



NHF Insights™ Patient Series
Episode 2: Symptoms and Diagnosis of Headache Disorders

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

This episode is about symptoms and diagnosis of headache disorders, and it is part of our Patient Series. Today we'll explore recognizing the many symptoms of headache disorders, what to share with your provider and how to advocate for yourself and why getting a diagnosis can open the door to better treatment and support. Let me introduce today's guest. Award winning author and patient advocate Ashley Hattle. Ashley has lived with cluster headache and migraine, bringing firsthand insight into both conditions. She brings a unique perspective on recognizing symptoms and seeking an accurate diagnosis. Welcome, Ashley.

Ashley Hattle:

Thank you for having me.

Jaclyn Duvall, MD:

Absolutely. I'd like to start with sharing just a bit about your story.

Ashley Hattle:

Well, I developed episodic cluster headaches when I was 18 years old, and my very first attack happened in July of 2007, when I was a summer lifeguard at my local pool. I had recently graduated high school, and it came on at around 2pm in the afternoon. And it came on so suddenly and so severely. I had no idea what was happening. I called over another guard to come cover my station, and I went into the bathroom, and I paced back and forth. I was holding my head and I vividly remember touching the cold brick. I can still feel the cold brick. And we had a dingy mirror in there and I could see my eye tearing up and it was very scary. It lasted about 90 minutes, and I just had this feeling of shock afterwards, like what just happened. And my coworkers and my boss knew about it. And I thought, wow, that was weird. And I just went about my day. But then the next day it happened again at the same time.

Then the next day it happened again at the same time. And that went on for two weeks. And I was two weeks away from moving to Denver, Colorado for school, so my father got me in to see a neurologist who said, I believe you have episodic cluster headaches, here's a burst of steroids. And that was it. They

went away. I thought, okay, that's over. I'm going to go off to college and live my life. But they came back six months later. And again, I had one attack every day for two weeks, and my friends were driving me to the ER, and the ER gave me painkillers. And then I came back the next day saying these painkillers aren't working. And unfortunately, I wasn't treated very well. They kind of let me know not to come back. And I just waited it out and suffered through that.

And then it happened again six months later. My worst cycle lasted two months and I was having six attacks a day. They occurred every 4 to 6 hours, and the nighttime ones were the worst, because I didn't have time to reach for a medication and I didn't have oxygen yet. So, it was a really rough time.

Jaclyn Duvall, MD:

I think it's so important that our listeners understand how different the symptoms can be. And in many headache disorders and migraine do not present the same. And so, it's important to really parcel out the symptoms you're experiencing. And one of the things that stands out to me as a headache provider is you pacing. And so that's a key distinction often between cluster and migraine, and that individuals with migraine typically want to get horizontal, to go lie down, to recluse. But the individuals with cluster, which has been deemed a suicide level headache, they pace almost escaping the pain. So, when you were first trying to understand what was happening, how did you start to piece everything together? Tell me about those early phases.

Ashley Hattle:

Well, I had recently moved out of state to attend college, and it was new territory for me. And I kept telling the ER doctors and the university doctors that I have cluster headaches. But back then it was considered rare for women to have cluster headaches, so they kept telling me, no, you have migraine disease. And it got to the point where I said, I don't care what you call it. Will you please just help me?

Jaclyn Duvall, MD:

So, you really had to start to advocate for yourself and even educate providers that that should have that knowledge and background. And a lot of people don't understand how many symptoms can be connected. I want you to also tell me, because my understanding is that in years you now have not only cluster headache, but you also are one of the unfortunate individuals have two severe diseases, and you have migraine also.

Ashley Hattle:

Yes. They started about six years ago on my journey to motherhood, and I had a couple miscarriages before I got my rainbow babies. And ever since, about once a month, I have a very long migraine, status migrainosus, I believe. And I have been diagnosed with that. And it is a very different feeling and is debilitating in a very different way.

Jaclyn Duvall, MD:

Talk to me about that. Talk to me about your symptoms and kind of the differences that you've noticed.

