MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD-LEADING EXPERTS

TRANSCRIPT

HOW TO GET BACK FROM CHRONIC TO EPISODIC MIGRAINE

STEPHANIE J. NAHAS, MD, MSEd, FAHS, FAAN
ASSOCIATE PROFESSOR, DEPARTMENT OF NEUROLOGY
THOMAS JEFFERSON UNIVERSITY

Introduction (00:05): So always to have an open line of communication and an understanding of shared goals and shared expectations. We also have to set reasonable stepwise goals. It's not as if we can decide on Day One that by Day 30, everything is going to be fixed. I mean, it would be extraordinary to fix things that quickly. You know, for many of my patients, I see them after they've been having migraine for decades. And, you know, I have to tell them: "This is a problem decades in the making. We're not going to fix it in a matter of days or weeks. This is going to take a lot of hard work. But, you know, I'm there for you. We're going to work on this as a partnership."

Amy Mowbray (00:49): When you're living with migraine symptoms daily or near daily, the idea of getting migraine under control can feel like an impossible dream. So many of us living with chronic migraine, myself included, are desperate to dial back the intensity and frequency of our migraine attacks. To help give those of us living with chronic migraine not only hope, but also specific strategies to help us revert to episodic migraine, is Dr. Stephanie Nahas from the Thomas Jefferson Headache Center. Dr. Nahas, welcome to the Migraine World Summit.

Dr. Nahas (01:20): Thank you very much for having me.

Amy Mowbray (01:23): Could you please start by explaining the difference between episodic and chronic migraine?

Dr. Nahas (01:29): We have a number of ways that we can subdivide the spectrum of migraine, and one of those is based on the number of headache days per month. Sounds kind of arbitrary, but this is how we differentiate episodic from chronic migraine. Currently, the dividing line is at a threshold of 15 headache days per month, at least eight of which must meet criteria for migraine or be treated as migraine. And if this persists for at least three months, then we label that chronic migraine. And the reason for making this distinction is because chronic migraine is far more burdensome than episodic migraine, it's more challenging to manage and it requires special attention.

Amy Mowbray (02:11): To accurately count the days affected, should we include days where we still have symptoms but no pain? And what about the days where we have a mild headache?

Dr. Nahas (02:22): This is a bit of an area of contention. How do you define a headache versus a migraine day? Because we know that migraine is much more than just headache, and sometimes migraine symptoms persist in the absence of pain, or with just mild pain. In my view, if there are any symptoms related to migraine even in the absence of pain, if those are present on that day, we could call it a symptomatic day for sure. And this is something that we're starting to ask about more in our clinical encounters, not just about severe headache days, or migraine days, or even headache days, but we want to know, in a span of 30, how many of those days were really crystal clear? Where that individual didn't have any symptoms at all of migraine and felt free of migraine completely. This is an important benchmark for us, too. So, if that number of crystal clear days is below 15, in my view, that person has chronic migraine.

Amy Mowbray (03:19): What is high-frequency episodic migraine?

Dr. Nahas (03:24): High-frequency episodic migraine is another one of these somewhat arbitrary definitions, mainly for research purposes. And also, to help us better understand the spectrum of this disease. We know that once there are eight days per month of headache, this is kind of a tipping point where disability increases substantially. And so, if we go from eight to 14 headache

days per month, right up to that line of 15, that's what we call high-frequency episodic migraine currently. Four to seven is a frequency at which episodic migraine should require some extra attention and possibly preventive medication. Three and fewer headache days per month is often an entity where that individual is not as burdened by migraine and probably only needs acute treatment that's effective, may not need preventive treatment.

Amy Mowbray (04:18): And who is most affected by chronic migraine in the general population?

Dr. Nahas (04:24): As with migraine in general across the spectrum, you know, chronic migraine also disproportionately affects women in their peak years of productivity. So, women between the ages of 25 to 45 roughly, that's where we see the peak in the prevalence curve, just as we do with episodic migraine or migraine across the board. Now, there are still plenty of men who are affected by migraine. The ratio remains about 3-to-1 for women to men in that critical period of the years of highest productivity.

