



JUNE JESSEE MEMORIAL FOUNDATION

# NAVIGATING NEUROLOGICAL CONDITIONS

• TAKING CARE OF YOURSELF  
WHILE CARING FOR YOUR CHILD

## TRANSCRIPT

This webinar is an interview between Genny Jessee, executive director of the June Jessee Memorial Foundation (JJMF), and Katherine Aravamudan, a licensed counselor who serves in a position funded by the JJMF to provide free mental health care to parents and caregivers whose children are receiving care on the neurology floor at St. Louis Children's Hospital in St. Louis, Missouri.

*This interview was recorded on on March 04, 2021*

**Genny:**

Welcome everyone to the second Navigating Neurological Conditions webinar. I'm so glad you're here. I'm your host, Genny Jessee, and I am a mom of a medically complex child and co-founder of the June Jessee Memorial Foundation. I'm on a mission to make lives easier for children with medically complex neurological disorders and their families.

Thank you for taking time out of your day to be here. I'm very happy to present Katherine Aravamudan. Katherine is a licensed counselor with years of experience providing therapy to families and adults in a variety of settings, with particular expertise in working with parents. She holds a master's degree in professional mental health counseling and is trained in trauma informed care, parent-child interaction therapy, and dialectical behavior therapy.

Today, Katherine and I are going to talk about caregivers' mental health and the importance of taking care of yourself while caring for your child. Welcome, Katherine.

**Katherine:**

Thank you for having me. Happy to be here.

**Genny:**

Thanks so much again for being here. Okay, so I'm just going to start. We have a lot to talk about today, so I'm going to just jump right in with our first question. Can you tell us a little bit about your role at St. Louis Children's Hospital and what your days typically look like?

**Katherine:**

Sure. So my title is staff therapist and I work within the perinatal behavioral health service. What that looks like day to day is that my job is to check in on parents and caregivers while they're in the hospital and offer longer term support once they're discharged home. So despite the name perinatal, I work with parents or caregivers who have a child age zero to five with a complex neurological condition, most commonly epilepsy.

Pre-pandemic, I would be there on the floor, set up in the epilepsy monitoring unit on the 12th floor of Children's. And I would go room to room for every caregiver, with the child ages zero to five in the hospital. Now it looks a little different. To limit contact, I start with phone calls. And I know service can be really spotty at the hospital, so I try the cell phone first, and then I can also speak with parents or caregivers using the room phones. And then, if for some reason that doesn't work, I can still go in, but we're really just trying to limit the contact and the exposure of all of our families.

And then, I just try to normalize any stress, anxiety or emotional experiences that they might be having. It's really hard to be a parent under the best circumstances, and when you're admitted to the hospital, certainly a lot more complicated than that. And so, I just try to go through a brief questionnaire, assessing for their stress level and anywhere where I might be helpful. And that's about half of my job.

**Katherine:**

And then the other half looks like providing outpatient counseling or therapy for those caregivers, and also attending the meetings and administrative stuff that goes with working within a medical facility.

**Genny:**

Wow. That sounds like you have your hands full and you're doing quite a lot for these families. So thank you. I mean, hands full in a good way, but you're just getting really involved with their lives, just in the hospital, but then once they return home, when a lot of the support and help is needed. So thank you so much for that.

What are some of your initial findings after working with this parent population and how has that changed since the pandemic?

**Katherine:**

Well, it's a really interesting job as a therapist, because I get to see parents in a variety of settings, but also learn about a more holistic range of needs. And so, I've learned a lot more about organizations like yours and financial funding, as well as just more wraparound resources, like connecting them with social work or local nonprofits that could help them find medical equipment, things like that.

About half of all the parents that I talk with are reporting some pretty high levels of stress, sometimes depression, and sometimes a combination of both. Sometimes that's related to the trauma of going through an ambulance ride or an emergency department admission. Sometimes it's processing a new diagnosis and sometimes it's just fatigue of years of caregiving. And so, depending on where a family is in their medical journey, their experiences can look very different.

But I use what are called assessments and those are just questions that are our most common symptoms of anxiety, depression, or trauma-related symptoms. And there's something called a clinical cutoff, which is where someone's scoring high enough that it's likely they would have some sort of mental health diagnosis. I don't go into diagnose families. I just go into gauge stress. And so, about half of all the families that I speak with that complete that diagnosis score pretty high, which indicates a pretty moderate level of stress.

