HEAD Wise

Episode 259: Back to School for Kids with Migraine

Lindsay Weitzel, PhD:
Hello everyone, and welcome to HeadWise, the podcast and videocast 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. We have a super exciting episode today. I am here with Dr. Alexandra Ross. Hello Dr. Ross, how are you today?

Alexandra Ross, PhD:
Hi. I am doing well. I am so happy to be here.

Lindsay Weitzel, PhD:
Thank you for being here. Dr. Ross is a pediatric headache psychologist who trained at Stanford and went on to found the Pediatric Headache Psychology Program at UCSF Benioff Children's Hospital. She is also the co-founder of a digital health company that provides cognitive behavioral health therapy for pediatric headache, called Streamind Health. I brought Dr. Ross here today because it is back-to-school time, and for kids with migraine, this can have a whole different meaning than it does for kids who do not have to think about migraine.

We want to give some pointers, some empowerment to those kids and their families in this episode today. Our listeners have kids with migraine of frequency and severity and with various accompanying symptoms that are just all over the map. And some may just need to go home from school every once in a while. Some may be coming back from a year where maybe they hardly got to attend school at all, and we are going to try to give a little tidbit for everyone.

Dr. Ross, let's begin with some of the information that's going to keep everyone with the least amount of migraine symptoms and most function throughout the year. What are some of the real-life advice or tidbits that you can give to families right now whose kids systems might be a bit in shock by going back to school, having homework, stricter schedules, loud sounds, all the expectations that come with end to summer and start of school.

Alexandra Ross, PhD:
I think we can think about both the home environment and the school environment. So as a parent, what are the things that we can do to take even the smallest bit off the plate of our children. We think a lot about regularity and how do we keep things consistent. And as you mentioned, that is just hard to do in the context of a busy school day and sports and activities and all the things we have going on. That might mean actually sitting down, and this can be true even with an adolescent, but sitting down and thinking about what is our nighttime routine look like, what does bedtime look like, and how can we stick with the consistent schedule and draw some limits to, I have an AP Bio test tomorrow, and I

have a lot to do, and I just want to keep studying. And so that's one way that we can think about keeping with that regularity and a little bit more structure.

Another specific way that a parent might do that might be thinking about breakfast in the morning and making sure that you've got some way to hydrate, like a big glass of water, something. And having that set up for kids in the morning so that that's good to go and it's another piece off their plate.

And there's a certain amount that we can do as parents. And then during the school day, we're not there. That's when your kid is by themselves. They are figuring out how do they access their tools, their supports, and how do they function. And I think you can prep and you can think about that with your child.

In some cases, it might make sense to set up a 504 plan with the school. This is an accommodation plan where the school essentially is providing the supports that your child needs in order to receive the same type of education as their peers. And so, this would come up if migraine is getting in the way, meaning they're missing school, maybe they're having trouble accessing some of the tools they need, if they need a dark room to rest in, or getting enough hydration, or even just going to the bathroom if they're hydrating during the day, and if they're having a lot of worry about having migraine in the school context.

And so, when we have these structured support plans in place in school, it makes it easier to step back and think, okay, as a child or a teen, what can I do right now? How do I optimally take care of myself? And we're thinking about patterns. So, if we talk through our kid's day with them and they notice, like I start off feeling pretty good, when I do get a migraine, it tends to be at the end of the day after I've had like a bunch of stressful classes and there's the focus and all the fluorescent lights, then we're thinking about how do we build in breaks. If they're noticing, like when something that's really helpful for me, is this social lunchtime where I'm laughing and kind of having a break from it all with my friends, like, are there ways that we make sure that if you're cutting back a little bit, that that's not something that we're cutting out. And so, we want to think about balancing, like having some of that structure, but then also thinking about our kid as the unique person that they are and noticing their patterns and the things that are most helpful for them.

Lindsay Weitzel, PhD:
There are so many things that can be in a 504 plan that can be helpful, and something that I've noticed is coming up in our area of the country right now is the schools are really cutting down on AirPods and kids that needed earplugs because of their phonophobia used to get by with earplugs easily. And now we have to get that in a 504 plan because they look like they're listening to music or something. So, it changes all the time. I love that you brought up the 504 plans. Thank you so much. And there's so many places you can look that up for the specifics in your area.