Amy Mowbray (04:57): How debilitating is chronic migraine? What does it stop your patients from doing and how does it impact their day-to-day lives?

Dr. Nahas (05:04): Chronic migraine honestly can be completely debilitating. For some of my patients, even if they're not experiencing symptoms every single day, their lives have been completely turned upside down. Because most days they have some sort of symptomatology and unpredictably, but invariably, several times during the month, they're going to be completely incapacitated from their symptoms or from the medications that they use to manage those debilitating symptoms.

Dr. Nahas (05:32): And unfortunately, for a lot of these folks, that's meant that they did not progress through school the way they had envisioned. They did not pursue the career that they had hoped to. They don't have the family life that they were looking forward to ever since they were young individuals. It really can be life-changing and pervasive for that person. They have to learn how to live around migraine, and live with it, and they can start to feel controlled by the disease. This is why an important aspect of what we do is empowering patients to take back some of that control despite the persistence of symptoms.

Amy Mowbray (06:11): Some people only get occasional migraine attacks, but for others, migraine becomes increasingly frequent and eventually chronic. Why is that? And how do we spot it early and prevent it?

Dr. Nahas (06:23): This is a very interesting question that we don't have good answers to. First of all, why does migraine exist? We don't really know. And why should some people only be bothered by attacks maybe a few times per year, while others have the experience of over time experiencing increasingly frequent and increasingly disabling attacks? We really don't know. It's probably related to a number of different factors, including biology, the environment, and random chance. But we do identify certain risk factors among individuals that put them at higher chances of having this occur to them — whether attacks start becoming more frequent, more intense, and eventually progress to chronic migraine. One of the most important risk factors is the number of headache days to begin with. Whether those are migraine days or just plain mild headache days, we know that the risk really starts increasing at a frequency of about once per week.

Dr. Nahas (07:24): This is why we start to get a little bit more careful and mindful of our treatment plans for patients who have four or more headache days per month. Other risk factors include comorbidities such as anxiety, depression, even asthma can be considered a comorbidity that puts a person at risk for increasing migraine. Obesity, which is becoming an increasing problem worldwide, really, but especially in developed countries. And overreliance on acute drugs to treat the attacks. And it may depend on what that drug is. For example, a simple anti-inflammatory agent, when utilized more than about 12 to 15 days per month, could put a person at risk for progression. But the threshold is much lower when you look at acute medications such as a triptan. We would prefer that our patients are not exposed to triptans more than about 10 days per month.

Dr. Nahas (08:26): Because over that threshold, we know again, that there's a risk for progressing to chronic migraine. Now medications which contain opioids or butalbital could be even worse, and that threshold may be as low as five days per month before the risk really increases for progression. But it's really different from person to person. It's highly individualized. I know some patients in my practice who can take frequent acute medications and they remain stable. This is what they need to keep functioning. They never progress. They're not very common in my practice, but they do occur. And then again, there are some other patients who have to be extremely careful with their exposure to acute medicines because maybe even just seven or eight days of an anti-inflammatory drug will start to spin them out of control.

Amy Mowbray (09:13): Thank you. What advice would you give to chronic migraine patients who are not currently finding relief through preventive treatments? Those of us who feel like they have tried everything and are still stuck in chronic migraine?

Dr. Nahas (09:27): It is sad to say that our treatments still leave us wanting for more. There is no single treatment that works for everybody, of course. There aren't even treatments that work very well for the vast majority of individuals in terms of both their efficacy and their tolerability, which we can lump those two together and call that effectiveness. So the effectiveness of treatments is something we're still striving to improve. Now, I would say to somebody — and I say this a lot in my practice, to patients who think that they have, "tried everything." Now, for sure, they may have tried lots of things and even beyond medications, lifestyle changes, vitamins, supplements, devices, physical treatments, relaxation, other things in the behavioral health sphere — you name it. But there's always something else that we can think of or some other combination or some other approach.

