



NHF Insights™ Patient Series
Don't Ignore Headache Disorders: Why Early Diagnosis Matters

Jaclyn Duvall, MD:

Welcome to NHF Insights, the National Headache Foundation's podcast created with the support of our industry partners, where patients and headache experts share candid conversations about living with migraine and headache disorders. I'm your host, Dr. Jaclyn Duvall. I'm a board-certified neurologist and fellowship trained UCNS headache specialist. I'm also founder of Headache Specialists of Oklahoma and a board member of the National Headache Foundation.

This episode focuses on why you should care about headache disorders, and it is a part of our Patient Series. Today, we'll explore why people delay care or settle for good enough, why early action and the right care matter, and moving past stigma and focusing on support. I'm joined today by published author, public speaker and communication strategist Qasim Amin Nathari. Qasim is a migraine patient advocate and founder of Black Men Have Migraine Too. He has lived with migraines since childhood and focuses on awareness, advocacy, and disparities in diagnosis and treatment in headache disorders. Welcome Qasim.

Qasim Amin Nathari:

Thank you, Dr. Jaclyn.

Jaclyn Duvall, MD:

Before we go into greater detail, everyone's migraine journey starts somewhere and I'd love to hear a bit more about your journey, your experience with headache and migraine and what it looked like.

Qasim Amin Nathari:

Thanks again. My journey is really interesting because it started as a child. I think it was second grade. I can recall just getting these like horrible headaches to the point where the teachers would go across the street to the restaurant and they would get me tea and toast because these headaches would have nausea. They would be accompanied by nausea. So finally, my mother took me to the eye doctor and the eye doctor said, nope, he's fine, 20/20 vision. These headaches continued, and I remember over like a one-year period of time, I had three different eye doctor visits. So, finally the eye doctor said, ma'am, don't bring him back here anymore. He has 20/20 vision. It's not his eyes that are causing his headaches.

So, they subsided a bit, or maybe I just decided at that point that I was just going to deal with them. And for the rest of my life, through high school and through early college, I always dealt with headache, which I often just attributed to lifestyle, because I was always doing things that would typically cause headaches. I was an athlete, so that goes to hydration. I was a DJ, so that goes to loud noise. So, it was always life factors that would make one think that that caused headaches. It wasn't until my early 30s

when they got really, really crazy that I went to see my primary, and he had experience with migraine and he diagnosed me as having migraine.

Jaclyn Duvall, MD:

Wow. So most three decades before a diagnosis.

Qasim Amin Nathari:

Three decades. And I later found out later through my neurologist, right when I turned 40 years old, he told me that I had migraine back as a child. But because I grew up in the 70s, science hadn't caught up. They didn't diagnose children with migraine then, so it wasn't until again my 30s and then going to the neurologist at 41 years old that I found out that I had, at that point, chronic migraine.

Jaclyn Duvall, MD:

How validating was it to have a name, a diagnosis behind what you're experiencing?

Qasim Amin Nathari:

It was very good. It was liberating to be quite honest, because it made me understand that these headaches that I had determined that I would just live with, that there would be a path forward for me that I could possibly get better and give myself some relief. Because headache had become such a common place in my life that I never thought that it would be anything other than that kind of life for me. So, it was very liberating when I got that diagnosis.

Jaclyn Duvall, MD:

Well, as we've already heard from you, migraine and headache can affect your whole life. And so, I'm wondering how today migraine has impacted your day-to-day life in ways others may not see.

Qasim Amin Nathari:

It's impacted it tremendously to the point that when I was at my worst, I had to end up changing careers because it just became unbearable for me to work in the setting that I was in. I hadn't been experienced yet with advocacy to know that there would be certain accommodations that I could ask for and all those things like that. So ultimately, I made a decision that I couldn't do what I was doing before. Then I got even worse and ended up having to go on disability. So, it was very life altering because I went from one income level to another income level. So that makes you have to totally rethink and recreate how you live. And I was a married father with children at the time I made that decision or that decision was made for me by migraine disease.

Jaclyn Duvall, MD:

We were talking earlier. You had mentioned an employer that said if you could let him know when you were going to experience a migraine. How did that feel?

