HEAD Wise

Episode 263: Navigating Access to Care

Lindsay Weitzel, PhD:
Hello everyone, and welcome to the videocast and podcast of the National Headache Foundation. I'm Dr. Lindsay Weitzel. I'm the founder of the education and support group MigraineNation, and I have a history of chronic and daily migraine that began at the age of four. Our guest today is Dr. Deena Kuruvilla. Hello, Dr. Kuruvilla. How are you?

Deena Kuruvilla, MD:
Hi, Lindsay. Good. How are you?

Lindsay Weitzel, PhD:
I'm good. Dr. Kuruvilla is a board-certified neurologist and headache specialist. She is also the director of the Westport Headache Institute in Westport, Connecticut, and an author and tech developer of BrainHealth MD. She is here today to talk to us about access to care. She's going to teach us all sorts of things that are going to help us with insurance and getting the things that we need as people with headache, migraine, etc.

Let's get started. Dr. Kuruvilla, I was talking to someone recently who was sort of accepting their first medication denial as if it was fact. And I remember they said that they just did not want to call their insurance company or ask any questions because they did not want to be seen as a pest, and they didn't want their insurance company to be mad at them. So, as a headache specialist, can you tell our audience how you see the dynamic between patients, insurance, physicians, and what role patients should play?

Deena Kuruvilla, MD:
That is such a complicated question, and I wish I had an easy solution. But let me start off by saying that asking questions does not make you a pest. Every patient should know that your insurance plan is a contract that you pay for with your designated insurance company, and so you are entitled to ask as many questions as you want. You're entitled to ask what's next if this is not covered, what can I do to appeal this. And you're entitled to continue to talk to different people within the insurance company.

So, I often tell people that try to keep notes if you can. I know it can be very frustrating and write down the names and times of people that you've spoken to. And your biggest advocate when you're trying to get your medication covered is definitely your clinician. Sometimes clinicians have little tips and tricks that we have in the background that can help us get medications covered a little bit more easily. I have my nurse ninja, who fights to the death for medications and to get things covered for patients as much as she can. And it's unfair, right? It’s unfair. The fight is unfair. I should say that as a bottom line. But it's

what we've had to do to get people the treatment that they need So I see the patient, the clinician, and the insurance company as a cycle, a life cycle that goes on and on. But it can be a vicious cycle at times.

Lindsay Weitzel, PhD:
Can you talk to us about the fail-first system? What is it, and what can patients do to navigate it well?

Deena Kuruvilla, MD:
That is a great question. Let me start off by saying that the fail-first system, or the step therapy system, is not something that we represent in our medical guidelines. So that is something that is invented by, produced by insurance companies, and doesn't necessarily match up to what the medical community writes in their specific guidelines.

So, to first start it off is on the insurance side, the fail-first or step therapy approaches are when you need to fail one, two or three treatments in order to get the treatment that your clinician has prescribed for you. And the prime example of this in our world is the newer CGRP medications, which were developed specifically for migraine. It's a disease-specific medication, but many insurance companies require us to go through seizure medications, blood pressure medications, and depression medications before they will cover that newer CGRP treatment. So, it doesn't make a ton of sense, especially because we know, Lindsay, that so many people with migraine don't get away with just one preventive. We often have to add or layer different preventive treatments, especially if somebody has chronic migraine.

Lindsay Weitzel, PhD:
Thank you for answering that. That's so important, because it can be really frustrating and take such a long time to get the treatment we need. But another term that people should be familiar with is medical necessity. How can patients document and report their symptoms so that they are most likely to convey how much they need certain medicines?

Deena Kuruvilla, MD:
In my experience, patients and clinicians should always end up documenting how many days a month do you end up having any symptoms related to migraine at all. We know that migraine is not just a headache, right? It can present as neck pain, brain fog, dizziness (or vertigo is the other term for that), sensitivity to light, loud noise. So how many total days a month do you have any of those symptoms. Oftentimes we make the mistake of only documenting the headache days. And that's not a representation of the total number of days that one might be disabled. That's the biggest thing I would have to say that I see is a mistake in many notes is just documenting those few headache days but not getting the general picture.

We also want to know how often you're needing your as-needed medication. That's another big factor that I, as a clinician, am responsible for writing in my notes. And that if you can keep as a part of your records the same type of information and share with me, it can really help to get treatments covered more efficiently. And I would say having some type of disability marker would be helpful too, how many days a month do you have to miss recreational activities, school, work, time with your family and

friends. The more you write about functional impairment can definitely help to cover treatments as well.

Lindsay Weitzel, PhD:
That's very helpful. Some of this is dependent on how your provider reports this information to the insurance company. If a patient is working with a provider who is not experienced in pushing through approvals for migraine medications, do you have any ideas on how this patient can work to sort of take ownership of the situation?