Ashley Hattle:

Well, for cluster headaches, they peak pretty quickly. Within 5, tops 10 minutes, it's a 10 out of 10 pain. And like you said before, like there's pacing, there's rocking. You're holding your eye. But with my migraines, they come on more slowly. And in that early phase, I don't always recognize it. It starts as kind of a brain fog or putting my thoughts together a little more difficult than usual. And if I don't take a rescue medication or an abortive, one that works really quickly to stop the pain, it's not going to work. So, I kind of have this window of I got to take it day one or I'm in for five days.

Jaclyn Duvall, MD:

And we were talking earlier about status migainosus, which is a migraine attack that continues for days on end. And so that is a very severe and debilitating form of migraine that, as you've mentioned, can be very challenging to treat because once the system has sensitized, it's harder to cool off. So, looking back, are there symptoms that you didn't realize were connected to migraine?

Ashley Hattle:

Yes. And I would say I'm still learning. I'm not always the best patient. So yeah, the early phase I get the brain fog, speaking is kind of difficult. And within the first 24 hours, it starts to feel like something is sitting on top of my head and squeezing my head very tightly. And that continues. And by day five, it's really broken me down and I'm not able to do a lot of things

Jaclyn Duvall, MD:

Completely exhausted.

Ashley Hattle:

And compared to the cluster headaches, it's a different kind of beast. But I understand that beast. I've lived with it for a longer. So, with cluster headaches, I know, hey, I got to treat this within ten minutes. I have my oxygen, I have my injectable medication, and that works quickly. I'm still learning with migraines the right way to go about it to get the best pain relief the fastest.

Jaclyn Duvall, MD:

And many individuals don't realize that that headache is one phase of a migraine attack. And so, learning all of the different phases or hearing about other people's prodrome, or what we call the warning phase, can help others to start to recognize theirs. Are there any symptoms, I know you have said that you're still in the learning phase of this, but any symptoms that you've started to identify that you've recognized as your warning that things are coming?

Ashley Hattle:

I would say the brain fog. I'm getting much better at identifying when brain fog, which I would describe that as reaching for a thought and not quite grasping it. And it often coincides with hormone fluctuations throughout the month, but also with barometric pressure changes. So, I think people with any type of headache disorder would make excellent meteorologists, because we can predict the

weather change pretty well. So when there's a big storm, I know that I'm going to have a challenging time.

Jaclyn Duvall, MD:

So, Ashley, I think you touch on an important point that is migraine is not just headache. And you've talked about brain fog and kind of the entire impact. And I find that many of my patients I'm seeing may often underestimate how many days they're actually impacted. They're counting headache days, but not impacted days where maybe they're not at full functioning capacity, or maybe they're having GI symptoms, cognitive, mood symptoms, nausea, or low-grade sensitivities, light sensitivity, etc. And so, I want you to talk to me because you've mentioned keeping a diary. And I want to know why is tracking symptoms so important and in trying to understand what's going on.

Ashley Hattle:

Keeping a headache diary I think is one of the best things you can do to improve your pain relief and your migraine attacks or cluster headache attacks, because it points out a lot of data points that you, like you said, don't realize. For example, I have a migraine attack for five days, but there's a recovery period after that because it really wears on you. And same with cluster headaches. And a headache diary can help so much with diagnosis and identifying symptoms, especially when you bring it to your headache provider. For example, for my cluster headaches, I know that alcohol, when I'm in an episodic cluster headache cycle, is going to trigger an attack. Nitrates in bacon and ham can also trigger a cluster headache attack for me. I know that hormonal changes will trigger a migraine attack as well. And keeping a headache diary really helped me see that. But it also helped me bring that to my headache provider and say hey, I am experiencing something new that I have not experienced before. And this seems uniquely different than cluster headache.

Jaclyn Duvall, MD:

I have many patients ask me how to identify triggers, and I think a diary is tremendously important. But oftentimes I think an e-diary can sort of even take it up a level because data is able to be so quantified over time. And you can really start to see these patterns. For many individuals maybe it is very clear trigger, attack. But for others it can happen sporadically or seem to not have an identifiable trigger, so I find that these e-diaries sometimes can identify patterns that we may be unaware of.

