Episode 207: Parenting and Supporting Children with Migraine

Lindsay Weitzel, PhD:

Hello and welcome to Head Wise, the videocast and podcast of the National Headache Foundation. I'm Dr. Lindsay Weitzel. I'm the founder of Migraine Nation. And I have a history of chronic and daily migraine that began at the age of four. We have a great topic today and a new guest that we've never had before. I'm happy to be here with Dr. Maya Marzouk. Hi, Dr. Marzouk, how are you?

Maya Marzouk, PhD:

I am good, thanks. How are you?

Lindsay Weitzel, PhD:

Good. Thank you for being here. Dr. Marzouk is a staff psychologist at Brown University Health. She trained in headache psychology with one of our regulars and favorite guests Dr. Elizabeth Seng. We all know who she is. And we're really excited to hear what Dr. Marzouk has to say.

Our topic today is parenting children who have migraine. I chose Dr. Marzouk as our guest because she's a published author in this area. I wanted to talk about this today because in my family we have three generations of kids with migraine, and I know that a lot of our guests are parents of children with migraine. I think we're going to learn a lot from Dr. Marzouk today.

I would like to start, since she's never been our guest before, by just asking you, Dr. Marzouk, why do you work in this field and what motivates you to do this?

Maya Marzouk, PhD:

Thank you. Well, I love working with patients with headache and migraine because I think that knowing that headache psychology is such an integral part of their care allows me to feel like I'm really involved in the getting better process. I've also just had the best time collaborating with the other people who work in this field: researchers like Dr. Seng, providers, medical doctors, psychologists. And I've had such a great time with the community that I think it's been really lovely to be part of.

Lindsay Weitzel, PhD:

Oh, great. I just wanted to make sure everyone knows who you are and give you a chance to let people get to know you. Let's start, since we are talking about children with migraine today and parenting these kids and just learning the best way to do it. Because it can be hard on us when our kids have migraine. Let's start with what is the rate. Because we know that sometimes, just like adults, kids with migraine can develop anxiety or depression, etc. What is the rate of anxiety and depression in kids who have migraine?

Maya Marzouk, PhD:

That's a really good question. I think for a long time, people believed that kids with migraine were more likely to have anxiety and depression than kids without migraine. And I think what's come about in the

last couple of years is that there's a lot of confusion around how much that represents what we're seeing. However, what we do know is that rates of anxiety and depression have grown extremely high in the last couple of decades for kids, regardless of migraine status.

Currently around 1 in 3 children has an anxiety disorder, and around 1 in 7 is diagnosed with an episode of major depression. And that's a lot of people. And so, it is possible that it's slightly higher in kids with migraine and it's possible that it isn't. But if you have a child with any other condition, there's a pretty good chance that they're struggling with their mental health as well.

Lindsay Weitzel, PhD:

Do we know if anxiety or depression can affect migraine severity in kids?

Maya Marzouk, PhD:

In terms of more globally and thinking about all of the different kids and adolescents, children, adolescents who have anxiety and or depression and migraine, currently none of the research supports that worse symptoms of migraine are associated with anxiety or depression symptoms. What that means is it's not the kids with the most severe migraine who are necessarily the ones who have anxiety or depression.

That said, sometimes people notice that it's really hard to want to do something when you have a migraine and you're already feeling depressed, because those two things impact our desire to make ourselves a little bit uncomfortable and do something we don't really want to do. And if they're happening together, we're even less likely to want to push through the sadness if we're depressed or push through the anxiety if we're anxious to go do something that's hard because we have a migraine.

Lindsay Weitzel, PhD:

Even if a child isn't clinically depressed or doesn't have clinical anxiety, I think that having migraine as a child and missing out on activities, playing with friends, missing school, and having to do makeup work, things like this can be difficult at times. And so, what can parents do to help if children are having a hard time with these things that they're missing out on, etc.?

Maya Marzouk, PhD:

It absolutely stinks and it is so unfair. And I often tell parents that the first best thing you can do is provide a neutral statement that lets your child know that you see how much this stinks. What we want to be careful of is that we're not spending so much time talking about how bad it is. That we're forgetting that things can be good, but something like, wow, you were really looking forward to going to that party and now you have a migraine and it's not going to be as fun as you wanted it to be.

