NHF InSights Series 3: Migraine and Comorbid Conditions
Episode 1

Katy Oakley:
Welcome to NHF InSights, the National Headache Foundation's podcast developed with our industry partners. This is where we talk about what's new in migraine and headache care, from the latest studies and research to real world experiences and treatment options. I'm your host, Katy Oakley, CEO and Executive Director of the National Headache Foundation.

For many people, migraine does not happen alone. It often shows up alongside other conditions like sleep apnea, IBS, or fibromyalgia. Today we're going to be talking about why that is, how it can affect your treatments, and what it really means from a day-to-day life perspective. Stick with us for upcoming episodes, because we're going to dive deeper into some of the topics as well, for instance, sleep and migraine, or migraine and anxiety and depression. The series on migraine and comorbid conditions is supported by Axsome.

Now let's get started. I am pleased to introduce today's guests. We have Dr. Fred Cohen, who is an assistant professor of medicine in neurology at the Icahn School of Medicine at Mount Sinai in New York. Dr. Cohen is actually one of the few headache specialists in the country who is board-certified in both headache medicine and internal medicine. He is also a board member of the National Headache Foundation. Welcome, Dr. Cohen.

Fred Cohen, MD:
Hi. Thank you for having me.

Katy Oakley:
Thanks for being here. And we also have Nancy Harris Bonk who is a patient. Nancy lives with migraine alongside other conditions. She is a leader in the migraine and headache community. She's one of our Patient Leadership Council members at the National Headache Foundation. She also volunteers with Chronic Migraine Awareness and serves on the board of the Alliance for Headache Disorders Advocacy. Thanks for being with us as well Nancy.

Nancy Harris Bonk:
Thanks for having me. It's a pleasure.

Katy Oakley:
Dr. Cohen can you explain to us what comorbid or co-occurring conditions mean and maybe give a few examples of what you frequently see with migraine?

Fred Cohen, MD:
Sure. So, comorbidity is just a condition that's commonly seen with another condition. So, in this case we're talking about migraine. Migraine has a lot of comorbidities. So, the common ones is from anxiety, depression, sleep conditions such as obstructive sleep apnea or insomnia. We also see several kinds of abdominal conditions. When you think about it migraine has nausea, gastroparesis, and things like that. So, it's just conditions again that are seen. And it doesn't mean one leads to another like friends. It doesn't mean if you have migraine, that means you're going to develop depression or a stomach issue. No, it just means that there are correlations that have been established that we see these together.

Katy Oakley:
Yeah, that makes sense. Why is it for migraine that there's such a link with so many other conditions?

Fred Cohen, MD:
Well, I guess you could think of it like this. What controls the body? The brain. So, this is something that's happening up in the brain. The brain has control of everything. And that's one reason that I think why we can see with so many different things. What's the brain doing? It's stimulus.

So, in a migraine, you can think of like this almost over stimulus. There's a lot of these pain signals going off. And it's why then we can see other conditions as well, because again we're dealing with the central computer of the body. And of course, being in a chronic state of pain can invite a whole slew of other problems. I think that's why we can see a good number of comorbidities when it comes to migraine.

Katy Oakley:
Yeah, that makes total sense. Nancy, you have lived experience, and I'm really excited for us to bring in that perspective into conversations like this. Can you talk about what your journey has been like living with migraine and having other comorbidities?

Nancy Harris Bonk:
Sure. I started my migraine journey back when I was getting my menstrual cycle and my attacks were easily managed with over-the-counter medications. That all changed in 1996 when I fell on concrete carrying my son to the car to run some errands, and I sustained a traumatic brain injury. That then began my life with chronic migraine, chronic head and neck pain.

And I really believe that triggered a lot of my chronic conditions that I have, which include Sjogren's, mixed connective tissue, fibromyalgia, restless leg, and a few genetic issues, conditions like high blood pressure, hypothyroidism. And it's really challenging living as a chronic pain patient with chronic migraine and all these other comorbid conditions. It takes a lot. It's taxing.

Katy Oakley:
It's a lot of specialists, a lot of different doctor's appointments.

Nancy Harris Bonk:
Yeah. I see a neurologist in addition to my primary care who acts as the captain of my ship so to speak. I see a rheumatologist, a neurologist who's a headache expert, a podiatrist, a cardiologist, a hematologist, and an ophthalmologist. So just managing all that is a lot. It could be a full-time job.