Dr. Nahas (10:26): So, to take a step back and to reflect on what's been tried so far, what had a little bit of a glimmer of hope, what was really not useful at all, try to separate those lists. And then we try to incorporate the things that showed some promise, even if they were tried before and not completely effective, perhaps it just needed a little help. So, we know that some of our patients need more than one preventive medication or more than one preventive approach. Now, you can't just keep piling medication upon medication upon medication. That winds up being a losing battle eventually. But adding other modalities to a medication foundation — such as biofeedback training, for example, or aerobic exercise program, slowly graduating up to weight training and even more advanced exercise type of approaches. Or incorporating something more relaxing like yoga or tai chi. And devices — employing devices which are drug-free ways of treating migraine through neuromodulation.

Amy Mowbray (11:31): We have members of our community write and say, "Help! My preventive medication is becoming less effective over time." What advice would you give to these patients?

Dr. Nahas (11:42): Certainly, if treatment of any nature is losing effectiveness over time, then a conversation needs to be had between the patient and the clinician. So, we start by assessing the medications at play and again, determining which ones have utility and which ones don't, and cleaning things up a bit. And then deciding if more medication is the answer, or perhaps a higher dose of the medication is the answer. Or perhaps a similar medication which works in a similar way but may have greater utility and greater effectiveness. Perhaps that is the answer. The other thing that we have to take into account is, again, those risk factors for progression or for persistence of disease. So, exposure to acute medications, comorbidities, confidence even in a socioeconomic and nutritional state.

Amy Mowbray (12:38): Amy H., a member of our community, asks: “I'm wondering how long CGRP injection should be trialed for? Are there any associated risks with long-term use of these meds?”

Dr. Nahas (12:50): This is a great question. About how long do you wait, on an injectable monoclonal antibody that targets the CGRP system, for it to work? Now, if you look at the clinical trial data — and most of these clinical trials were done over the span of just three months for chronic migraine — we can see a signal of some improvement as early as the first month, perhaps even the first week or the first day, depending on how you do the statistical analysis. But we know that for some individuals it took longer in the course of the trial, two or even three months. Now, three months is where the double-blind portion of these clinical trials typically ends. So, beyond that, we don't necessarily know in a firm scientific sense of the word. In reality, what we've seen is that for some patients when we prescribe these medications, their chronic migraine indeed does start to improve very early. Or it may take two to three months, and in some cases, it might take even longer.

Amy Mowbray (13:52): What role do infusions play in chronic migraine in patients?

Dr. Nahas (13:56): I get asked about infusion treatments a lot. Probably because we do it a lot in our practice. And this is of critical importance for patients who have been left dissatisfied and disappointed by their treatments that they can do themselves at home. So, when we talk about infusion treatments, we're talking about putting an IV into a vein, and infusing medications over the course of several hours. And this can be done repetitively throughout the course of one day over several hours, or even over repeated days. This can be done in a clinic with a specialized infusion center like we have in our clinic and like many others have in their clinics, or it can be done in the hospital when that needs to be intensified even further.

Dr. Nahas (14:44): And these are some of the nicknames that we would give to this kind of treatment: a cycle breaker, a brain reset, rebooting the brain. In a sense, it's trying to detach the brain from the migraine state and to let it resettle, giving it a break from pain. And then once we've achieved that, we can start to pull back on the intravenous therapies. Reduce the doses, make sure everything stays stable, and give that patient perhaps similar medications that they can implement into their armamentarium of acute treatments, so that they can better manage the disease over time. Not that it's the headache is never going to come back, but that disease activity is suppressed to a degree that when a little fire comes up, we can put it out.