It can help a child feel like someone gets them. Someone sees how hard they're trying. I also love building a toolkit with your child. Less of skills and migraine things which we also do, but also just fun activities that you can do almost all the time. Some kids really love coloring or word games, or reading books, or being read to, or listening to something on audible. And these are things that they feel that they can do even when they feel the absolute worst physically. They feel they can still kind of find enjoyment in that.

And it's really hard to think of that list when you're in the moment. And so if you're able to find a time to sit down with your child and come up with some things that they can do that are maybe not the most fun in the entire world. Like we're not going to jump on a trampoline or go on a roller coaster, but what can we do that's still enjoyable most of the time that we can participate in. And then in those moments where we're not feeling so great physically or emotionally, we have something to rely on that can still be something we can do to find joy or to find connection if we're doing it together.

Lindsay Weitzel, PhD:

That's great advice. Often those of us who are parenting kids with migraine also have migraine ourselves. Has anyone looked into whether having a parent who can relate in this manner might be beneficial to the child? Or does the fact that mom or dad also has migraine, can that sometimes cause a problem for the child?

Maya Marzouk, PhD:

It's a really interesting question. Dr. Seng actually did a study that I was part of several years ago that looked at adolescents and parents and we asked questions of both of them. And we did see some impact of being a child of a parent with migraine.

To my knowledge, no one has specifically looked at what that experience is like. But I can share clinically that what I sometimes see is that things that work for parents will work for their kids as well. I've had a lot of situations where a parent comes in and tells me I have migraine, my kid has migraine, I use ice, and it really works well for the kid. I think we also know that kids who have migraine, whose parents have migraine, are more likely to be diagnosed earlier. Probably because they know what to look out for.

Lindsay Weitzel, PhD:

I know one of the big questions I see for so many of us raising a child with migraine is how much should we focus on missed school and makeup work versus social life and activities? Can you comment on this balance? Because you're often trying to make up for the loss of both at the same time. And it's so hard to find that balance. Can you comment on which is more important and how do we find that balance?

Maya Marzouk, PhD:

I think that all of that is so important to think about. And it really comes down to a conversation for each family about what lines up with your values as a family. For a kid who really cares about school and school is their primary focus, they might want to choose school and choose missed work over social opportunities. For a child and family where the main value is that we participate in sports, it might be that that's the thing that comes first. But I think this conversation about what matters to us, what matters to you as a as a child and adolescent, what matters to us together as a family, really figuring that out and then prioritizing where are we going to put the energy when we have it.

The other thing is, I think this is true for families where no one has migraine as well, is that many of our kids are very highly scheduled. And so, if there are many activities happening at the same time, and we

feel like we're always, always playing catch up, it can also be helpful to think about if some of those activities aren't serving us as well anymore. But that again is something that it really comes down to the preference of the person whose life it is. Because I tell this to kids all the time, this is your life, this is what you get to decide to do. If you love art and you want to never miss art class, then never miss art class.

Lindsay Weitzel, PhD:

That's great advice. Do you notice sleep problems at all in kids who have migraine? Do you have recommendations for parents in this area?

Maya Marzouk, PhD:

Another one I think people, especially children and adolescents perhaps are really struggling with sleep these days. And I think that difficulty sleeping can really impact migraines for many people. A lot of times people will tell me like, oh, I noticed that I really like sleeping until 10 on the weekends, but then I always have a headache on the weekends. And so, what I work on with patients often is maintaining a consistent schedule. So, trying to go to bed at around the same time and wake up at around the same time. And that will sort of limit the impact that sleep has on migraine.

There's also a number of recommendations, depending on the age of the person, about how much sleep we should be getting. And I will say it's a little bit more than we think. Most people under the age of 18 actually need more than eight hours of sleep and are probably not even getting the eight. In terms of recommendations for sleep, I think the easiest one to give, but the hardest one to follow I know, is putting screens away about an hour before bedtime, if not more, and switching over to another activity that's calming and enjoyable but doesn't have a screen involved.

Lindsay Weitzel, PhD:

How about distraction techniques? What are good distraction techniques when the child needs to be distracted from the pain? I ask this because I have run into so many families who believe the child needs to be put into a dark room and stare at the wall, and so the migraine goes away. And I know that personally, I'll go berserk if I don't have a distraction from the pain. So, I like to give families some ideas of what the child can do.