**Genny:**

This isn't on the question, it just made me think. Once you notice that a family has a high level of stress, what do you do from there? Where does it go from there?

**Katherine:**

Sure. Yeah. So any time, I mean, for any parent, really, when I'm going room to room or when I'm talking with them on the phone, I'm trying to assess for coping skills, so what they do to relax or recharge after a stressful day. And I'm also providing information on what that might look like while they're in the hospital, so utilizing the rooftop gardens if the weather is amenable to that, getting breaks if they're able to have a nurse sit with their child so they can go get some lunch or get some fresh air, something like that.

**Katherine:**

And also talking about how they use their family, friends and other supports out in the community, so that they are really advocating for themselves to be cared for in the same way they advocate for their child to be cared for.

If someone is scoring high on one of those assessments I talked about, I do recommend some sort of support, whether that looks like a support group or individual counseling, and that can be with me or I can help them find someone closer to home if they're traveling in for an appointment like that. We also have psychiatry through perinatal behavioral health service. If they'd want to explore medication or have questions about that, I can help them get that set up with an appointment like that.

**Genny:**

Okay, thanks. So you went through to see some of their coping skills that you suggest, that going to the rooftop garden or utilizing family and friends, and to find ways to take care of themselves. And that's something that I used to hear all the time. A lot of well-meaning people would say, make sure you're taking care of yourself. It was an issue that everyone knew had to be addressed, but it was a lot easier said than done. And sometimes, it would stress me out to think about things, finding ways to do that. And what are some easy ways that you suggest parents can take care of themselves, especially right now, when it's a lot harder for everyone to take care of themselves?

**Katherine:**

Yeah. Something has really happened with the term self-care. I think it's been taken over, and it can actually create a lot of stress when I ask people what they do for self-care. So I try to ask it in sneakier ways, like how do you relax or what do you do after a hard day? And especially at the beginning of the pandemic, I noticed how external self-care has become, when people would say something like, "Well, I can't do any of my coping strategies because the gym is closed or the salon is closed," or "I can't get my nails done." Or "I can't go and have a glass of wine with my friends at this place where we usually go."

And I think coming back to the simple idea that self-care is taking care of yourself, it's acknowledging that you're a human being with some very basic undeniable needs. And so, in the hospital, the quickest, easiest thing that I like to recommend is just a quick body scan, assessing yourself for some basic human comforts. It's usually cold there. You might not have seen sunlight in a few hours or a few days, depending on how long you've been there. Oftentimes, there isn't a kitchenette in your room or anything like that, so you might not be drinking water as much as you need to, or eating the foods that you like. You might be having a lot of cafeteria food, which leaves you feeling uncomfortable or just unsatisfied. So going through those really basic human needs is step one and just the most basic level of self-care.

**Katherine:**

There's an acronym called H.A.L.T.S. that one of my supervisors used. So are you hungry or hot, or in this case, cold? The A is for angry or anxious. The L is for feeling lonely or running late. T is tired or thirsty, and S is stressed or sick. And that just gets you a basic idea of things you can check in on. If you had a maintenance manual, those are things that you could address.

And then, the higher level of self-care is treating yourself with the loving kindness that you treat other people with. And so, that can look like how you talk to yourself or those comfort things. If you enjoy having your nails painted, having your nails painted. Or making room for yourself to listen to music, take a walk, permission to leave the bedside and walk in Forest Park and get some fresh air and some sunshine.

**Genny:**

Wow. Those were some really, really great tips that you just, all of what you suggested that we can readily use right now. And I love that idea of just checking in on sensations and if you're hot or cold, and about sunlight, because sometimes if you don't think to ask yourself that, you won't notice it. And once you notice it, then you can just make a big leap forward. How can I get sunshine? And it does really feel so good to feel the sun on your face when you've been in the hospital for so long. So I think that was really great.

You mentioned some mindfulness exercises and I wondered if you would mind sharing a specific mindfulness exercise that you suggest to patients. And you previously shared one with our June Jessee Memorial Foundation group, and I found that particularly helpful as a way to take a few minutes to tune into myself. I mean, you can even take me through it if you want, pretend I'm your client. I don't know if you say patient or client, but pretend that you're running me through it or however you feel comfortable doing it.

