NHF Insights™ Patient Series
Episode 4: Managing Migraine and Headache Disorder Diagnosis: A Guide for Patients

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 UCNS certified headache specialist. I'm also founder of Headache Specialists of Oklahoma and a board member of the National Headache Foundation.

This episode is about managing your diagnosis and is a part of our Patient Series. Today we'll explore what it's really like to live with a headache disorder long term, balancing migraine care with work, family, and everyday life, and how treatment needs can change over time. Let me introduce today's guest, an award-winning writer and storyteller and lifelong headache patient and advocate, Michael Pollack. He is also a National Headache Foundation board member who brings firsthand experience with headache disease, and a passion for helping others find relief and better care. Welcome, Michael.

Michael Pollack:
Thank you, Jaclyn.

Jaclyn Duvall, MD:
I was hoping we could start by you sharing, just briefly, a bit of your journey with migraine disease.

Michael Pollack:
Sure. I remember having headaches since my high school days, which was a long, long time ago. So, I've lived with headaches for as long as I can remember. And I think that anyone who's lived with me or been part of my life at work, at home, has lived with them as well, the unsung heroes, my backup team of people that are also affected. So, the thing about headaches is it's not just the patient. The patient is at the epicenter of the experience, but orbiting the patient are a lot of people who are similarly affected, so I'd have to include them in my story.

Jaclyn Duvall, MD:
Absolutely. And it's important that you have those supporters out there. Well, you've lived with migraine for a long time. And in the midst of that, you've almost become a professional patient at this point. So, I'd love to hear with so much experience what you wish people living with headache or migraine disease knew.

Michael Pollack:
Well, that we live at a unique moment in time. People have had migraines for as long as there's recorded history. Julius Caesar, Charles Darwin, there's so many documented. Thomas Jefferson, John F Kennedy. And in the current landscape, I think Serena Williams, Lady Gaga, these are all people who have made their journeys known, and then the millions of others of us who have suffered.

But the amazing thing is that at this particular moment, thanks to research and breakthroughs in medicine, we don't just have to suffer or use medications that were developed for other purposes that maybe help headache sufferers, but they're actually things that now exist that can really address the headache. And we benefit from that. So I just would love for anybody who suffers from headaches to know that there's more hope today than there's ever been. And that's really true. And we're going to talk about that.

Jaclyn Duvall, MD:
I love that. It's incredible because you're right. I tell my patients that this is not your grandmother's migraine, that our treatments have evolved for so long now, to the point that we are having migraine specific treatment options that are generally better tolerated, more efficacious. And so, we have so many patients that have perhaps not brought migraine up for so long because of fear of side effects or not being heard. And so I just encourage them to seek treatment again to see if maybe something different is out there.

Well, you've had a wealth of experience at this point about navigating various treatment options, both acute and preventive. And so, I wonder if you have some tips or advice in the world of migraine medications.

Michael Pollack:
I do, and I'm going to start by just flashing back to where that journey started with medical treatment. I think it used to just be take two Tylenol and maybe they made a dent. I can't remember that they ever did, not the severity of the headaches I got, maybe for someone else. And that's another interesting thing about headaches. Everybody has different kinds of headaches. But because someone else's relatively mild but annoying headache is what it is, they fail to realize the severity of the migraine sufferer. Or even if it's not a migraine, severe headache is a different animal. So someone else's Tylenol is like water to me.

But the first really serious medication that I think I was ever given was when I was in college, and I'd go to the infirmary with a horrible migraine and they would give me codeine. That was the narcotic level med, and it did take the pain away, or so I thought. What I now understand is it simply masked the pain for the period of time that it was in my blood, and hopefully I could fall asleep and maybe I could wake up without the headache. But it didn't make the headache go away, just hid the pain.

And that was the solution for like a decade, I suppose, of my life. Then over time, maybe I went to a neurologist, and they introduced other medications in different categories that may have helped, but I don't remember anything being significant. Certainly, nothing ever stopped a migraine once you got one. And then I think another category of drugs came along that I considered maybe escape because they did kind of get you out of the headache. They didn't always work, but they worked sometimes. So the journey has been progressive. But the miracle of the moment, at least for this patient, is the

existence of a whole new class of drugs that weren't even out there back then, the CGRP monoclonal antibodies. It took me years to be able to say that, but what I can say with no trouble is how incredibly effective they are for this patient.