Some kids either have learned some techniques to keep their pain and other symptoms at a minimum on their own, or maybe they've met with a pain psychologist like yourself. And they may find that they can be helped by employing certain skills regularly throughout the day, like breathing techniques, visualization, or grounding or relaxation, etc. Do you have any hints on how they can incorporate those skills while they're in school during the busy school day?

Alexandra Ross, PhD:
Yes. Again, I think thinking about, like really thinking about in advance and talking through that school day is so helpful. Because if we're waiting until we're at school and then we're trying to plan and figure out when we have a break, the school day is so busy and there's so much else that is on kid's minds already, and that they're needing to focus on that that gets really hard. And I think there are different approaches. I really spend a lot of time when I'm working in therapy with the child of thinking through this for them, oftentimes, of how we can build those breaks and how we can build those strategies in.

For some kids, we might think about when are those natural times that are a little bit more of a lull. So for example maybe you have a study period, maybe you have in your journalism class there's like a work time at the end where you can leave the classroom and go for a walk, and you have in your accommodations plan that you can put in your AirPods so that you can listen to a song while you're walking up and down the hall, or you're going to the counselors office and laying down and doing a relaxation exercise.

But it's really built in these natural times. When you know that it's hard to leave, when the teacher is doing some direct instruction or a test, those probably are not going to be optimal break times. But thinking logically through when it's a little bit easier. I think also planning with teachers in a 504 plan can be part of this, or just a qualitative conversation with the teacher of when I step out, making sure there's a plan, can you get notes from a classmate, or is the teacher going to provide you with what you missed if you do take a break. For some kids, it can be helpful to have a reminder. I'll work with kids who will put like a Post-it note on something. As you're mentioning, it's getting harder with devices at school, but if they do have access to a device that can send them a little buzz of, like, you've been in school for an hour and a half, this might be a good time to use one of your strategies, that can be helpful.

And then for some kids, breaks are just really hard for all of the reasons that you were mentioning of there's so much going on. They're so busy. Their friends are there. There's tests coming up. And so, we often talk about micro breaks or mini breaks too that don't need to be like leaving and laying down and doing your whole thing. If I stop talking for a second, I can be breathing diaphragmatically secretly. You don't have to know. I can do that at my desk. A child can do that at their desk when they're working on something. Or they can, if they're able to listen to something, zone into that. Even we'll think about mindfully drinking water sometimes. So, if you're going to be drinking water at your desk anyways, using that as a time to reset and really go into like, I'm just going to focus on the sensation of drinking my water and holding the water bottle. And so, some kids are going to think that stupid. It just depends. Something has to resonate with the individual, but finding something, planning it in advance, and knowing what it's going to be so that you have that structure prior to the school day and all the busy, crazy stuff starting.

Lindsay Weitzel, PhD:
That is great advice and I love that you said the micro breaks. I had a kid tell me recently that they were working that into their routine, and they hadn't managed it yet. They hadn't mastered it, I should say, but it sounds like something that really works for some kids, so thank you for bringing that up.

This is a big question that I think is really important to kids. Let's address the stigma surrounding migraine at school. It comes from so many directions, other kids, teachers, staff. How does a kid stay strong and empowered in the face of migraine stigma, especially if they've had to miss some school?

Alexandra Ross, PhD:
Yes, I agree with you. I think it's a big question. I think it's so important. I think my response would be different thinking about adults, thinking about staff members and teachers versus other kids. So, when it comes to staff members, I think as adults in our children's lives, I think we can do a lot to make this easier for kids. I think it's a lot of responsibility to put on kids to have them trying to explain, like, I have migraine and let me explain what that means. So, I think we can set them up for success by making sure that the school has some documentation. So maybe they have a letter from the doctor. Maybe there's great resources through the organization Migraine at School that have a lot of ways we can teach about migraine, that we can actually give to school administrators or teachers or a quick email from a parent just explaining what's going on, so that if a child or a teenager needs to ask for something, they're just referencing back to things that teachers already know, especially if they've missed a lot of school rather than trying to explain it themselves.