Ashley Hattle:

Absolutely. And I think that's especially effective with food. I know people who have gone very strict with the headache diet and only eating chicken and rice for a while just to see if that improves their pain and reduces their number of migraine attack days per month.

Jaclyn Duvall, MD:

Right. And I think sometimes individuals might be correlating a food incorrectly. We may not be looking at when the migraine started, but when the headache pain started. And so, they may be wrongly identifying triggers. There's some data in the migraine community to suggest that foods high in serotonin may be cravings in a prodromal phase. And so people may start to identify those as triggers, when in fact they're part of trying to help migraine naturally.

It can be overwhelming, especially if you've met providers that are trying to tell you what your symptoms are or who maybe have misdiagnosed you. But I think just communicating with the provider at times can be overwhelming or hard to explain everything. And so, if you could go back to your first appointment, what information would you make sure to bring or share?

Ashley Hattle:

Well, my very first appointment in Nebraska when I was diagnosed correctly, I would ask, are these going to come back? Because I left that appointment thinking, this is over. And I had no idea that I had a lifelong condition at that point. If I could go back to the provider that I saw in Colorado, I would describe my symptoms more, specifically the duration or how long the attacks were lasting, and what I felt compelled to do during the attack. For example, rocking and holding my eye. And the fact that they lasted 90 minutes and then came back several times a day. And when it came time to get my diagnosis of status migrainosus, it was a lot easier because I had the language and the tools and the connections to get help faster.

Jaclyn Duvall, MD:

Right. I write a letter to our patients before they come to their appointment, because we ask for a lot of information on the front side. But a big part of this is to allow them time before the appointment to gather their thoughts, to think about the symptoms they're experiencing. So things like duration of the attacks, the severity levels, the associated symptoms, do you want to lie down or are you moving, is there a positional component to your pain. And I tell my patients, because some of them will come back with the paperwork almost empty, and I tell them, if you are not able to share your symptoms with me, I am not able to guess at what they are. And so, you have to make it very clear what you're experiencing. And I think doing that in concise language before that first appointment is pivotal, so I'm really happy to hear you say it in those words.

Some people worry. In fact, I've had patients who get themselves dressed up and ready to go to the ER. They're afraid they won't be taken seriously or be offered the right treatment, or they won't know what to say. Before having a diagnosis, how did you advocate for yourself when you knew something wasn't right?

Ashley Hattle:

I was really fortunate to have a group of college friends that were really supportive. One of my best friends from college had been diagnosed with migraine disease early on when they were younger, and they were more sympathetic, and they knew kind of which hospital I should go to in Denver. And bringing them with me to the appointment was really helpful, because then it wasn't just me telling the doctor or the emergency room what was going on. I had my support system with me saying, yeah, she acts like this, we can see this and it lasts this long.

Jaclyn Duvall, MD:

Well, symptoms are one thing, but many people don't realize that migraine is a disease that has a diagnosis. And so how did understanding your symptoms and your body change the way you viewed your symptoms and condition?

Ashley Hattle:

Well, getting the correct diagnoses was so validating because I had been fighting for so long to get providers to believe me and believe in my pain, that when I found my doctor, who ended up being a primary care physician who was well versed in headache medicine, he was the first provider that I saw in six years who actually looked up how to treat cluster headaches and prescribed me oxygen. And I cried in his office. I was so thankful that someone was finally paying attention and doing a little homework to figure out what was going on with me.

And I think that was a turning point for me, because I didn't feel like I was out of control anymore. I felt like I had a team. And he would call my insurance company if they denied my injectable medication and he would really go to bat for me anytime I needed him to. And that validation and that trust was huge. And patients with migraine disease need that. It's an invisible disease. And you need to be believed, and you need to feel heard. And that's one of the steps to getting better and learning how to thrive in life instead of just surviving day to day.

Jaclyn Duvall, MD:

And what about the diagnosis of migraine? How did that validate or change the treatment course?