**Katherine:**

Yeah. So if we were working together, I would start by talking about mindfulness as a lens to view the world rather than a destination. So it's not somewhere where you go for a few minutes. We do use exercises that take three to five minutes to practice the skill. But the overall goal is just to have you more in tune with each moment and checking in with yourself on a regular basis. And so, I know you want an exercise and I will get there, but first starting with the idea of mindfulness and what it is can be really helpful.

There are three main ways to practice mindfulness and that's to observe, to describe, or to participate. And so thinking about what you need in each moment. And then there are how skills for how you practice mindfulness, and that's non-judgmentally, so just sticking to the facts, noticing what is real, what is true and not necessarily how you're feeling, but just checking in with what the facts are and when mindfully, so focusing solely on one task at a time or one activity at a time. So those are the wet skills and the house skills of mindfulness.

### **Katherine:**

So if you're in the hospital and you're feeling pretty stressed, describing your emotions in that situation might not be the most helpful thing for you, just describing might not be the mindful skill you want to try. So thinking about those other ones, you could observe an object in the room and describe it in as many details as you can. Or you could try participation, which can look like putting in some earbuds and listening to your favorite song and mouthing every word to it, or just really letting yourself be engaged with one thing for three minutes that's not overwhelming or stressful for you.

What we talked about earlier was a [body scan](#), when we were talking about checking in for those basic body sensations. And so, that's one that I use pretty frequently, especially early on. It's just having a client sit comfortably and close their eyes if they feel comfortable doing that. Not everyone with a trauma history will feel comfortable closing their eyes, especially with someone they just met.

So do whatever's comfortable for you either resting your gaze with your eyes open a few inches in front of you, or closing them and just noticing how you're sitting, making sure you're in a comfortable posture with your back straight and starting with the top of your head. And just trying to notice how your mind feels. Is it racing? Is it active? Is it confused? Is it empty? How are you feeling? And trying to just let any thoughts pass by like cars on the street going past, without judgment or without attachment to any of those thoughts.

And slowly working down, a lot of us carry tension in our neck or shoulders. And so, noticing, again, without judgment or any self shaming, are my shoulders up here? Are they relaxed? Is one side more tense than the other? And if there's any adjustment you could make to make yourself more comfortable, shoulder roll or sitting up straight, anything that you could do to just relax even further. And so just slowly moving down your body in that way, noticing your lungs, your breath. Is it feeling tight today? Is it fast paced, slow paced? Using those nonjudgmental, factual, descriptive words.

Moving down to your stomach. Do you feel hunger pangs? Do you feel full? Do you feel any tension there, sometimes nausea or some queasiness if we're feeling stressed? Moving down your legs, are they crossed? Do you have both feet on the ground? Is there anything you could do in this moment to make yourself, again, a little bit more comfortable. And slowly moving down to your feet and your toes, can you wiggle them? Can you scrunch them up and relax them? And then, at this point, I would ask the client what they noticed.

### **Genny:**

Well, I just did that with you and I already immediately just feel just more centered and calmer. And I don't know if that's what some of your clients feel, but just even that quick body scan, I feel just a little bit like, Oh, okay. I could maybe take a nap or I could maybe go on with my day a little bit.



**Katherine:**

And I did it as I was talking about it, and things like this make me nervous. And so, it helped ground me in the middle of this conversation and check in with myself. And I think often we judge ourselves for how we react in a moment. Oh, I shouldn't have said that or, Oh, I came on too strong. And we don't notice that we're carrying around all of this tension. How long were my shoulders up by my ears? Or how long was I sitting uncomfortably on my third zoom call of the day, or something like that, without checking in. How long has it been since my last glass of water?

**Genny:**

Yeah. Yeah. And I think it also takes ... Mindfulness is something that was introduced to me a little bit before I had June, but a lot with June. And I think it does take practice to be able to all of a sudden, I think you and I immediately felt something. It does take practice to get that sensation. I remember before, when I first did it, like, okay, this is weird. Because like you said, the judgment, but the more you do it, the easier it is to get that immediate, or not immediate, but that calming sense, I think. I don't know if you think that too.

**Katherine:**

Yeah. Another really accessible exercise is focusing on your breath. So doing something like square breathing, where you're breathing in for the count of four, holding it for the count of four, breathing out for the count of four, and holding it out for the count of four. So all you have to be able to do in that situation is count to four. Anybody can do it, and breathe. Anybody can do that and practice that.