Katy Oakley:
Yeah. Yeah, absolutely. Dr. Cohen, I'm curious why it can be hard to manage multiple conditions at the same time.

Fred Cohen, MD:
Well, that for someone, I guess to answer that is unique for everyone, depends on their condition. But absolutely that if you have multiple conditions that are both heavy weighing, it's only so much you can do in one place. As Nancy said, one of the most important things as a primary care doctor, as a provider, as the captain of the ship, you know prior to being a headache specialist I was a primary care provider in the Bronx, where I did my residency, and a lot of what I was doing was keeping track of my patient's condition. They come for a visit, okay, your blood pressure, your kidneys, this and that. And a good number they might have forgotten about. And that's my job. I have to make sure that these were still on track, being treated, not forgotten about. And it could be difficult. If you're listening in and you have one condition, I don't want to say count your blessings. I'm not trying to come off negatively.

Yes it's common to take our health for granted. It's easy to find it difficult when you have to manage multiple things and there's only so much energy and resources we have, that it can be very difficult to manage multiple conditions, let alone when they're both active in different ways. You have a foot issue, a head issue, etc. Especially if you don't have help, it can be rough.

Katy Oakley:
Yeah, absolutely. Nancy, on your side, can you speak to the challenges that you've experienced by managing a number of different specialists as we talked about and appointments? Share a little bit more about your experience if you can.

Nancy Harris Bonk:
Sure. As Dr. Cohen mentioned, living with these co-occurring conditions can be exhausting. And I find one of the issues is there are some days where I don't know what's causing what pain. The last few days I've been struggling with a migraine I can't break. So, I called into my doctor, and she's going to hit me up with some steroids for a number of days.

I don't typically do well with the short taper, so she's going to extend it a few days. So, we have that component. My joints are killing me because of the weather. So, is that mixed connective tissue or is that Sjogren's disease? My restless leg has been out of control, I think because I'm not sleeping well. So it's an exhausting process. And I don't mean to be a Debbie Downer, but the facts are it's exhausting living with multiple comorbid conditions.

Katy Oakley:
Yeah. And that's exactly why we want to talk about it, because it's so common for people who live with migraine to get to the bottom of it, to give help and support and how we can make it better. So, let's actually talk about that. Dr. Cohen, when it comes to treatments, how do you see providers working together across specialties to support patients?

Fred Cohen, MD:
When I'm seeing my patients for their headache disorders and migraine that I bring up the other conditions. And when I recognize that maybe something is not being well managed, then I raise it as a point. Now, unfortunately I can't treat everything as much as I want to. And being my background in primary care, I still fall in the habit of all right let me do this. But it's like, okay, hold on, I only have so much time with the patient. Let me take care of the headache part.

So, one, I make sure that they are following with their primary care. You'd be surprised. Sometimes I talk to my patients and they're like I haven't seen my primary in three years. And I'm okay, first things first. Primary care is most important doctor. Listen, cardiologists, surgeons, I'm sorry, guys. Even headache doctors, we're not the most important. PCP is, because that's where everything gets kept together. It keeps the wheels spinning. So, I make sure that they do follow up with the primary care, and I say, hey, listen. And I write it down. I want you to talk to your primary care about blood pressure, about this, about that.

Now, given my background, if I could start the ball rolling, I try. I send a lot of sleep studies off because I know how to prescribe that, maybe start a blood pressure med. It all depends on the patient and what's going on. I try to, but again, because I'm a specialist, I'm not able to follow this up. I don't want to leave something unmonitored. So, the most I would say, if you're interacting with your specialist with this, that it's the message of, okay, I need to follow this up with that kind of provider. So, it's making sure a follow up happens.

We can all want to know it's like we discussed. I'll give Nancy as an example, okay, mixed connective tissue. We discussed it and patients always usually follow up in two weeks. I know cool she has follow up versus she's like oh I'm not sure when I'm seeing my rheumatologist next. Okay. Well let me solve that. Okay. Well, you need to set an appointment within 30 days, etc. So now, while before she saw me, there wasn't an established follow up and now she'll be like okay cool, I got that accomplished for that problem.

Katy Oakley:
Yeah absolutely. Can you also speak to treatment options if there's overlaps that could help other conditions or even hurt other conditions that you have?