I take a monthly injection, a self-injection. And I know some people are squeamish about oh, I could never do that. To which I say, the sting of feeling something for less than five seconds, if you count one Mississippi, two Mississippi, you stop even feeling that by the time you got to five. And if you compare that to the suffering that you know lasts for hours, if not days, it's ridiculous to think that you can't administer this kind of a treatment.

But this is my 45th month of taking this medication, and it's been 45 months that I have not had a single migraine attack. And in my life, I never went three months, or six months, a year. It's three and a half years, is amazing. So that's what I mean and I really just want people to know. I also know it doesn't work for everyone. I know other people have suffered like I had and have tried it and it had no benefit. I know other people have tried other things that did work that didn't work for me. And that, I think, is the unique nature of headache is it's really different for everyone in that it just makes it very complicated. But there's really hope.

Jaclyn Duvall, MD:
Well, I do want to point on a couple of very specific things that you've mentioned is that I'll have some patients perhaps not respond to the CGRP class of medications and they'll see themselves as a failure, what's wrong with me. And I think it's important to understand that we don't yet have a cure for migraine, that these treatment options for many people have been life changing and very impactful. But medications fail you, not the reverse. Patients are not failing. Their disease pathophysiology is different and that may not be the right family of meds. And I love hearing, you are what I refer to as a super responder to these type of medications. And we hear it in a number of different ways, complete migraine freedom, super response, etc.

And I do think it's important to set expectations before treatment with patients that although we're searching for migraine freedom, many of our patients see a 50% or more response and are just as thrilled as you've been. So, I think keeping in mind that complete migraine freedom may not be for everyone.

I wanted to go back. You and I have spoken earlier, and you actually taught me a trick that you used with one of your acute treatments. And I thought it could be helpful for some of our listeners.

Michael Pollack:
Yeah. Oh, I'd love to share it. Despite or apart from my great success with my CGRP therapy, which I can't say enough about, I do occasionally wake up in the middle of the night with a headache. Maybe the weather condition has changed and there are still triggers out there. It's not like I'm free of the triggers. And so, if I wake up in the night and I fear that I might be getting a headache. And by the way, that's just to go off on a slightly different thing. One of the things I've learned, really, through my knowledge at the National Headache Foundation, is the importance of acting quickly and being proactive. When you sense the signs of a headache approaching, reach for a solution sooner rather than later.

And I know other people I've talked to sometimes think I'll wait it out. Let me see. It's only mild right now. Maybe I don't have to take something for it. That resistance that you think is bold and strong is really weakening your chances of beating it. Because every successive hour, I think there's data that shows how much less effective meds that can be really effective if taken at the very onset. And once I saw some graph that just showed the reduction in effectiveness, I realized and I found myself preventing headaches that I otherwise might have succumbed to.

But back to my trick. The product that I use, if I take at onset is really effective, comes in pharmaceutical packaging that's really complicated to open. Either there's like a notch you have to fold and you have to twist. And sometimes when you refill that prescription, you're getting it from a different pharma that doesn't have that mechanism. You have to like find the corner that you fold down and peel off the foil. If you wake up in the middle of the night and it's dark and you have to find that item and you can't, you don't want to turn the light on, it's only going to exacerbate what you're already starting to feel. It's just so counterproductive to get to the medicine and to have to make your headache worse. So, I recommend, and it's very effective, when you refill your prescription and you figure out what it is and you're feeling healthy, break open those notches or peel back those corners, so that in the dark you can access that medication without struggle. And it will make your relief come that much easier. And it's so much less stressful, which I think also exacerbates the experience of the headache.

Jaclyn Duvall, MD:
Absolutely. I love having a plan before the migraine strikes. I even encourage you to let loved ones know what your treatment plan is. I have some patients who in the midst of migraine, the brain fog, the cognitive impairment, really makes it confusing for them to remember, wait, in my toolbox what do I go for first. I think of one patient in particular that her husband knows this is number one, this is number two as far as her medication order. But simply opening the package if you've waited until migraine hits can be challenging. So, making sure that you're familiar with that, that you know how to access it.

I want to go back because we've talked about preventive and acute treatment, but some individuals who are sort of starting on this treatment journey are unfamiliar with these terms. And I hope that maybe you could describe the differences in these treatments.

Michael Pollack:
Between preventative and acute, is that it?