Deena Kuruvilla, MD:
Absolutely. I will say I have had a few patients lately who have emailed me before their appointment with a really beautiful history and a list of everything that they've tried in the past for treatments, for preventive treatment of migraine and the as-needed treatment of migraine. And I have found that incredibly helpful. So, keeping your own diary and your own log and sending it electronically to your clinician can be so helpful because we can just include that in our notes.

The other thing that you can do, a lot of patients are telling me now they can communicate with their insurance company via phone or even through chat or a text. To save a little bit of time, you might be able to multitask in that case and ask your insurance company, what's your drug drugs coverage criteria. Please email that to me, to me the patient. Show me the clinical policy and your prior authorization criteria. Once that is in your possession, you can also make sure that when you go to your visit, everybody's prepared. Okay, we have to do this, this and this to get this covered. And I would make sure that no matter where you go to see your clinician, that they have a specific person who's dedicated to prior authorizations. They're able to jump through those hoops a little easier that way.

Lindsay Weitzel, PhD:
Talk to me about appeal and denial. Should we just expect denial sometimes? I know that I'm at the point with how long I've been a patient, how long I've been doing this, that I don't even really bat an eye at a medication denial. And I kind of feel like people maybe should get there so that they don't panic, don't get nervous or anxious if you get a denial. It's just sort of part of the process. So, can you talk to us about appeals and denial?

Deena Kuruvilla, MD:
Absolutely. This day and age, it is much more likely that you will get a denial than an approval. The reason for that is that the payer world or the insurance world has not caught up with how fast we've moved in science. And so, with that said, just as an example, maybe you've been through this Lindsay, I'm not sure, but the payer will say you need to go through topiramate, and you need to go through propranolol before we're going to cover atogepant for migraine prevention. And so, most of the time when we're writing for that migraine disease specific medication, it's getting denied. Like you said, I always expect a denial, and then my nurse will start the process of appealing it.

And oftentimes we get a choice. It's either going to be an appeal or it's going to be a peer-to-peer where I as the clinician need to speak with somebody at the insurance company and we have to battle it out, over the phone of course. So, there is, I would say 95% of the time, there is something that can

be done. So don't take no as an answer right away and be at peace with it. They usually want you to come knocking a few times at the door of that insurance company to get things covered.

Now, that example that I gave, the topiramate versus propranolol, needing to try those first before getting something like atogepant, doesn't make a lot of sense, right? We have the guidelines that came out just a few weeks ago from the American Headache Society and the American Academy of Neurology that says that we should be considering topiramate, propranolol, and some of the CGRP medications such as atogepant or galcanezumab first. So, we just need payers to catch up with the medical science that's just really pushing forward into the future.

Lindsay Weitzel, PhD:
So, my favorite topic is manufacturer assistance programs. They are everywhere. If you're paying money out of pocket for any of your medications, please listen up. Let's just talk about what these manufacturer assistance programs are.

Deena Kuruvilla, MD:
They are so underutilized. And part of that, Lindsay, is that many larger hospital centers now do not allow samples and do not allow co-pay cards because they're seen more as a branding tool. A lot of people don't know about these programs, including pharmacies. And so, there's three types of manufacturer assistance programs.

There's the most common one which is called the co-pay card or the savings program that's available for commercially insured patients. Once your clinician writes a prescription, you can activate the co-pay card. Especially if it's a newer medication it probably has a co-pay card. You can find the co-pay card for free online just by googling the name of the medication and activate it. And then when you go to pick up your medication from the pharmacy, you share that with the pharmacist. Oftentimes, there's a QR code that they can activate, and the company will take care of your co-pay for that medication. So, this has been really helpful for so many because the co-pays for some of these newer medications can be incredibly expensive.

The second type of program is the Patient Assistance Program. It's usually income based. And typically, my nurse will fill out paperwork for that Patient Assistance Program highlighting the income of the person that we're applying for and stating what type of insurance that they carry or don't carry and put some other information in there and submit it for review by the drug company directly. And if approved, the pharmaceutical company will provide the drug for free.

The third type of program is the bridge or quick start program. Once your doctor has written for one of these newer medications and we're waiting for that prior authorization, appeal, peer-to-peer process to happen, it can be a while, the company may supply you with that medication while that coverage is pending. So, these are just three different ways where you don't have to delay your treatment, and you can get started sooner hopefully.

Lindsay Weitzel, PhD:
The bridge one is one that we don't hear about very often, so I'm glad you brought that up. That one is super interesting and all of them are so underutilized. So, thank you so much for that.

Something you bring up in your work on access to care is the importance of coding and documentation. Is this information only for healthcare providers, or do you think there's a way for patients to use this information to help themselves?

Deena Kuruvilla, MD:
That's a great question. I hate personally putting administrative burden on the patients. I do feel like we as clinicians need to know more about coding, because in the migraine space, there are some basics of coding that we need to know. For example, if I'm recommending onabotulinumtoxin for a patient, the only code that insurance covers for that is chronic migraine. And so, I'm recommending that for my chronic migraine patients, and I should be coding for that in that particular case.