Maya Marzouk, PhD:

I think this is another one where it really depends on the interest and the symptoms specifically of the child. I know reading might work really well for some kids but might be really tough for kids who have visual symptoms that accompanies their migraine. I think really listening to what your child is saying makes them feel better. I often ask that question the first time I'm meeting a child who I'm going to work with, with migraine. I say, what do you think makes your headaches feel worse? And then I say, what do you think makes your headaches feel better? And they always have an answer.

So, I think that children typically know. But for some good thoughts, I think drawing and coloring work really well. Audio audiobooks are really nice because they allow our eyes not to be exposed to bright lights, but we still have a lot of brain stuff that's happening when we listen to books. So that can be really distracting. Music can be nice for someone who's not very sound sensitive. I think it all depends

on what symptoms are bothering your child the most, and then trying to find something that's enjoyable, kind of gentle, and allows us to feel comfortable while we're doing it.

Lindsay Weitzel, PhD:

What advice do you have for parents who may be dealing with teachers or family members who try to tell you that your kid is milking it or faking to get attention from you. Or even just people who generally give migraine advice, like if your kid just drinks more water they'd be fine. This can be very frustrating for parents and for the children as well if they hear it.

Maya Marzouk, PhD:

It can be very frustrating. Unsolicited advice from all kinds of people is not anyone's favorite. And I think what I would love to highlight is that your child is waiting to hear what you say. And so, it's so important when especially in that first group of scenarios that you brought up where we have people who are doubting or thinking that someone's being dramatic. It can be so powerful to say, I believe them. They don't want to be missing school. They do not want to be missing this activity right now. They are doing the best that they can. They are giving it their all. Because what will matter most to your child is the way that they hear themselves being defended by you, not what a stranger or a teacher may have to say.

That said, for school I also strongly recommend speaking with your child's doctor about getting a 504 plan. I don't know if those have been covered on the podcast before, but I can do a couple of sentences on them. Which is that, a 504 plan is a plan that you make with your doctor and your child's school that allows the school to meet its legal requirement to supply your child with a fair and accessible education. And so that might mean that for children with migraine they have extended time on tests. They might be able to go to the nurse when they need to. And it gives us the opportunity to interact directly with their teachers and say, this is a medical condition that my child is receiving medical treatment for. These are the things that they need at school and sort of to put forth a plan.

migraineatschool.org, which has some phenomenal resources for teachers, school administrators, coaches, any other adults that work with a child with migraine, that can help parents explain to these adults what a child with migraine needs, what migraine is, and what we can do to support them across those environments.

Lindsay Weitzel, PhD:

I was about to ask, what resources do you know of that are available to parents of children with migraine? Are there any others besides the website you just mentioned?

Maya Marzouk, PhD:

I love Migraine at School [migraineatschool.org]. The other really great one that I recommend a lot is the Headache Relief Guide [headachereliefguide.com], which has some great videos. And then of course, the NHF website has some really great handouts. There are some books that are geared toward parents of children with chronic pain. I've had some parents with migraine who have found that helpful. However, chronic pain is a little bit different and so I often hesitate to have those two things be presented as the same. That said, if it's something someone really wants to do, and is prepared to take

what they read with a little bit of a grain of salt, my favorite one is called *Managing Your Child's Chronic Pain*, and it's by Tonya Palermo and Emily Law, who are two pain psychologists.

Lindsay Weitzel, PhD:

Okay, well, thank you so much. Is there anything else you'd like to add on this topic before we go today?

Maya Marzouk, PhD:

I'm just thinking that maybe I should write a book for parents of children with migraine.

Lindsay Weitzel, PhD:

There's not enough out there. Yeah, that would be amazing.

Maya Marzouk, PhD:

Outside of that, I think the best thing that we can all do for our children is to just hear them and allow them the opportunity to tell us what they need. I think it's so easy to get swept up in the day to day that we don't take that time to pause and say, what do you need from me to live your life as a person with migraine. What can I do to support you. But I think kids are smarter than we think they are and they often have an answer to that.

Lindsay Weitzel, PhD:

Well, thank you so much for being here today and answering our questions about parenting a child with migraine. This is such an important topic, and it can lead to a lot of family frustration. And I think parents need to feel supported so that they can in turn support their kids. So, thank you for answering our questions.

And thank you everyone for listening and I hope everyone learned something today. Please join us again on our next episode of HeadWise. Bye-bye.