Jaclyn Duvall, MD:
Yes

Michael Pollack:
The acute is you feel the headache, you're in trouble, you have pain and you need relief, so you've got to reach for something. And that leads you down the road of all those different medications. The preventative is the fantastic thing that I found in this monthly injection. I was prescribed like beta blockers, which I guess for maybe a generation were believed to have some preventative effect. I think when it was introduced to me and I took them for maybe ten years, I'm finally off of them because of the success of my CGRP. But I remember when I was introduced to them, I was told it won't stop you

from getting headaches, but you'll probably get less. It's not something you can even quantify. And I guess that's what your journey is with patients is just trying to improve the situation, hopefully solving it. But that's a big reach. And any progress that you can make. So I guess there's different levels of preventative, and you got to try them. And you have to find a practitioner who you really trust and feel that that collaborative spirit is there.

I think from the patient side of the table, when you hear things like, this doesn't always work for everyone, it does sound sometimes like, I don't want to say an excuse, but you're not helping me. You're protecting the fact that this may not help. And that's what it sounds like to the ones suffering. But now that I'm not on that more, adversarial side, I recognize the truth in that, what you say. And that must be hard, actually, as a practitioner, because you really do want to help your patient. And your patients sometimes may feel frustrated at the fact that that help is not as forthcoming as they wish it would be.

Jaclyn Duvall, MD:
Well, I think it is seeing one another and finding a great collaborative relationship moving forward. But I think many of my patients are very surprised when they hear about the option for prevention. Many people assume that we can only react to migraine or headache when it happens, but actually the ability to prevent attacks before they ever begin. We as providers tend to say 4 to 6 days per month of head pain days is where we start to look at preventive treatment. And many patients are surprised by this. But I also balance that with that acute treatment and particularly migraine specific acute treatment is important. We have studies that show us that poor response to acute treatment can have 2-to-4-fold higher chance of progression into chronic migraine. So, I love that you've touched on both of these and then the tricks that you've used.

Michael Pollack:
And let me touch on something else in that spirit. When I talk about the collaboration between the patient and the practitioner, one of the things that I find early in my journey was the tracking my intake of meds, keeping a diary. I'm a writer, so like keeping lists and noting my patterns is often revealing to me. And it's revealing because it gives you an objectivity about your situation that you lack if you don't record it. You don't realize how many pills you're taking a week or a day, how many attacks you're getting, how many times you've increased from level 1 to level 2 to level 3. And that information helps inform your practitioner so that they can actually take more aggressive or more knowledgeable steps. If you just come in and you ballpark what you think you've been doing, it's less accurate. And I think that that compromises what your partner can do in that.

Jaclyn Duvall, MD:
It is. And it turns out that with all of the things that our brains are keeping track of all day, we're not the best historians at remembering back to three months ago. And in fact, I'll have patients tell me, I think I'm using a rescue treatment 1 to 2 days a week, and a loved one says, we went through the entire bottle of over-the-counter in one month. And so those are things where tracking or keeping a diary, as you've mentioned, can be very helpful.

Michael Pollack:
And another thing that the diary can reveal are the triggers. If you note that it was a rainy day, or if you suspect that you drank last night, or you didn't sleep or you missed a meal, there's all sorts of triggers. I had one trigger that I used to commute on a train into the city, and if it was a sunny day and I sat on the side of the train that the light came through the trees in a flickering manner, I noticed, like I could get headaches from that. So, I made it my business to sit on a sunny day on the other side of the train. And these are things that you might not notice if you're not taking note. And it won't stop you from getting headaches, but it will reduce the frequency because you avoid triggers.

Jaclyn Duvall, MD:
We also talked about that you've run into times where you were bringing your provider so much information. And I told you that as a provider, I love patients who are keeping track, diarying, and really being a team player, really the quarterback of their healthcare. But sometimes as a provider, it can be overwhelming if a stack of data is brought to me. And so, talk to me about how you've learned about that throughout the process. What do you do now with your provider to communicate?

Michael Pollack:
Well, I still keep the diary. I don't share it anymore as a printout because her reaction, not unlike yours, was I don't need to look at all those pages. But the mere fact, like anything, if you write a note to yourself, you're more apt to remember what it is that you wrote than if you didn't write it. So, the mere fact that I continue, even as successful as I am, I got to tell you, I love that my diary has almost no entries in it. My one entry is every month when I do my injection, I write that I did that, and on the occasions in between that I reached for that other product I described, I note that because I'm on the lookout, like, is that increasing. So, when I go to a neurologist check in, I can say, you know, I've noticed I've been taking that more than I had earlier in my successful treatment. What's going on? So, then she'll think about it and we'll consider whether there's something to be done. So yeah, it just gives yourself knowledge.