Qasim Amin Nathari:

She said to me one morning, Qasim, it would really help me if you could give me a heads up when you're going to have a migraine, because I have to kind of rearrange the workflow for the day. And I understood her position because I was in a very important position. I was working in city government at the time, so a lot of things that needed to get done would run through me or through people that I was responsible for. But I had to tell her that, unfortunately, migraine disease doesn't work that way, and if it did, it would sure help me a lot in terms of managing my day-to-day life. So ultimately, I ended up having to leave and went into another situation that ultimately led to years later that I had to just go on disability.

Jaclyn Duvall, MD:

Well, and I think unfortunately that reemphasizes the stigma we see in migraine where individuals are acting like somehow you've caused this or something you've done. And what I see with many of my patients is they start to blame themselves. They're walking on eggshells to try to mitigate their environment so that they don't trigger. And if they do, they feel like it's somehow their fault. And I think having a diagnosis of migraine disease and recognizing this is not your fault. It's genetic makeup and a multitude of factors.

Qasim Amin Nathari:

Yes. I mean, it makes all the difference in the world. And those things that you mentioned, Jaclyn, are like, really, the fact that we grow up, and I say we I'm talking particularly about men now, we grow up with this societal stigma that you're not supposed to let anything like a headache derail you. You're supposed to find some way to push through it. Men are providers and we tough it out. And I'll add the added effect that me as a black man, part of the culture around the black community is that men traditionally don't talk about pain. We're usually the last ones that go to the doctor. So all of these things, they just have a trickle-down effect in terms of how they impact people living with headache disease or migraine.

Jaclyn Duvall, MD:

Right. I think I also was sharing with you how oftentimes if a man comes into an appointment with me, many times it's his wife or significant other kind of dragging them in. And like you mentioned, feeling like they just need to be okay and kind of deal with it and find a way around it themselves. Which again, I want to emphasize this is a disease and there's treatment. It has to be managed.

Qasim Amin Nathari:

And it's such a beautiful thing when you have a wife or a support system that will encourage you to go in and get diagnosed and begin the path to treatment. And that's very important because nothing can start you on your migraine journey or your journey to get better than being diagnosed. You have to see a provider.

Jaclyn Duvall, MD:

Well, that's a great transition because of course a diagnosis allows for treatment options. And what I think we've started to see is that patients may be unaware of new treatment options or treatment

options at all. They may think that managing migraine is all diet and lifestyle factors. And what I've started to see is that so often people are settling for good enough. And so, I'd like to hear in your words, have you ever felt that care was just settling or something that you had to live with?

Qasim Amin Nathari:

Early on, but honestly, once I got the diagnosis from a headache professional, which was a big difference because my primary could only take me to a certain point. So, I started out on pretty much the entry level medications that they give you when you're first starting out. But those didn't help me. But once I got to the point that I connected with a neurologist, then it was like eye opening for me because I saw that there were so many different treatment options available, things for prevention and treatment on both sides. So that helped tremendously. It just opened up a whole new world for me.

Jaclyn Duvall, MD:

Well, I hear that very often, that I've mentioned this to my primary care. How were you able to seek an appointment with the neurologist? Did your primary care refer you?

Qasim Amin Nathari:

I was laying in the bed one night, and I started feeling this numbness in my foot, and it started to slowly travel up my leg, up to my entire side of my left side of my body, to the point that I thought I was having a stroke.

Jaclyn Duvall, MD:

Yeah. That's scary.

Qasim Amin Nathari:

So that next morning I went to the emergency room. They gave me the EKG and tested me for stroke and all that. None of that. I'm clean. But as they had me there hydrating with IV, the attending physician said to me, he said, you know, Mr. Nathari, you mentioned when we went over your history that you have migraine. I'm not a neurologist, but I've heard my colleague describe a type of migraine that mimics stroke, so I'm going to give you a referral to our neurology clinic. And when I went to the neurology clinic the next week, that's when they explained to me that I had what is called a hemiplegic migraine. So, at that point is when I really, really started to just be diligent about going to the neurologist, staying abreast of treatment options, and all those things like that. And it just helped me on that path, so that even once I got worse, I was still able to navigate my way back to being in a better position like thankfully I am now.