And another one that I do, just when I have like a couple of minutes between sessions or something, is listening to a bell. And you can use YouTube to find singing bowls or bell sounds. And then, that gives you something to focus on, because if you tell someone to meditate for five minutes, then their thoughts are just racing most of the time. So I really like having the bell and you just listen to it fade. And so, it reminds me how attentively I can listen when I'm really trying to listen. I can hear the faintest sound of the bell as it fades into the background, but it also gives me an anchoring point to focus in on.

**Genny:**

I love that. And you said you can find those sounds on YouTube, just-

**Katherine:**

Yeah. I can tell you, I keep ... This was my son's that he didn't want, but I have this little bowl. And I apologize, this sounds really tinny, but just that little sound and then I listen to it fade. And it just sort of-

**Genny:**

I love that.

**Katherine:**

It's something easy to do.



**Genny:**

Yeah. I do know also with breathing, for me, with breathing, sometimes ... When you said the breathing count to four, sometimes I'm like, I can't breathe that long. The weirdest things cause me anxiety, but then sometimes that makes me ... But I have learned that if you lie on your stomach and then try to take a belly breath through your stomach, it's easier for me to access that deeper breath. I don't know if you've heard that or if there's any other breathing. Am I missing anything with mindfulness or breathing that you would like to cover?

**Katherine:**

You were, I mean, speaking to a feeling that I was having, where I think I said something was easy a few times, and it's not easy to start. And when I say easy, I just mean easy to explain, not as easy to do. And also, it's going to be different for everyone. So when I said a box breath of four, that's my comfort zone, and someone else's might look like one or two counts, or three. So really experimenting and using those mindfulness skills or those body scan skills of what feels good for me. And you were saying it felt good to lay down. And it's not something that is in a textbook that I've read, but it's about your experience. And if it's bringing you comfort, then that's very real and very important.

**Genny:**

For some reason, it's easier for me to take a breath, a deeper breath, if I'm on my stomach.

**Katherine:**

Yeah, it helps your lungs expand in the back. It's easier for you to breathe deeply that way. And I do think there is science that backs that up, but it's about what's comfortable for you, rather than me telling you what the best way to do anything is.

**Genny:**

Yeah. Okay. Great. Okay. In your opinion, since this is something that, this is your job, your career, why is a caregiver's mental health something we should focus on more, especially in pediatric care?

**Katherine:**

Coming into this job specifically and working with people like Dr. Thio, I think it has been well-researched that being a caregiver of a medically complex child comes with a lot of stress. There have been lots and lots of papers that I've come across since starting this job two years ago that really support that. And I'm always left with this question of, well, what did they do next? They did this study, there are measures. I can find a worksheet that will assess caregiver stress. And then, at the end of the worksheet, that's it, and there aren't next steps or a phone number you can call or things like that.

And a lot of the families I talk with have been told things like, "Oh, well, this will really be difficult for your relationship," or, "A lot of parents of medically complex kids end in divorce." And they carry that weight around, knowing that it's a fact, or knowing that they're experiencing more stress than what they see in friends' relationships or what they see in friends who are caregivers or parents. And so, having that information, but then not having resources, just adds to an already difficult job.



**Katherine:**

So I've always really loved working with parents in all settings, just giving basic parenting skills or support groups, because I, as a parent, feel like it's a very isolating job on your first go around. It's hard to make decisions. As your child gets older, you have to become an expert in a whole new set of skills and relationship styles, and deciding what you as a parent want to set for your values. It's really hard. And then, on top of this, the families that I'm working with have to become experts in their child's medical care, remembering every dose, every medication schedule, every therapy appointment, all of the equipment, and feeling like they're walking encyclopedias with that information.

A lot of parents I speak with feel like they're the only ones that know everything. And they're constantly having to inform other specialists or other therapists, or their own spouse sometimes, about what happens next or what happens if. And so, this was that next step of what you can do. We can recognize, Oh, that looks really hard. Oh, that looks really stressful. Oh, you have to do so much. And this is just one soft place where you can let that down and hopefully gain some skills that make it a little more manageable.

I think parents might get tired of hearing, "Oh, you're so brave," or, "You're so strong." It's like, you didn't ask for this. It's not like you set out to become this expert in epilepsy or infantile spasms or anything like that, it was forced upon you. And so, giving people skills to better manage that stress is really important.

