



Episode 236: How to Transition Migraine Care for College and Beyond

Lindsay Weitzel, PhD:

Hello everyone, and welcome to HeadWise, the videocast and podcast of the National Headache Foundation. I'm Dr. Lindsay Weitzel. I'm the founder of MigraineNation, and I have a history of chronic and daily migraine that began at the age of four. I am here today with someone who I love. This is Dr. Hope O'Brien. Hi, Dr. O'Brien. How are you doing today?

Hope O'Brien, MD:

Hi. How are you, Lindsay? Good to see you.

Lindsay Weitzel, PhD:

Good to see you. Dr. O'Brien is the CEO and medical director of the Headache Center of Hope in Cincinnati, Ohio. Dr. O'Brien is a board-certified neurologist and headache specialist. She is also a board member of the National Headache Foundation. We are super lucky to have her here today. Not only is she very kind, very fun, she's very knowledgeable about our topic and all things headache.

Our topic today is continuity of headache care for young adults and the transition to adulthood when you have a headache disorder. So, when I first was coming up with questions for this episode, I was planning on focusing on people who were graduating high school and going on to college. But then, of course, life presented me with a couple issues that I thought would be great to talk about as things go.

I'll start with a scenario that's a little bit focused on somewhat younger kids. My first question to you is this, at what age are most kids ready to manage their own medications, and how do we know if they're ready? I had an incident recently with my son, who's quite a bit younger, where he was really great with his medicines at quite a young age. And then I noticed that maybe he does need to check in every once in a while. So, what advice do you have for parents with kids and taking their own medicines and managing their own medicines?

Hope O'Brien, MD:

Well, that is such a great question. And I will tell you, for those of you who don't know this, migraine does begin in childhood and affects up to 16% of adolescents and young adults. And we look at long-term perspective studies. What we've seen is that more than 50% of children diagnosed with migraine continued to have them into adulthood, so your question is very valid.

And so, what I would say is that most kids are ready to manage their own medications when they demonstrate both maturity and consistency, rather than reaching a specific age. And as you know,

readiness is individualized. And the key signs include when a child and parent feels comfortable and the child can explain what the medication is, what's it taken for, when to take it, and if they can reliably follow through without reminders. And it's important for the parent to observe this, and it's critical that the child shows responsibilities in other areas, not just taking medication, but also completing their homework and following rules. And those are good indicators that they may be ready to take on medication management.

Lindsay Weitzel, PhD:

And I think one of the things that I would interject from personal experience is then if your child starts taking one of our medicines that causes cognitive issues, maybe check in again, and make sure that they aren't forgetting the dose of one of those medicines. Or if they are getting a lot of breakthrough migraine with cognitive issues or brain fog, that's when maybe another check in is a good idea. So, thank you for that. That's great advice.

Let's move on to kind of what I was what planning more for this [episode]. When do most people transition, let's say, from their pediatric neurologist or headache specialists to an adult healthcare provider? And what advice do you have around that transition?

Hope O'Brien, MD:

Again, another important question. And I'll tell you that unfortunately there are very few neurologists who can manage both kids and adults with migraine. I mean, specifically, I was actually trained to manage both pediatric and adult headache. So, I would be what you would call your typical transition headache specialist, but it's not very common.

Most people transition from their pediatric neurologist or headache specialist to an adult headache provider between the ages of 18 and 22. And it's often around the time when they finish high school or start college. And the exact timing depends really on the individual's maturity, their medical needs, and comfort level. So, in terms of guidance from both the family and the healthcare team, the smooth transition is important to ensure that continuity of care.

Lindsay Weitzel, PhD:

So, this is really important because, I mean, thinking way back to even when I started college and this was really early on, we didn't have many migraine medications back then. And I was super sick. And I'm thinking of some of the people I know at that phase of life. You don't know if you're going to get sicker, better, stay the same, and you might be moving to a whole different city away from your support system. This is a big deal for people with chronic migraine, with other headache disorders, who really, if your headache disorder really impacts your life already, this is a big change.