Jaclyn Duvall, MD:

That must have been tremendously scary experience.

Qasim Amin Nathari:

It was a very scary experience.

Jaclyn Duvall, MD:

How wonderful that you had an ER attending that recognized or was able to say, gosh, this isn't my expertise, but I think you need a neurologist. You need someone who's focused on this.

Qasim Amin Nathari:

For sure. Yeah. And it's lifesaving. But again, this is why when you are in these situations you're seeking help, you have to share your story. You have to talk about all these things, because sometimes those key points in your history can be the thing that will inform the doctor that's treating you about things they need to look for, and things that can give you some relief.

Jaclyn Duvall, MD:

What advice would you give someone who maybe hasn't been to the ER with migraine and maybe is repetitively seeking care in a primary care setting, and maybe not seeing that help they're looking for? What advice would you give to that individual?

Qasim Amin Nathari:

Immediately, priority 1A with an asterisk, find yourself a neurologist or a headache specialist immediately. Because you can't do anything on this journey until you get your hands around, because everybody's migraine reality is different.

Jaclyn Duvall, MD:

Well, one of the things we've learned with time is that migraine is a progressive disease. And the sooner you get treatment, the more successful oftentimes it could be or potentially reducing your risk of transforming from episodic or less frequent migraine into chronic or more frequent headache days. And so why is it important to seek help immediately?

Qasim Amin Nathari:

A couple of things. Closed mouths don't get fed. So, if you want to be better, you want to have a better quality of life for yourself, immediately, it's not something that you can put off. Because the progression, the nature of the disease progression, is just going to get worse. It's not going to get any better through your neglecting what you know you're already dealing with what you're experiencing. There is no push through. Immediately, you need to find yourself a provider and see what options will work for you.

Jaclyn Duvall, MD:

I love that. I also find that sometimes the hardest part is really trying to explain to a provider what you're going through. Doctor's appointments can be rushed. You're trying to convey all of this information. But as a provider myself, sometimes it's overwhelming if we're just kind of presented too much or information isn't maybe concise. And so, I wonder if you have advice to individuals about how to talk to their provider or ways to share their headache history that could be helpful?

Qasim Amin Nathari:

Well, I've always kept meticulous notes so that when I would go to appointments, I would be prepared and I would know exactly what it was that I wanted to talk about. But you have to develop a comfort level with that particular doctor. Until you develop that comfort level, it's like you're wasting your time. And once you do that, then that person is patient with you and then you're more forthcoming in terms of explaining really what's going on with you. And then you can get results and get to the bottom of it. Other than that, if it's not a relationship that's based on mutual trust and mutual patience, then it's not going to work.

Jaclyn Duvall, MD:

Could you share the story you shared with me earlier today about a provider who maybe wasn't hearing or listening to your concerns?

Qasim Amin Nathari:

This was when I relocated from New Jersey to Florida. And I had an excellent primary, and I started finding myself with increased migraine episodes, increased migraine attacks. And I said to him, I need a referral to a neurologist, so he gave me a referral that was in network. And right off the bat there was some things that were red flags for me. But when we actually had the discussion, when I had the consultation, he listened to me, went over my history. I felt like we kind of rushed through. But then he immediately went to prescribe me a medicine that previously I had disastrous results with. And as I'm trying to tell him that that didn't work for me, he was adamant that nope, this time it would be different, to the point that we almost became argumentative, but I didn't. I accepted the prescription, and then I went back and told my primary I need another referral because I can't deal with him. I felt that that was one of the few times that I felt unheard. He didn't hear me.

Jaclyn Duvall, MD:

I tell people often that you don't have to settle with a provider, that you can seek second opinions, that if you are in a relationship with a provider, that you don't feel like you are together in choices that are being made, that that's probably not the right provider for you. So, I think it's so important the steps you took, that you knew I'm kind of finished with this relationship. I need to seek out someone else.