Amy Mowbray (15:30): The Chronic Migraine Epidemiology and Outcomes [CaMEO] Study highlighted the magnitude of barriers to effective care for chronic migraine patients. Can you talk us through some of the barriers patients face?

Dr. Nahas (15:42): Yeah, this is another problem with managing migraine. It's not just migraine itself, but society and the healthcare system and the barriers that are imposed by it. And an important barrier, probably the primary barrier that many people face when they're dealing with migraine, is the stigma associated with the disease, which demotivates them from even seeking help. You know I've talked to literally thousands of patients who didn't realize that they've actually had migraines since they were a child. And part of going through childhood with migraine is stigmatizing because when a child complains of anything, they're often not believed. It's often felt that they don't want to go to school, they don't want to do their homework, they don't want to do their chores. And a child with migraine who goes through childhood that way without really any good attention to their disease, now they're at higher risk for — as they get older — they're likely to start having more and more attacks that they can't ignore.

Dr. Nahas (16:49): And by then, it's like the horse is out of the gate. You're sort of behind the "eight ball" — a huge opportunity has been missed for years and years to learn more effective strategies for managing the disease. Now, let's say, you know, that stigma isn't necessarily part of the problem for an individual — they grew up with a supportive environment. In a household with migraine, for example, perhaps mom, or dad, or an older sibling, also had migraines. So they had that support and that understanding. They got to medical care — to an understanding doctor. They had a school that was supportive for them. But again, as they got older, their attacks became more intense. And they're motivated to go seek care from a specialized adult practitioner. But when they get there, they may find that, again, that clinician doesn't have the knowledge, the expertise, the interest even, in managing that disease. And they may feel stigmatized and shamed in that regard.

Amy Mowbray (17:49): How often should chronic migraine patients be using acute medication?

Dr. Nahas (17:54): Now, when it comes to using acute medication, when you have symptoms almost every day, how do you pick and choose the days that you're going to use it when you know that the more you use it, the worse you might get? This is that catch-22 that I and my patients, we struggle with every day on how we work around this. We give our patients general guidance that they should be limiting their exposure to acute drugs to about two to three days per week on average, or nine to 10 days a month, again, on average. But it also depends on what's being utilized. Anti-inflammatory drugs, simple analgesics, may not be as dangerous in terms of the risk of over-exposure, leading to chronic migraine. But triptans carry that risk. And opioids and butalbital-containing medications carry a much higher risk.

Dr. Nahas (18:48): Combination analgesics also carry risk. And what I mean by combination analgesic is a product that combines acetaminophen plus aspirin plus caffeine — a very popular combination that one can get without a prescription. But overexposure to that combination, again, can destabilize migraine. Now, we're glad to report that the newest acute drugs — some of the newest acute drugs — namely the gepants, these small molecules which target the CGRP system, don't appear to be associated with this phenomenon of rebound headache, or increasing headache with increasing exposure. And, in fact, they can be utilized on a preventive basis. This is extremely interesting to us, this phenomenon.

Amy Mowbray (19:31): Living with chronic migraine can often feel like you're always somewhere in the attack cycle. How do you ensure these patients are treating attacks early when they don't always experience a distinct start and end to a migraine attack?

Dr. Nahas (19:43): This is another challenge that my patients face and talk to me about all the time. How do I treat early when I'm always having some kind of symptoms, and how do I treat early when my symptoms escalate so frequently? This is part of where being attuned to one's body and one's environment and one's propensity — guessing the chances that the symptoms are going to get worse — becomes very, very important.

Dr. Nahas (20:11): Now, I don't want to put my patients in the position of having to keep very detailed journals day after day, week after week, month after month, hyperfocused on what their symptoms are doing in relationship to their activities and their environment. It can become maddening. So for my patients, if they're going to track nothing else, if the only thing they're going to — if they can only track one thing — I ask them to track when they're taking extra medication to treat their attacks.