So, putting myself in the shoes of these people and back where I was back then, let's just start with I think that perhaps one of the biggest questions here that we could address might have to do with onabotulinumtoxinA (Botox), because a lot of people have to have this every three months or so. And if you're moving away, this transition could be a big deal. You might have to find a new provider or come back home, or insurance could be a problem. We have a headache provider shortage. Please talk to us about this. What sort of advice do you have for these people and or their parents?

Hope O'Brien, MD:

Well, we've just started the new year and towards the end of the summer. This is something that I was working on is how do I transition my patients to a provider in their area. So, this is one of the biggest challenges that young people face when moving away is maintaining access to consistent migraine care, especially when a specific in-office treatment is involved.

So, my advice is to plan ahead before leaving home, work with your current provider to identify specialists in the new city who can continue treatment. It's also important to contact your insurance company early to confirm coverage and avoid unexpected costs. And parents and students should keep copies of their medical records and treatment schedules to make sure that the transition is smooth. And then finally, I encourage students to advocate for themselves by scheduling appointments in advance, staying organized so that their care is not disrupted during this important stage of life.

Lindsay Weitzel, PhD:

So, I have an interesting question related to that. I remember I used to never bring my medical records because it was almost insanity. I remember having a doctor that I had been with since their clinic opened related to procedures etc. for my migraine, and they would literally laugh at me when I'd ask for my medical records. And so, in that instant, because there were so many, in that instance do you ask your health care provider for some sort of summary? What do you do in that instance?

Hope O'Brien, MD:

That's a great question. And first of all, I want to apologize that you were laughed at. We should never be laughing at our patients. And so, I apologize on behalf of the medical profession. In that case, a transfer of care packet can be very helpful. This transfer of care packet is a way to sort of summarize not only their diagnoses and what has been done in the past, including the current treatment, the doses that are there, whatever procedures is done, is done typically on a 1-to-2-page format.

Especially in providers who may not have a lot of time. And if you're coming in with years and years of treatment and what's worked and what hasn't worked, side effects that have occurred, whatever allergies or intolerance you had to medications, that's going to be really important. So, what I would recommend or advise is this transfer packet that kind of summarizes your care, what you've been through, and kind of what the last step was prior to you ending the care of your last provider.

Lindsay Weitzel, PhD:

Let's move on a little bit to, I'm still kind of focusing on this college transition. If people are having trouble whether they can't find the provider they need, can't get to them, etc., do you feel that student health centers can be helpful for people with migraine or other headache disorders?

Hope O'Brien, MD:

Well, student health centers are usually a good first step for basic medical needs, but they are often not equipped to manage migraine and other headache disorders in a comprehensive way. So many providers there have limited training in headache medicine, which as you know, can make it difficult for

students to get the specialized care they need. I remember one of my patients who ended up going to their student health and they refused to write for any of their migraine medications.

And so that individual ended up having to come back and get what they needed. So, for this reason, it's often best for students to connect with a neurologist or headache specialist in the community for ongoing management while using the student health center mainly for general health support or as a point for referral.

Lindsay Weitzel, PhD:

And if they do, because we know we don't have enough headache specialists for our community of people with migraine and other headache disorders. If they're having trouble getting into one or finding one, I do remember this was way back when our only real migraine medication was Imitrex injections back when I was in college. Sorry, I just dated myself. My parents used to have to ship me my medicine. Is this something? Do you recommend this? Can we still do this? Can we still ship medicines? I don't even know. I'm so old now. I'm just like, gosh, how old am I?

Hope O'Brien, MD:

You don't look your age, okay. Well, I'm just saying that because I know when sumatriptan was approved. So, I will tell you this, shipping medication, I would advise against that only because medication can get lost and you worry about the stability of the medication. So, what I would recommend is if the provider that the patient has been seeing can send the prescription to the college, that would be best. And you'd be surprised, some of these medications, especially the newer agents, can stay stable for a certain period of time. The other thing they could do is they can write in to their insurance company or ask permission if they could get advance doses that will last them the 3 or 4 months while they're away until they do come back home to get that refill.