Qasim Amin Nathari:

Yes. My primary actually apologized. He said I hate that that was your experience. We will find you someone else. And then we ultimately found someone else that worked better. But then shortly thereafter, I ended up back in New Jersey with my original neurologist. So now, I have I have a certain comfort level, and because of that, I'm doing much better. But I have to say this, my relationship with my current provider, with my current neurologist, I would attribute that to be a major factor in why I'm doing better. The relationship is that solid. Like, we hear each other. He accommodates me. And even during COVID, if I had issues and I couldn't get in, we did televisits and we always stayed connected so that there was always this exchange of how I'm doing versus what can be done differently. And it got me to a good place. So that's why the relationship is important. And not delaying the relationship is the first thing, not delaying finding the person that you build that relationship with.

Jaclyn Duvall, MD:

Tell me how that trust and your provider open treatment doors for you, or maybe enables you to be open to a discussion with him about options?

Qasim Amin Nathari:

It was it was a two-way street. One of the things, Jaclyn, is that when I started out initially, sometimes I wouldn't be as diligent listening to him. And he would always come to me and say like, okay Qasim, it's your migraine. He would always remind me of that point. And that made me really begin to have to know that I have to take ownership of this, and he's going to be serious about I can only make the recommendation. You have to follow through with it. So, him having that level of relationship with me, it just opened up the lines of communication so that it was just free flowing. And it really was a beautiful thing for me because there was a time that he and I had to disconnect because of insurance issues when he went to a cash practice. But he found a way for me to go back under his treatment, and ever since then it's been much better.

Jaclyn Duvall, MD:

I was sharing with you earlier that sometimes it can be challenging because as providers, we may be limited based on insurance restrictions of medications or treatment options we can choose initially. And I think it's important to understand because a provider may not have fully explained, gosh, that these are the steps that we need to take first in trialing different things. And so, patients may think, okay, this is the best and last, when in fact there are treatments down the road, so I think that that's the flip side.

Qasim Amin Nathari:

Yeah. And that's why knowledge is a very important thing. You know there's a saying that I live by in a lot of aspects of my life and my work. I say, and I don't know where it comes from. If anybody knows we can attribute it. It says that if you knew better, you would do better. So, once you know better, then you begin to act differently. You begin to respond differently and you get better results. Because now you're moving from a proactive standpoint as opposed to what we talked about earlier, where you're just settling and you're kind of like this is the best that it's going to get for me, so I'm just going to ride it out. Once you make the decision that you're not going to do that, and you arm yourself with the tools that you need and the resources like that are available at NHF, then you're going to really be in a position where your quality of life can be impacted dramatically for the better.

Jaclyn Duvall, MD:

I love that, arming yourself with the tools. We talk about a toolbox approach often in migraine care.

Qasim Amin Nathari:

It's a must. Yeah. No cookie cutter. You got to have a number of things in your toolbox because sometimes it's situational.

Jaclyn Duvall, MD:

And what is perfect or wonderful for one individual may not be for the next. We're all uniquely made and we have treatments that we prefer over others. And just like your experience with not loving that medication. That could be the right choice for someone else, but it wasn't for you.

Qasim Amin Nathari:

Yes. And it wasn't the fact that, I mean, obviously I didn't love it because of the side effects. I mean, as a speaker and someone who relies on my brains at a certain level that may be different from other professions, I just couldn't be on a medicine that had that type of effect. And the fact that I had a provider that apparently couldn't understand that, that was a deal breaker for me. So thankfully there's options. And I was able to advocate for myself and move forward.

Jaclyn Duvall, MD:

I tell our patients we need a medication that works, but we also need a medication we can take it at work. And if we're not fulfilling both sides of that, then it's not the right medication for you. That's not something you're able to stick with. I want to hear, what's something you wish your provider or even the people around you understood about migraine disease?

Qasim Amin Nathari:

Interesting you phrase it that way. There's two different conversations completely. The provider conversation is just being able to get them to know the specifics of your life and how migraine affects you so that you can arrive at a treatment plan that will work for you. The people that are around you, oftentimes you're starting from entry level migraine 101 with having to explain to them how this is something different than just a bad headache. So, it's a completely different conversation. And they both have their own nuance to it. So, I try to pretty much just be very transparent with people in my life and people in my circle that I'm never hiding from it, to the point now that I'm pretty much the only surrounded with people who have a working understanding of what migraine disease is about, because I'm open about it, I'm transparent. And I'm not one of these folks that is content with just suffering in silence and not making it a part of my conversation. It's part of my life, and I need people around me to take that part along with the parts that might be a little bit more pleasant for them.