I think when it comes to kids on the other hand, with little kids, with younger kids, like, yeah, maybe we're going to do a little bit of education. With teens, they're going to think that's weird. That education can come from the parent. It's really helpful to learn and to practice how to talk about migraine yourself. And when I'm when I'm talking about this with kids, I talk a lot about the spotlight effect, which is a construct that is not unique to migraine, but this is this idea that we all feel like we're under a spotlight. It increases, understandably, this increases in adolescents. Like we all feel like everybody's thinking about us all the time, and it can make us feel anxious in social situations. And so, it can be hard to try to explain, like, I miss school and now I'm back. But really, that person you're talking to is probably thinking about maybe their mom's mad at them because they did bad on a test, or they have a game they're stressed out about, or they said something awkward in front of their crush and they're spiraling about their own thing.

And so, if you're going into it with that in mind, and then you've practiced and you have a structured approach, and so that's something you can actually practice with your kid. So, you can think about what is the amount of information that I feel comfortable sharing about my diagnosis and my symptoms. And it can be pretty minimal. And then how do I redirect the conversation back to something that feels forward moving. I don't really want to spend a lot of time talking about migraine. So, you might say something like, maybe if your peers said like, where were you last semester, you were gone? You might say something like, yeah, I did miss a lot of school last semester. I have migraine, and it was really bad. It was not a super fun semester for me, but now I've got better medication. I've got a better plan, so I'm excited to be back. And shifting into except for like an AP Bio because how is he giving us an example already? I can't believe that's happening. Or I heard you made the varsity swim team. That's cool. Like, how has that been so far?

I want to do this with my own patients. I let them come up with examples because when I try to do it, I sound like a middle-aged woman instead of like a teen talking about normal teen things. But the idea being, give enough information and then kind of shift the conversation and move forward and know that you're going to use your accommodations or you're going to take the breaks you need. You need to keep moving forward, and you'll give people the amount of information that's helpful for them to know.

Lindsay Weitzel, PhD:
I love that you said that, that it's kind of age specific. Because I'm remembering when my son was smaller. If you asked him about migraine or anything like that, he'd be like, look, a spider. They'll change it to something age appropriate. Like he literally could not focus on the word, like he would change it to the silliest thing, so I've noticed that. It's very true. And I love everything you said in answer to that question. Thank you very much for all of that.

Can you say a little bit about the balance of academics, activities and social life for kids with migraine? Because we all know that can be very difficult because we often get in a spot where we have to miss something or if we miss school, but now we feel better, do we go to gymnastics or whatever? Does that seem weird? There's all these situations we run into.

Alexandra Ross, PhD:
Another great question. I think it's tricky in our society. There's a lot of emphasis on school and academics, and I think there can be this idea that if academics isn't 100%, if we're not all the way there, then social stuff, that activities should really take a backseat. And sometimes there's concrete rules in schools around that too. We know that pain, migraine, health all exists within a biopsychosocial context. So, the biological, obviously migraine is genetic. The psychological, we know that pain is worse when our stress is higher when we're focused on it. We've all had the experience where we step on something like a Lego that our kid left on the floor or kicked a hard object that our partner left somewhere. That objectively hurts worse because it's also annoying and you're irritated about it. As compared to that you're on a hike and you're having so much fun, and you're talking about something with someone that you love, and you stub your toe in the same way, it doesn't hurt as much. So, there's psychological. And then the social, so there's lots of research on this too, that when we're isolated and we see this among seniors, we can see this during the COVID-19 pandemic, that when we're isolated, people actually experience more pain, more health symptoms in general than when we're connected.

And so that is a long way to say we should be thinking about all of this stuff at the same time and building everything up together. And sometimes that might mean cutting back a little bit academically so that you can be doing the social activities and the other activities that you care about as well. And it can come up. I've had conversations with school personnel of this child really seems to be laughing and engaged and having a good time with their friends during lunch, and then they go to history and they seem checked out and they seem less focused and like they're in more pain. That's normal. That makes sense. It's easier to do that in the social context. And like I'm glad that they're doing that. So, let's think about building some of those skills to make your classes easier too. But it all interacts together and it's all important. And we want to be if we're cutting back, cutting back a little on everything and then building everything up too.

Lindsay Weitzel, PhD:
I think it can sometimes make kids feel like they're expected to be miserable all the time so people would believe that their migraine is truly a miserable experience. And that's not how you want your kid to feel. So, thank you for answering that. And that was really good. Can you say a little more on what you said, talking about ways to build up the social studies or math experience so that it's not so different between lunch and talking to friends and going to social studies.

