and then, treatment appropriately given.

Nicole Shaffer: You're absolutely correct. This to me, everything that you just said, and we've been talking about is very reminiscent of all of the mental health diagnoses. So, it's no it's something you can fix on your own. It's something that you hide. So, we've come a long way in bringing mental health forward. And talking about those conditions and helping people to understand that those are not things you can prevent either that there is a chemical imbalance.

It is something happening in your brain, and we need to be able to do the same thing with migraine to get that education out there, to move it forward so that more and more people can understand in the workplace as well, because they need support in the workplace as well as in their personal life.

Hope O'Brien: this has been a wonderful discussion. I'm so happy that we had this opportunity to talk and share with those who are listening. and, and hopefully both will be empowered to go ahead and speak up and, and talk about this, condition, not just with their health care providers, but with their friends and family as well.

Thank you so much.

Nicole Shaffer: Thank you.