You know, you always hear about you have to be your own advocate. You can't be your own advocate if you don't have knowledge about what's happening in your body and how your body is reacting. So, the diary, I'm really big on that. But again, what writer wouldn't be?

Jaclyn Duvall, MD:
I do want to go back to, you have had tremendous success with your preventive migraine medication. Can you talk to me about accessing that medication?

Michael Pollack:
Yeah. I hate to talk about it because it's such a frustrating process. And as great as it is to have discovered this, what I've also discovered is that now that I'm on Medicare and that just changes the whole landscape, that the medication that I used to be able to get through my employer cosponsored coverage at a very reasonable price, rose, I forget the percentage, but it was like 1,200%. I couldn't believe it. And when I presented the manufacturer’s coupon, which used to reduce the $35 three-month supply to $5, I was told. oh, that's not acceptable when you're on Medicare, which you would think that that's exactly when it should be acceptable. And then to make matters worse, I get a

notification from the drug plan I'm on that my very successful, proven medication, that I needed to qualify for by failing in two different steps to use meds that weren't necessarily developed for headaches and only then would my insurer cover me. but it was being dropped from the formulary. The formulary being the meds that that insurance company deems legit for their plan. But they were recommending an alternate in that CGRP category, which I was willing to move over to. I consulted the neurologist. I said, will this still work. She said, well, you never really know until you try it, but probably it should.

So I was willing to switch because they switched in the formulary. She sent in the prescription. It was denied for coverage. I appealed the claim. It was denied again. I could never get an explanation other than I did not meet eligibility requirements, which I had to have met to have gotten the first CGRP treatment.

And it's just been a never ending, horribly frustrating process to pay an enormous amount of money for a med that they won't even cover now for a reason they will not even give me. So, I hate to bring this out when I'm normally so positive, but this is a reality. And in my role at the National Headache Foundation, I've really become an advocate for access and for trying to fight for access, because I think so many people are suffering unnecessarily because they can't even access the meds that can truly bring them the relief.

Jaclyn Duvall, MD:
Well, and it has to be even more frustrating to have seen what good looks like and to be living your life fully with a medication that you're tolerating, and then almost have it pulled away. I can't imagine.

Michael Pollack:
Yeah, and I talked to a lot of people about this, and I get a lot of suggestions because I can't get it through my own insurance coverage. And like, is that what we've come to? It's really quite sad, but I don't want to dwell too much on it. I think I've put it on the table. And National Headache Foundation is going to really try to fight and improve that.

Jaclyn Duvall, MD:
Well, that can be so infuriating to have seen success with treatment and then almost have it pulled or ripped away from you. In fact, I've had some patients where if they've had a gap in effective treatment and they revisit it, it may not be as effective. But I also have patients that I want to touch on. And I'm glad you haven't necessarily experienced this, but so many of my patients have perhaps had a preventive medication that is seemingly doing a great job stop working for them. And I have to go back. We have to really, this is where things like diaries keeping track of symptoms can be very helpful, because sometimes it's not that it stopped altogether. I tell people that even with migraine prevention that there are highs and lows. There are good months and bad months because it's not a cure.

And so perhaps without that preventive, the low could have been even lower. And maybe it is simply pushing through that low time or finding additional ways to manage during that time. But sometimes we need to revisit treatment and that really that preventive has stopped working and we need to pivot to something new or different.

Michael Pollack:
I have a question for you on that subject. It's not my experience, but I've heard from others who suffer from headaches that whatever they've been taking as a preventative, it's not that it's stopped working, but they've had to up their dosage. Is there a point where you realize you're a ceiling and if you need this much, we need to look into something else. Does that happen?

Jaclyn Duvall, MD:
Certainly. We call that in the medical world tachyphylaxis, where you've almost developed this kind of resistance or the medication just isn't doing what it was before. And so sometimes you have room and simply the answer is increasing the dose of the medication. But absolutely there are dose range that are safe and therapeutic. And so, if we're getting to an upper window and we're still not seeing that efficacy we're looking for, I think it's time to reconsider.

And sometimes when we find these medications perhaps are not working, individuals, of no fault of their own, can get into this pattern of taking their rescue treatment too often. And that's a condition we see as medication adaptation headache, where as a result of taking rescue treatments too often, headache frequency can actually increase. And this is a vicious cycle for individuals because they're trying to manage day-to-day life and function, not recognizing that perhaps the rescue treatment they're taking could be part of that culprit. It's almost a double-edged sword, as I tell my patients.