Alexandra Ross, PhD:
I think it's variable. I think it's going to be based on the, the child. But I think if you think about what what's helpful during lunch, probably that like you're engaged and you're focused and what you're doing and maybe your stress is a little bit lower. You're probably also eating and drinking, which is helpful. There are pieces, social studies probably inherently going to be a little bit more stressful, but maybe they need to learn some skills. Maybe the child needs to learn some skills to manage the stress. Perhaps a therapist would be helpful if stress is really high in that class. Maybe it's the focus piece and we want to think about some of those strategies you were talking about earlier, how do we shift our focus, do like a brief relaxation exercise, and we want to incorporate that throughout our academic classes as well. But if it is feeling like tension and concentration is kind of mounting throughout the class, taking some of those little micro breaks we were calling them before and building those into to some of the more academically heavy or concentration heavy times that we have.

Lindsay Weitzel, PhD:
Thank you. What do you think is the most important thing parents can do to support their kids with migraine who might have struggled a bit in the past to stay in school so that they have an awesome year coming up?

Alexandra Ross, PhD:
I feel like I keep going back to have a plan, but that is genuinely my answer too. I think when some kids have trouble getting to school, some kids start the school day and then might end up leaving school early, but I think it's thinking about what are the patterns that you're noticing for when your child is able to get to school and stay in school for a full day, and then what's happening when it's harder.

And there's all the preventive stuff we're already talking about, that's really important. But then there's also when your child does have a migraine attack, what happens? Are they calling right away? Do they have access to all of the things that they need when they're at school? So, making sure that there's a good plan for they have, and they likely will need a letter from medical provider for this part, but so that they have access to their medications at school, whether that might be from the nurses administering it, or they have permission to carry their medications, that they have access to a dark, quiet room where they can rest.

And that really that's the first plan. That doesn't mean they can't eventually call a parent if they need to, but that they try that first. They do some of their relaxation strategies in that rest place, before that they immediately go home. And so, we see we kind of practice doing those skills a little bit more independently before shifting back to the home environment.

Or similarly in the morning, if you're working on getting to school, it can be a lot for a kid to think about, okay, I need to get up, get dressed, go to school, get through all my classes, then I have basketball after school. This all feels like very unmanageable. It’s too much for me. So, you can help break that down into smaller pieces and think, okay, number one, what can we have taken off the plate the night before? So, can we have clothes ready to go. Water, food, all the stuff is just set up, so there's not a lot of planning that has to happen. And then we just do it one step at a time. So, we're getting out of bed and going to the breakfast table and eating a tiny bit and drinking. Then we're thinking about getting dressed and just doing again little, little pieces and building them up instead of trying to think about all the stuff that's happening together. So, a long way to say plan.

Lindsay Weitzel, PhD:
Yes. Thank you so much. Is there anything else you'd like to add to the topic of going back to a school when you are a kid who has migraine before we go today?

Alexandra Ross, PhD:
I think if you're a kid with or you're a parent of a kid with migraine, I think there's a lot we're talking, I'm throwing out like a lot of different advice, like, try this thing and then do that thing and get an accommodation from school and make sure there's a letter from your medical. There's so much, so there's a lot to balance. And I think making sure that you have a team to lean on is really helpful. Your medical provider is your ally, is there to support you, so making sure that you're reaching out to that medical provider to help with some of that documentation. If your child already has a therapist or it would be helpful to have a therapist, I think that's a great person that can actually call and talk to schools if needed.

And the school, I think, especially when we can start off earlier and really have those conversations in advance of any problems coming up at school. And we can get on the same page and make sure the school knows the plan, child knows the plan, parent knows the plan. The school is your ally. And then your child ideally has a point person at school, someone they can go to if they're hitting a bump and they're not quite sure what to do. So, I think having that team, those people that are supporting your child and supporting you as a family is super, super important

Lindsay Weitzel, PhD:
Okay, that's great advice, so thank you so much for being here. And thank you everyone for tuning in to this episode of HeadWise. Please tune in again next time. Bye bye.

Resources:

1. Dept of Education Recognizes Migraine as a Disability
   https://headaches.org/blog/dept-of-education-recognizes-migraine-as-a-disability
2. Section 504 Protections for Students with Migraine
   https://www.ed.gov/media/document/ocr-factsheet-migraine-108821.pdf
3. Migraine at School
   https://www.migraineatschool.org

This episode is for educational purposes only and is not intended to provide medical advice. Please consult your healthcare provider regarding your individual symptoms and treatment options.