Fred Cohen, MD:
Sure. So, I mean this is how we decide what medication, one of the reasons why what will dictate what treatment to start on migraine. I can't talk about other conditions, but I'll give you an example. If someone came to me, they had blood pressure issues and migraine. Okay. We have several medications that have good evidence for migraine, such as propranolol, metoprolol, candesartan. These are blood

pressure meds that will now two birds with one stone. Is sleep an issue? Okay. Treatments like amitriptyline, nortriptyline, which are common first line treatments will help with that. Is weight loss an issue? Topirimate has that as a side effect. Vice versa, are there contraindications. Topiramate, if you have a history of kidney stones, I'm not prescribing that. Or in the setting of, and let's say you are under the blood pressure meds, then I'm not going to give something that could exacerbate that. So those comorbidities do take a factor in what treatment a headache specialist will prescribe.

Katy Oakley:
That makes so much sense. It's really great I think when you can have a holistic approach and look at everything that's going on to see if you can support other comorbid conditions.

Nancy Harris Bonk:
You know, many times if we do have sleep issues, an antidepressant like amitriptyline will be used. But sometimes from the patients I've spoken with the message gets missed. All they hear is I'm taking an antidepressant. So, they're thinking, I don't need an antidepressant. I'm not depressed. And somehow we have to get providers to get a little more in tune with how, I'm not saying that to you, because I know you explain things very nicely.

Fred Cohen, MD:
Yeah Nancy.

Nancy Harris Bonk:
If the provider is saying here's an antidepressant for your sleep, they're not going to hear it's for sleep. They're just going to be stuck on the antidepressant.

Fred Cohen, MD:
Correct. When I prescribe these medications, I make it clear. I do tell them the class. I'll give amitriptyline… I'll do Topamax because that one does concern a lot of patients when they hear about it. I explain this is an anticonvulsant that came out many years ago but was later on to find evidence for the treatment of migraine. You're not getting the same dose as one would use for epilepsy, which that's the key thing. Same thing with depression. You're not getting the dose designed for that. You're getting a dose designed for migraine. I make that very clear. Because again, you're absolutely right, I can't tell you how many times patients get very and they're right to think so defensive because hey, whoa, I don't have depression. Put me on a blood pressure, put me in a seizure drug, are you crazy? And it can absolutely seem misleading.

But that's the world of medicine. A lot of drugs have multiple purposes. The biggest example is Viagra. Viagra was not invented for erectile dysfunction. It was created for people who have high blood pressure in their pulmonary artery. That was the purpose of it. Then they found a little neat side effect and it's given for that. But that's a common story with a lot of medications. And migraine meds are not exclusive to that.

Nancy Harris Bonk:
Yeah. And I think patients are so used to being gaslit by many providers, the public in general. And then the stigma and the self-stigma and the external stigma that play part in migraine disease and other comorbid conditions. That's something we all really wrestle with. And getting a good provider to be able to explain things so we get it, maybe the first, maybe the second time, is so important.

Katy Oakley:
I couldn't agree more. I had a head injury ten years ago, and all of the things that you just said Nancy was what I experienced when I was starting the first round of treatments. I didn't understand it. So, I think providers talking about it, but also patients learning about it and understanding that treatments can be used for multiple different conditions. And as Dr. Cohen mentioned that there's an array of different reasons why a medication could be prescribed.

Nancy Harris Bonk:
Early in my journey I was prescribed lithium for chronic head pain. And they didn't tell me anything about the drug. Of course, I looked it up when I went home. I was like, what is this? And it made me so sick for a week that I stopped taking it. Now had I continued it and maybe that side effect would have lessened, but I couldn't do it. So, there's a prime example of giving me a medication that I had no clue about, and I took upon myself to figure it out, which we are own best advocate. We have to advocate for ourselves. But I've been on so many things without a good enough explanation, but that doesn't happen anymore.

Katy Oakley:
Yeah. It's such a good point. Nancy, I'm curious on your side, you are such a really thoughtful person and really great patient advocate. What tips have you experienced that have worked really well for you when managing conditions across different providers? And I mean especially the treatments of making sure that you're finding ones that work best for you.

Nancy Harris Bonk:
A lot of questions, and I realize recently that a lot of doctors are not real thrilled with a lot of questions. So, I'm careful on how I phrase a question so not to put someone on the defense. And I don't mean to be a negative slur on all medical providers because most of them are wonderful. But when you see a provider over and over and over again and you start asking questions, that happened with my previous cardiologist, he just retired, and he looked at me at one point and he was like, you know, you have a lot of questions. I was like, well it's my heart and my health. I should have a lot of questions, shouldn't I?