Jaclyn Duvall, MD:

I try to encourage my patients to have this dialog with people around them, especially if they come across someone like you mentioned, your former employer, who maybe doesn't have an understanding of what this disease is. Well, I have migraine disease, actually, I can't predict often or I don't know. If I could that would be life changing for me. Or if someone is perhaps using dialog that really is placing stigma, to share I have a disease. This is not just a headache and really encouraging them to speak up for themselves.

Qasim Amin Nathari:

And we have to. And we always have to be mindful that we have to start from a place of assuming that they're not doing this out of any malice or anything like that. Oftentimes it's just the unknown for them, and they don't have any familiarity. And it's particularly a challenge for me, Jaclyn, because again, as a black man. And I say this oftentimes, that for so long in some circles, migraine has been looked at as kind of like, and I say this respectfully, you know this, a middle-aged white woman's disease. If you look at the advertising and you look at some of the things that are there among some of the other resources, you would think that a black man with migraine, like, what is this? No, it has to be something else. And this is why so many people that look like me go undiagnosed because they live with these headaches and they don't even know that it's something way beyond a headache. It's actually a migraine, a headache disorder, a neurological disease.

Jaclyn Duvall, MD:

Well, there are so many people along that line that feel the need to push through or keep this to themselves. And so, what has helped you move past that, living with this disease for so long?

Qasim Amin Nathari:

A couple of things. First and foremost, just being the type of person that I am, I'm able to just be honest and transparent. I've always worked in public spaces and part of that public spaces that when you're the face of many things, you have to be transparent. And I felt that my transparency would just make the situation easier for me because it wasn't something that I was willing just to hide. And then when I became involved in advocacy, which is a completely different topic that I'm sure will be explored, that made me understand even more so why it was important to proactively talk about it and discuss it. Because only through that advocacy and awareness can you really paint the picture for folks of what it is to live like that. And then they will notice that not only in their interaction with you, but maybe other people that live with migraine disease that they've encountered, and they had no idea that impacted them at the level that it did.

Jaclyn Duvall, MD:

I'm curious, since you lived undiagnosed for so long, how that dialog or conversation changed in your life? How did you talk about migraine, not knowing it was migraine in your teens?

Qasim Amin Nathari:

It's funny, because one of the first conversations I had when I was diagnosed, I told my mother, I said, mommy, those headaches I was getting in second grade, we know why now. Those headaches that I used to get in high school coming home from basketball practice, I wasn't just dehydrated. Those were migraines. So that opened up the door for me to begin to have these conversations. And then it became more important for me to have those conversations, because I wanted to do whatever I could to make sure that people didn't have to live like I lived, meaning just going along with it, grin and bear it, and all those things that typically come along with men living with illnesses. So that opened up a completely different set of dialog for me.

Jaclyn Duvall, MD:

Well, this has been fantastic. I appreciate you.

Qasim Amin Nathari:

Thank you so much. I appreciate you.

Jaclyn Duvall, MD:

I appreciate your insight, experience. You've given us so much information that I think will be tremendously helpful for patients.

Qasim Amin Nathari:

Thank you. And we need folks to know that there's help out there. I'm doing much better than I did. I went through the chronic period as we talked about. And those were some dark days. But through working with a brilliant provider who was empathetic and all those things, it got me to the place that I'm at now where I think I'm doing pretty good for myself, for a person who's lived with migraine disease most of their life. And now I'm at six decades in, I think I'm doing all right.

Jaclyn Duvall, MD:

Well, I'm thankful to hear that you've gotten the treatment you need and that it's been a journey. But now that you're able to help others and help advocate for this disease.

Qasim Amin Nathari:

Thank you. And thank you for the work that you do in this space. I appreciate you, and I really appreciate being able to have this conversation with you.

Jaclyn Duvall, MD:

Thank you for joining us. We hope this conversation helps you feel more informed, empowered, and confident in managing your headache or migraine disease.

This episode is part of a series designed for patients and providers to help navigate diagnosis, treatment, and finding the right care. Find the full series at headaches.org. Thank you again for listening. Until next time.

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