Ashley Hattle:

It was really cool because I knew that something else was going on. And I had been tracking what was happening, and it had happened for maybe three months. And I went to my headache provider and said, hey, this is really different than anything I've experienced with cluster headache or a college hangover or tension-type headache from looking at the screen. And it's lasting so long and I'm not sure what to do. And they heard me, which was wonderful, and asked me to describe the pain and how long it lasted and how I felt before and how I felt after. And it was a much simpler process because I had a team already. And I think that's why what the National Headache Foundation has done with the map of headache providers of the United States, because you can go to the website, you can find somebody that's near you who knows what they're talking about with headache medicine.

Jaclyn Duvall, MD:

I think that's so important. And if you have a primary care provider who's not well versed in headaches, you can help in getting access to a provider by just looking up who in your area has that headache specialty.

Well, I also want to go back, because I think that the step that your provider took is really to be commended. He didn't have the answer right away, which is providers makes us nervous in an appointment. We are almost expected to be invaluable. And the truth is that we're human too. And for many primary care providers, their time and education in headache disorders is very limited. And in fact, most of that is spent on life threatening headaches, things like a brain bleed or a tumor, etc., which comprise some of the most rare types of headaches, but they are emergencies. And so, education surrounding migraine and cluster is limited. And so, he listened to you and then took the next step to research. And I think that's important. And I think sometimes if you don't have access to a headache specialist, being your own advocate and maybe bringing in information at times could be

helpful or letting them know, I know that maybe your specialty isn't headache. I've been told in research that maybe I have migraine and cluster. Could you help me? And so really being very poignant in that conversation.

Ashley Hattle:

Yeah, absolutely. If I could toot his horn a little bit more, I think it's so important for as a patient, I see doctors and headache providers as regular people too, who don't know everything. And I have heard that most physicians get one hour lecture on headache period in their education, school. So, recognizing that you don't know and looking for more information, no patient is ever going to be upset about that.

Jaclyn Duvall, MD:

And we appreciate that as providers. I've had times that I've told a patient I'm not sure what's going on right now. I want to mill on this. I want to think about it. I want to talk with colleagues. And patients, knowing that you're thinking about that and coming back whenever you have more information, I think can be empowering for them.

On the flip side of that, many patients have a fear of what a diagnosis could mean. I don't know if that was ever the case for you, but once you had a diagnosis, how did that change your care, your treatment plan, and your ability to move forward?

Ashley Hattle:

It was life changing for me. I ended up going to a headache center in Michigan, and I brought seven years of a headache diary with me and a list of 40 questions and both of my parents. And it made the process go much easier, I think. But once I got that diagnosis, they said, okay, well, now we're going to find you a headache provider back home. And then I saw that headache provider and I learned more. And then I found out about advocacy groups and support groups. And then I met people like me.

And having the correct diagnosis lets you get the right kind of help, because there are so many different types of headache disorders, and some of them are very unique and require unique treatment. And if you don't have the right diagnosis, you won't get the right treatment and your life won't improve to the extent that it could.

I think sometimes that fear can come from seeing a diagnosis as kind of a label and having that on your chart. I've ran into a lot of people in life who have migraine disease and have never gone to a provider. They're just kind of struggling through it. And having the diagnosis, it's not a bad thing. It's a wonderful thing because it gives you the opportunity to get the right treatments and get better.

Jaclyn Duvall, MD:

Right. I also will point out that oftentimes for access to many medications, having the right diagnosis is important. So, understanding that really does open the door for your treatment success.

Ashley Hattle:

Absolutely.

Jaclyn Duvall, MD:

So, as providers we look at different headache criteria. We have what's called an International Classification of Headache Disorders. And it basically parcels out the different type of headache disorders. And having a diagnosis puts you into a specific category of headache.

Ashley, this has been an amazing discussion. I want to thank you for your insights and expertise as you've navigated this, highlighting the many symptoms of headache disorders and why getting the right diagnosis matters.

Ashley Hattle:

Thank you for having me.

Jaclyn Duvall, MD:

Well, thank you for joining us. We hope this conversation helps you feel more informed, empowered and confident in managing your headache or migraine. This episode is part of a patient series designed to help patients navigate diagnosis, treatment, and finding the right care for them. For the full series, visit headaches.org. Thank you again for listening. Until next time.

This episode of NHF Insights™ was supported by AbbVie, Lundbeck, and Pfizer. The content was developed independently by the NHF.

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