Michael Pollack:
And to keep coming back to it, that's where the tracking of how much you're taking and how often you're taking it can be very revealing, because when you're in the day to day, you're just kind of reaching for the relief without looking at the larger picture.

Jaclyn Duvall, MD:
Certainly. Sometimes people will come in and say they're fine or they're doing okay. Or sometimes I'll have patients who maybe think that they need to settle. Looking back, were there treatments that you sort of just settled for? And what did that look like for you?

Michael Pollack:
I think I touched on that in the fact that I tried meds that worked to a point, and I accepted that. And then I just paused in seeking more. You know, as a headache sufferer known in your family and community as such, whenever there's a report on the news about, you know, or some product is good, some discovery, some breakthrough, I've probably heard about it already anyway. But there's often a lot of information coming your way. And 9 out of 10 of it is I'm not eligible for, it’s inconclusive. And people are well-meaning, but it's a tedious process to filter through all of that. So, you just kind of, at least I probably just step back, and I don't want to hear it anymore. I think that's what this patient's reaction was, not particularly good one. And then, like I said, somebody has to push you and say, isn't it time to check in and see what's new.

Jaclyn Duvall, MD:
Well, managing migraine is also about balancing everyday life. And you mentioned your family, but also we've talked about a career. And so, I'd like to hear in your words about that balance between a chronic disease and life.

Michael Pollack:
It's hard. It's really hard. And if you take your job seriously and you want to show up and you're professional, then you can't let a headache stop you. But a headache will stop you. And there are times that you simply cannot show up. And in certain circles, that's really unacceptable. How do you balance that? You find an empty office. I worked for a long time in a creative corporate atmosphere, and I would sometimes have to find an unoccupied office to lay down in, or I'd have my head down on my desk and close the door. And it was an odd dynamic. It sent a weird signal. People are uncomfortable. They don't want to see that.

If I had an escape med, which I did, which was also an injection that you have to get a little undressed to administer. So you'd have to go to a bathroom to do it. Or when you're having a migraine attack and you are nauseous and you have to throw up, and you're in an office environment where there is no place to do that other than a shared stall situation. It's just a horrible, humiliating thing to have to do that in your office where you try to show up and be a professional. So, I wish that workplaces, I know I've heard of certain workplaces, and maybe in today's more progressive environments they have safe spaces that you can retreat to, or dark room where you can get a little rest and administer some medication and give it time to work, but in my day, that was not available and it made a bad situation worse. And it made it worse for those around me who had to pick up the slack and be on eggshells around me for that period. The one silver lining to it, I will say, is that when I came out of that headache, which might not be till the next day or the day after, there's an unexpected high of sorts, and I would be hugely productive and very much wanting to overcompensate in my gratitude to those who helped me out. So, I became a super worker. But I would never want to be in that position again.

Jaclyn Duvall, MD:
I think your story is so similar to many individuals and oftentimes trying to suffer in silence is a theme I hear recurrently. Well, we're going to wrap things up and I want to highlight that I think your story in and of itself, Michael, has been one of hope. But I wondered if you might have just any last bits of hope for those living with migraine.

Michael Pollack:
Well, I circle back to the opening note. We really live in an amazing time and we're part of a community, a really great community. There's millions of people. I think the stats are like one out of four households in this country. There's a brotherhood of people who really understand what it is. You know, if anyone around me shows the slightest sign of a headache, I am there for them. I used to carry escape pills with me everywhere I went to always have. I don't anymore because I don't need them. But they're never really far from me because I know that there's other people who need, I mean, I can't give them the things that are prescribed, but things that at early onset I can give them that might help.

And everybody knows that if I'm in the room and they need that kind of relief, go ask me, because I'm not going to be far from doing that. So, there's a secret brotherhood out there. And so that's one thing I'm happy to report.

And also to just underscore what I've said before, the med that works for me doesn't work for someone else, but something that works for someone else didn't work for me. So you got to keep looking and you got to keep hoping, because there really can be a better life than one where 15 days, 6 days, even 1 day a month is it's just too much to lose out of your life.

Jaclyn Duvall, MD:
Thank you so much, Michael, for your insights, your experience. This has been a great episode learning about managing life with migraine. So, I want to thank you again. Thank you for joining us. We hope this conversation helps you feel more informed, empowered and confident in managing your headache and migraine.

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

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