**Genny:**

That was a great answer. That was just very beautiful. I don't know if beautiful is the right word, but it was just, yeah-

**Katherine:**

That was very nice of you.

**Genny:**

I just thought it was really great. I know you're making a difference. I hear from parents. And therapy was such a help for me and it made such a big difference. And I'm just so grateful that you're able to provide this to parents, to help them, just be a life raft for them during this time. I just am really grateful for you.

So this is my last question. How would you recommend parents find a therapist to connect with, and what advice would you give them for making that initial contact to reach out?

**Katherine:**

Sure. So I know we're based in St. Louis and if people have any questions or want to speak with me directly, I'm very open to that and will provide my [contact information](#). If a parent is insured, I would look at EAPs or calling the insurance company. It's a great place to start to find someone that accepts their insurance. A website that's really easy to use is called [Psychology Today](#). And you can search by your zip code and your insurance coverage. And if you have a preferred type of therapy, if you've been in counseling in the past and done something that really worked for you, you can also search by that specific modality.



**Katherine:**

I made some notes about this, so I just want to review them. Yeah, I think EAPs and [Psychology Today](#) are a great place to start. If a parent is in the NICU and they're seeing this, either at Children's or other hospitals across the country, I think it's pretty common for a position like mine to be in the NICU. And usually asking for perinatal behavioral health is a good start.

And there are some social workers and trained psychologists that work in children's hospitals for neurology, specifically. I think this is a pretty new field and I haven't been able to come across a program that's exactly like the one that you've helped create here, Genny, but just asking about the hospital. They may have a list of therapists that are better ... Sorry, are more specifically trained in working with parents of medically complex kids or have experience doing this.

And then, when you're interviewing, I think remembering that you do not have to go with your first choice. Trying out, a lot of therapists will offer a 20 or 30 minute consultation where you can get a feel for their style and whether or not you feel comfortable with them. Be sure to bring your questions and let them know anything that has been helpful in the past or even not helpful. I really didn't like this sort of exercise, or worksheets are not something that I have time to follow through on. So having that self-awareness can be great.

If it's your first time to counseling, I would just focus on the relationship, because I think studies support that the relationship is the most important thing of any sort of therapeutic relationship. And a lot can vary with the different styles or techniques that therapists use, but if a patient doesn't feel comfortable, then you're not going to get very far.

**Genny:**

What is EAP?

**Katherine:**

Employee assistance programs. So a lot of employers will offer three to five free sessions for their employees. If a new diagnosis comes up or there's a hospitalization that's a specific amount of acute stress. And you'd think that three to five sessions would be helpful, and EAP is a great way to go because it's very cost-effective, often free. Otherwise, going through insurance or looking at [Psychology Today](#).

**Genny:**

Okay.

**Katherine:**

I think the pandemic has, in some ways, been validating for families. At the beginning, I heard them say, "Now people get it. They're washing their hands. They're being cautious. They're wearing masks. They're thinking about cold and flu season differently and they understand how seriously we've been taking cold and flu season since our child was born, or since they've had this diagnosis."

**Katherine:**

And there was a camaraderie of respecting healthcare workers. And in the beginning, it was maybe validating for some of our families. But longer term, it's been further isolating. Families have lost a lot of their therapies or in-home nursing support. I've gotten a greater sense from caregivers that it's all on me to do this. I have to be everything for everyone, and also somehow work from home and be a teacher and be a physical therapist, and do all of these telehealth appointments. And so, that's really shifted the dynamic. And I think that we just don't have a lot of good supports in place for our caregivers.

**Genny:**

Yeah. I would agree. And I heard another mom say, now she's early on in the journey, like you said at the beginning, but she was saying how the rest of the world is grieving, so grieving at the same time she is. And that has felt a little bit less isolating in some ways than if everything was going on as normal as possible during all of this. But I've also heard similar things to what you've said at the beginning. But I can see how as time goes on, it would just be more isolating too.

**Genny:**

Thank you, Katherine, for taking time out of your busy schedule to be part of our Navigating Neurological Conditions webinar. We really appreciate your insight on caregivers' mental health and why this is so important. Thank you for everyone for tuning in. And if you have questions, please visit [JuneJessee.org](http://JuneJessee.org), or you can visit us on our social channels.

**Interested in continuing the conversation? Visit [junejessee.org](http://junejessee.org) to find events, resources and support for the needs of children with undiagnosed, neurological conditions and their families.**