Dr. Nahas (20:41): And I also counsel patients: "Hey, if you're having a bad week, go ahead and treat for four days out of that week if you need to. Especially if you only treated one or two days the week prior. And if you think that's going to give you a better chance of having a good week the following week, and you're only going to need to treat once or twice." You know, it's not just on this weekly basis, we can expand that out to a monthly basis. And I also make patients aware that, typically, it's overexposure for more than just a few weeks that becomes a problem. It's when it's happening for several months, that's when it tends to become a problem. And in fact, sometimes what we'll tell patients to do to get them back on track if we don't want to go up into infusion treatments, is I'll say, "All right, here are two, three, or maybe even four acute-purpose drugs that are all compatible. I want you to take them like a concoction. And I want you to take them two to three times a day for the next three to five, maybe even seven days. This is your cycle breaker; this is your power pack."

Amy Mowbray (21:41): That's fantastic advice. How can patients better help their doctor help them when living with chronic migraine?

Dr. Nahas (21:51): Communication really is key to achieving success. And so, you know, what I want most from my patients is for them to be giving me the straight story. Don't tell me what you think I want to hear. And don't withhold information that you might find embarrassing — but which is actually critically important to us achieving success. So always to have an open line of communication and an understanding of shared goals and shared expectations. We also have to set reasonable stepwise goals. It's not as if we can decide on Day One that by Day 30 everything is going to be fixed. I mean, it would be extraordinary to fix things that quickly. You know, for many of my patients, I see them after they've been having migraine for decades. And you know, I have to tell them: “This is a problem decades in the making. We're not going to fix it in a matter of days or weeks. This is going to take a lot of hard work. But I'm there for you. We're going to work on this as a partnership.” So, advocating for yourself to explain what the goals that you have are for yourself, and making sure that the clinician also shares those goals.

Amy Mowbray (23:11): Many chronic migraine patients also have daily background head pain. How do you manage this in your patients?

Dr. Nahas (23:18): Yeah, first you have to identify it. Because I've, again, had a lot of patients who didn't even verbalize that they had this constant background headache, especially if they've had it for so long. They're just like, "Oh, well, you know, that's just part of my existence." And they only focus on the days that are really bad. And again, this underscores why it's important to ask about crystal clear, symptom-free days, because sometimes we're surprised at the answer. Even if that individual is only having exacerbations a few times per month, that constant background headache, that still means there's a fire lit underneath. And we need to try to put it out if we can.

Dr. Nahas (23:56): You don't want to go overboard on medications, but here's, again, where devices can become quite critical. And there are devices which are safe to use every day. In fact, some of them have clearance to use on a daily basis as a preventive treatment in addition to using them for acute relief. So here's where I really like devices. Here's also where I really like lifestyle modification and biobehavioral approaches like meditation, biofeedback, cognitive behavioral therapy, mindfulness work, exercise. And it doesn't have to be vigorous exercise necessarily. Partly, it's just taking time out to do something physical. To move — even if that's just going for a walk every day— start low and build upon that.

Amy Mowbray (24:43): What would you recommend to patients who are seeing a headache specialist? They're trying the lifestyle measures. They have been able to access the newer drugs but are still not finding relief.

Dr. Nahas (24:55): This is a tough problem, too. And this circumstance is one that we're familiar with dealing with in our center, being a tertiary referral center. These are the kinds of patients that we see new to our practice every single day. Sometimes it just takes a fresh set of eyes. Perhaps the diagnosis isn't just chronic migraine. Perhaps there are other things going on that also need to be addressed in order for improvement. So again, this is coming back to the idea of comorbidities. Is there insomnia that's not well controlled? Is that insomnia because of obstructive sleep apnea that has not been diagnosed? Does that person have hypermobility syndrome? Meaning, flexibility of the joints, which can lead to — what that results in — is high demands on the musculoskeletal system to keep these hypermobile joints more stable. And it's critically important in the neck. So, somebody with a very loose hypermobile neck, their brain can start to become confused at the signals that are coming in from the neck. In terms of the head and neck position, their balance, what they're seeing in the world, and how it's all adding up. This can be confusing to the brain and can activate migraine symptomatology. So in those cases, we want to send folks to physical therapy to help them get their necks stronger.