What I would do is, many folks have access to their notes, just to make sure that whatever your doctor has written in the note as far as headache days or symptom days I should say is accurate. And just make sure that if you know something, if you were able to call your insurance companies and get a list of covered diagnosis codes, you can always call in to your clinician and ask to make changes or add or subtract whatever is needed. And we are very obliging. We want you to get your treatment covered.

Lindsay Weitzel, PhD:
That is very good advice and it's very interesting, so thank you so much. Let's move on to what is network gap exception? Or sometimes it's called out-of-network coverage.

Deena Kuruvilla, MD:
This is a practice model that I moved to about six years ago. I moved to be an out-of-network clinician, so I am not on any insurance panels at the moment. The reason that I've done that from a clinician standpoint is so I can have more time with each patient and really look at the patient as a whole and study all the different medical, other medical conditions they have and make sure that we're doing the right thing. It also offers me to have the flexibility to work more with when we're fighting insurance, like, for example, spending more time fighting for specific medications or imaging and other modalities.

One thing that you can do as a patient is document which in-network providers that you've already seen. Or if you're specifically going for a headache specialist, there's a chance there may not be a headache specialist within your network. And so, you can always submit a request to your insurance company before the visit to see if they will give you a network gap exception. This is the clinician I need to see. She or he specializes in headache medicine, and either you've already been to other headache specialists and things are not getting better, or you don't have an in-network headache specialist in your area. There's so many different reasons for which your insurance company will give you a network gap exception. And that's the key word: network gap exception. It's mouthful, but specifically asking about that can get visits with clinicians like myself who are out of network covered.

The process, if you have out-of-network coverage or you can get a network gap exception, your clinician can give you a super bill after your visit, which can then be submitted to your insurance company to get you reimbursement for the fees from the visits. Sometimes we hear, oh, that person is out of network. I'm not even going to go for it. But just keep in mind that I myself have gone to in-network clinicians and gotten much larger bills than going to an out-of-network clinician. And so don't shy away from

getting the specialists that you need or the expertise that you need by that in- and out-of-network terminology.

Lindsay Weitzel, PhD:
There's another question I want to ask that is very interesting. People might not think about this, but if you know you're going to need an expensive treatment, procedure, anything like that, is there a better time of year to request that?

Deena Kuruvilla, MD:
Absolutely. Certainly, it depends on your deductible. And so, some people, if they're expecting to have a lot of medical expenses over the span of the year, they'll want to spend as much as they can for their medical treatments early in the year so that everything else is covered throughout the year. But the bottom line is once your deductible is covered, that tends to be earlier in the year for most people, that towards the end of the year is when you want to get your more expensive treatments in like if you need an MRI of the brain or if you need infusion therapy, for example, which can be very expensive.

So, most people want to save their treatments for the end of the year and get everything in before January when that deductible restarts, the formularies for your insurance company can change, some prior authorizations end up expiring, and your co-pay card limits are going to reset. From my experience, January and July is where the table flips with coverage for insurance companies. And so, you kind of want to time your treatments based on that. Because I've had folks who for example, they've been on atogepant since January. And now it's September and then the insurance company decides, sorry, not formulary anymore, and then we're in trouble. They need their treatment. They're disabled without it. And so, then we have to do a last-minute fight. There's a week where there's no treatment, and then my office is trying to pull strings over there. But then they've gone 1 or 2 weeks without treatment and it's a disaster. So, really making changes and getting those refills as much as possible is important.

Lindsay Weitzel, PhD:
You just said something that I bet made people's ears perk up. You said they really need their treatment. They're disabled without it. And that's why I think people really panic when they get some sort of denial from their insurance. I got a denial recently for something I have been taking for probably 25 years, and it was just so random. And it happens and it's like don't panic, just go through the process. But it is, some of us are disabled without certain treatments. And so, I think everyone really appreciates that you said that. Is there anything else you would like to add to this topic before we go today?

Deena Kuruvilla, MD:
Absolutely. Thank you for having me today, Lindsay. This is such a great conversation.

Lindsay Weitzel, PhD:
Thank you for being here.

Deena Kuruvilla, MD:
I hope it's useful for everybody out there. I'll just say one more thing. You deserve treatment. Go see the person that you want to see, that you need to see. And ask your insurance if you can see the person that you need to see to get better. The system is incredibly frustrating, but don't take no for an answer after that first denial. It is my job and the other clinicians' job out there to do the legwork to get your treatment covered. And we'll do anything we can to get your medications covered and help you navigate through this. And don't be afraid. You're never a pest to the insurance company. You're paying them. You're contracted with them. Ask as many questions as you want and tell them I need the bottom line for getting my treatment covered.

Lindsay Weitzel, PhD:
Well, thank you so much. Thank you for being here. Thank you everyone for listening into HeadWise. And please join us on our next episode. Bye bye.

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Resource:

- Patient Assistance Programs and Savings Cards
  https://headaches.org/patient-assistance-programs-and-savings-cards

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