Lindsay Weitzel, PhD:

That's awesome. So, let's talk about a little further down the line. What about transitioning from your parent's insurance to your own. I remember that phase of life. That was scary. At what point does this happen? What advice do you have for people in this stage of life? What should they look for if they have chronic migraine or another chronic headache condition? What questions should they be asking about this potential insurance?

Hope O'Brien, MD:

So most young adults stay on their parent's insurance until about the age of 26, but the transition can happen earlier if they get a job that offers benefits. So, the key advice is to review insurance options carefully before the change and then paying close attention to migraine treatment coverage. I can't tell you many times I've looked at the formularies of certain insurance companies, and they don't cover certain medications. So, make sure that the provider and also the medications that they are on are within the network. And it's also wise to keep copies of the medical records and treatment authorizations so that the care can continue smoothly. Again, planning ahead and asking questions early can avoid gaps in coverage during this important stage of independence.

Lindsay Weitzel, PhD:

I'm going to step back and ask you a question that might help some of these parents. I know some of them who are just really nervous when they send their kids off to college who have chronic migraine and other headache disorders. They're like, gosh, how can I best help them take their medicines, remind them, or when they get there, if they get sick or the parents feel guilty they're not there to help them. What advice do you have for these parents?

Hope O'Brien, MD:

So I would say have a conversation with the provider. I do a lot of transition of care because I do see kids and young adults. And so what I do is I plan ahead. So, let's say at the beginning of the year, as they're thinking about that, they've gotten into their colleges, and they're now knowing that they're going to have to move away, that I have that conversation early about the medications they're taking, making sure they understand how frequent and the relevance of them taking it in order to maintain good control.

And then I have a plan. So, I will give letters to the child or to the transitioning individual so that the school can know that they have migraine and that there are preparations that can occur. So, I'll write a letter that will allow for, let's say, early registration. So instead of waiting until the last minute, usually as college freshman their last to register. This gives them priority registration so they're not having to take classes too early in the morning or late at night so they're able to get the sleep that they need so it doesn't trigger a migraine.

I also offer special accommodations so that they're not in a bright lit area. They're taking tests that are in a quieter area. Again, really advocating for the patient's needs. And then finally, I will provide an emergency letter. So that is a letter that they can actually take to an outside facility, whether it's to the emergency room if they were to get a migraine attack that they couldn't stop with their outpatient medication, so that the plan is carried out by that headache specialist to that other provider. And if there's any questions that receiving provider can call and ask questions.

Lindsay Weitzel, PhD:

Oh, wow, that's great advice. I love that. Thank you. I wasn't expecting to hear that. That was awesome. What have we forgotten? Is there anything else that you would like to add to this discussion?

Hope O'Brien, MD:

Well, I think what's important to note is that, unfortunately, transition of care is not a standardized process, especially in headache medicine. And even though the American Academy of Neurology recognizes the importance of transition, and there's been an article that was recently published in *Cephalalgia* talking about the importance of a structured transition protocol and access to providers skilled in headache medicine management, we need to make sure that when a child is transitioning with migraine that there is a continuity and consistency of care that they need. And most importantly, that we involve the teenager in learning how to self-advocate and be able to explain their migraine experience, which fosters independence in the adult care setting.

Lindsay Weitzel, PhD:

Okay. Well, thank you so much. This topic is a little different than what we usually do, but it's just so important. And I don't want anyone to feel alone, like they're the first person to ever go off to college with chronic migraine. And honestly that is what it feels like for some people. So, thank you so much for addressing this for us.

And thank you everyone for listening. And I hope there was something for everyone in this conversation. And please join us again on our next episode of headlines. Bye bye.

Hope O'Brien, MD:

Thank you for having me. It was a pleasure.

Lindsay Weitzel, PhD:

Thank you. Bye bye.

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