Amy Mowbray (26:26): And finally, do you have any success stories of chronic migraine patients who have gone back to episodic migraine that you could share with us?

Dr. Nahas (26:35): Sure. I mean, this is why we're in this game, is that we love to see somebody that we can help. And we pull them out of the trenches and give them their lives back, in large part. I can think of one patient in particular who I like to use as an example for my students and my trainees. And she came to me on daily opioid medication with not a lot of hope. In fact, she said, "I've pretty much lost hope and I even hesitated coming here because I didn't think anybody could help me. And you are my last hope." I always get a little nervous when somebody says that to me because now I'm really under the gun. I've gotta get this person better. But I just build up my confidence and say, "All right, we're going to work on this together."

Dr. Nahas (27:18): And that's one of the things that she remembers the most of that very first meeting that we had. That I imparted upon her that we weren't going to give up. That it was going to be a lot of trial and error, but we're going to keep trying until we get things better. So, we did the medication-list-cleanup thing, where we're trying to identify what's useful, what's not, whittle it down. Now she was on a lot of medications for other health problems like high blood pressure and gastrointestinal problems, etc., etc. So we had a little bit of that to deal with. But again, setting small goals. And one of the first goals was to start to reduce her exposure to opioid medications. So, she was very diligent about bringing that down slowly. And a lot of patients are surprised to find that they can take these drugs away and yeah, they're still in pain, but it's the same.

Dr. Nahas (28:05): And they're like, "Wow, what was that drug really doing for me other than just making me not care about the pain?" Ah, indeed, that's what opioids do. You still may have pain; you just don't care about it so much. And then we got her onto a more rational plan of care. We eventually got her to a place where — although she still needed medications, although she still needed to come every few weeks for injections of the nerve block (trigger point injections), and every 12 weeks for the onabotulinumtoxinA injections — she was mostly symptom-free with that treatment plan. And we were even able to reduce some of her medications further. And we got to a point in time when the only time she was having symptoms would be maybe a little bit in the few days before she was due to come back for either her nerve block and trigger point injections or her onabotulinumtoxinA injections. And she loves to tell that story to all my trainees, too.

Amy Mowbray (29:02): Thank you so much for sharing that. That was — I'm sure there'll be so many listeners at home who'll be so — hopefully, instilled with a new wave of hope from hearing that. Where can we learn more about what you're doing or follow your work?

Dr. Nahas (29:14): Well, you should know that I am an associate professor of neurology in the Department of Neurology at Thomas Jefferson University in Philadelphia, Pennsylvania. And I am the program director for the Headache Medicine Fellowship Training program at the Jefferson Headache Center within Thomas Jefferson University — it's a division of the Department of Neurology. So, you can follow the work of our entire center online. We've got a website; we have a Twitter page. I also have a personal Twitter handle, StephanieJNahas. I'm also on Instagram as Stephanie Nahas Geiger. And I tend to post what I'm doing in the field and especially in my advocacy efforts. Advocacy is an important part of what I do and what I take joy from in this field. So, for example, I'm highly active in Miles for Migraine and the Alliance for Headache Disorders Advocacy, among other advocacy activities. So please join us.

Amy Mowbray (30:17): It has been a pleasure to speak with you today, Dr. Nahas. Thank you for taking the time to share the practical strategies that those of us living with chronic migraine can take to help reduce the frequency and severity of attacks and move towards episodic migraine. It is so reassuring to hear from a doctor who not only understands the nuances of living with chronic migraine, but also clearly cares so much for her own patients. Thank you.

Dr. Nahas (30:43): Thank you so much. It's been a pleasure and an honor to be here with you today.