So, keeping track of everything, there's one tip. Scheduling appointments when you need to. As Dr. Cohen said get in with those specialists when you need to. Keep track of all your information. Keep track of your clinical documents and advocate. Be your best advocate because you're the expert in your body regardless of the stigma and the gaslighting that goes on.

Katy Oakley:
Gosh, I love that. That's seriously such great tips. Dr. Cohen, any thoughts on your end of how a patient could approach a provider in the best way when they do have a lot of questions?

Fred Cohen, MD:
As Nancy was saying, you are your best advocate. Every doctor is different, meaning that I can't tell you how many people see me and they go, oh, you're different. First of all, there's doctors like me. I'm not some Messiah doctor, like, oh yeah, I'm the best. No, but you know, so meaning it's easy to paint the one brush fits all.

And also there could be a lot going on their end. Unfortunately, one of the biggest issues in healthcare is giving, and I'm not trying to get political given there's been decrease in reimbursement with visits, it's sort of forced doctors. We have to see more patients, hence less time. People always say, oh, I don't get to spend a lot of time with doctor. I'm like, it's usually not a decision by their part, it's just what has become of our healthcare system.

And when it comes to advocating for yourself, bring it up. You might be surprised because again, especially in primary care, when your provider is thinking of five different things, they may not realize that this headache is as cumbersome as it is, unless you make that known. And vice versa, if you're seeing any kind of neurologist, headache specialist, I can't say enough, speak up about something because they might not realize it's a concern for you. Such as, oh, I really feel uncomfortable with this side effect. Oh, I really don't want to be in this class of medication. If you bring up your opinion, they might be, oh, you know what? I can offer an alternative because I wasn't aware that this was impacting you as such.

So that's why I always encourage, it should never be. The sign of a bad doctor, and I'll say this, is being dismissive. When a patient brings up anything and they're like, oh, I'm sorry for asking this. I say, no such thing. I mean, only say sorry if you're insulting me. Otherwise, there's no such thing as a silly question. Bring it up. That way, because the last thing I want to happen is you leave the office confused, and therefore that you're not able to follow the treatment plan and then you're not feeling better. I always say, if there's an issue, bring it up.

Nancy Harris Bonk:
Yeah, that's a great point. I saw my PCP, I think it was in April, and we had a lot to go over. And I had my list and I checked my list off, and she was very responsive. She's a fairly new PCP to me. She spent over 25 minutes with me, and at the 15-minute mark, I was getting apprehensive for her because I know her time is very valuable and I'm sure she had a waiting room full of patients.

So here I am as a patient trying to get the best care that I can, worried about the doctor who's got to see more patients. She was fabulous. I was so impressed that she thought of things that I hadn't even thought of, which was a first in my 63 years of seeing doctors.

Katy Oakley:
Yeah. That's so great that you found a provider. I think so much of it, it's a partnership. It's a relationship that you have with another person, and you definitely want them to be understanding you and believing you. Yeah. Yeah, absolutely.

Dr. Cohen, I'm curious about if people have a number of different conditions, how do you prioritize? What tips would you give there? Especially because there is a little bit of a chicken or an egg, right? If I'm not sleeping, it could lead to migraines, or my migraine attacks could prevent me from sleeping. What advice would you give someone for prioritizing?

Fred Cohen, MD:
It's a little bit difficult. That is a question I get a lot which is meaning which was first. And there's not a unique answer to it. It can really go both ways. Meaning again, assuming we're talking about, because again I think of this from a primary care standpoint, assuming we're talking about a condition that is a known comorbidity.

I'll use sleep as an example. I don't dig in too much of which came first. I got to treat both. The how they respond to treatment dictate, all right, what is sort of responsible for the other. For instance, if by treating migraine, sleep gets much better, okay then we know, versus the other way around. The point is to treat both. I don't really, unless there's such a clear, obvious answer that someone's getting like horrible, basically no sleep, someone comes to me and they only get an hour sleep, okay, well I need to address that. But if it's great I treat both, and we see how they improve and adjust.

Katy Oakley:
So, Dr. Cohen, when there's multiple providers involved and there's a side effect of a medication, how would you deal with that?

Fred Cohen, MD:
Depends. Because what's the medication, the side effect, how necessary is that medication. For instance, is it something like a blood thinner. That can be very serious that you need to be on. Versus is it something not. And if it's something let's say that is necessary, then it's like, okay, hold on. That's a very serious drug that you still need to be on. We need to talk to your doctor right away.

Or let's say if it's not that serious of a treatment, I might get involved and say, all right, discontinue this for now. And always let the doctor who prescribed it know. But it all depends on what is it for and how serious of a side effect. If it's like you have very difficult blood pressure and we need that to maintain it, okay, we may not want you to stop that. I understand it might be making headaches worse, but not to minimize pain, I want to keep you alive. So again, it depends what the drug is for if I get involved in stopping it.

Katy Oakley:
That makes total sense. Nancy, before we close the conversation out, I really want to make sure that we talk about what it's like to live with comorbid conditions. It's exhausting. It's daunting. And I'm

wondering if there's any wisdom that you can share on that front, because it is a unique experience that not everyone in the world lives with.

Nancy Harris Bonk:
Yeah. It is. It's a unique experience. And you're right, it's exhausting, daunting, and frustrating to be perfectly honest. What I've learned in my journey is when I first started out, I wanted to know what would the cure was, how to fix it, and what the root cause was. As I've lived with all these comorbid conditions and migraine disease, I've come to realize that's not necessarily the most important thing, to me anyway.

The most important thing to me is how do I live my life with these diseases, sort of like in spite of them. Because, I mean, they're going to be there whether I go to the grocery store and have a migraine attack or stay home and have a migraine attack. I'm not trying to make light or be flip about things, but I seem to, by shifting that thought process has helped me navigate things a little smoother. And again, being your own best advocate and not giving in to self-stigma is really important.

Katy Oakley:
It really is so important. I know when we talked about this previously, sometimes folks feel like they're collecting diseases and that's not the case. Like Dr. Cohen had mentioned, everything is interconnected, so it would make sense for there to be additional conditions happening simultaneously.

Nancy Harris Bonk:
Right. And I didn't set out for my life to look like this. I didn't want to collect diseases. This has upended my trajectory, my career, my family life. My marriage dissolved. So there's some real negatives. But on the other hand, there's some real positives, because I'm really passionate about helping people and being a patient advocate. But none of us asked for it.

And the other thing is, since we didn't ask for these diseases, we're not all equipped on how to deal with them. So, I'm a big proponent of getting some therapy. Now, I know when I say that people are going to be like, I don't need therapy. There's nothing wrong with me. That very well may be true.

Fred Cohen, MD:
I'll say it. Everyone needs therapy. Put it on the record.

Nancy Harris Bonk:
Well, exactly.

Katy Oakley:
I agree and second it.

Nancy Harris Bonk:
Because you can learn some wonderful coping mechanisms. Like I said, we weren't born to live with chronic illness, excuse me, the majority of us aren't. So it's not an easy thing. Coping skills, strategies, just how to get by on a daily basis, a therapist can be a wonderful tool. And you don't have to do it for the rest of your life.

Katy Oakley:
I love that. I think your mental health is such an important piece of the puzzle, especially when you're managing a number of different conditions at the same time. Because it is. There is an impact to your life. It's kind of hard for it not to be. Do either of you have any last-minute advice or things to add that we maybe didn't get a chance to talk about?

Fred Cohen, MD:
My main thing to say is that no one should suffer in silence. This is why I take action in the National Headache Foundation, AHDA with Nancy, Miles for Migraine, because there's so many people out there who are not aware that they're dealing with migraine. I didn't know I had migraine until I was 25. I just was like, all right I have a strong headache once a week and that was that. This is a story I get told every day at work. Really like there's always stuff that can be done. No one should feel minimized by their provider from their migraine or any of their health conditions, and to always advocate for yourself.

Katy Oakley:
Yes. Gosh, I'm so grateful for both of you. I feel like your personal and professional experience, I mean, that's exactly why we're having conversations like this, is to shed light on it, to have people be aware of that they are not alone, and that there are really great resources out there to people to help them to navigate the journey. So, thank you both so much for being here.

And for our viewers out there, thank you so much for your time today. We hope that you learned something and that you stay tuned for the next episodes of this mini-series of NHF InSights supported by Axsome. We will do a deeper dive into sleep, anxiety and depression, is what's next on the schedule.

If you have any questions on these topics or other conditions, please let us know in the comments. We would love to hear from you and to help you in whatever way we can. Thank you so much and have a great day!

This episode of NHF InSights was sponsored by Axsome Therapeutics.