

Ep #112: Parental PTSD (Part 1)



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With Your Host

Lisa Candra

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You are listening to episode 112 of *The Autism Mom Coach*, Parental PTSD (Part 1).

Welcome to *The Autism Mom Coach* podcast. I am your host, Lisa Candra. I am a lawyer, a life coach, and most importantly, I am the full-time single mother of a teenager with Autism. In this podcast, I am going to share with you the tools and strategies you need so you can fight like hell for your child without burning out. Let's get to it.

Hello, everyone and welcome to the podcast. I am so glad you are here and I hope you are doing well. Before we get started, I'm going to read a review from Julie Speak. The subject of the review is, must listen for Autism parents. Julie writes, "Thank you for sharing your story. It has helped me immensely. This podcast is powerful and life changing for anyone with a child with Autism or any disability." Julie, thank you so much for the review. I appreciate it so much. And I'm so glad that you find this podcast helpful and as a support in your journey.

This is exactly what I want to do with the podcast, I want to support as many Autism moms as I can. I want to teach you all of the things I wish I knew when my son was diagnosed and all the things that I continue to learn on this journey to support you the best that I can. And to do this, it's really helpful to have reviews for the podcast. The more written reviews, the easier it is for moms like you to find me and to get the support. It will only take you a few minutes, go to Apple Podcasts, scroll to the bottom, write a review, submit it and I will read it on the air.

Okay, onto today's topic of parental PTSD. I am going to address this topic in two parts. In this episode I am going to talk about PTSD, what it is and how it shows up in Autism moms specifically. And then in part two I'm going to talk to you about some of the ways that you can support yourself if and when you are experiencing symptoms of PTSD or the effects of chronic stress in your day-to-day life.

To talk about PTSD, post-traumatic stress disorder, we first need to talk about trauma. Trauma is defined as a deeply distressing or disturbing

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experience that overwhelms an individual's ability to cope. It can result from a single event or ongoing chronic stress from living in a war zone to taking your child with Autism to the dentist, from being assaulted by a stranger to aggression by your own child.

The point here is that trauma and PTSD are not reserved only for things like war or rape, which, to be honest, for the longest time I associated PTSD only with veterans of war. I think that is where the term PTSD arose from, the study of the experiences of veterans, but it's not limited to their experience. Trauma and PTSD can arise from many situations. Trauma is not about who, what or where. It is about how an individual experiences the trauma and the impact on their ability to cope.

As some of you might know, there are several studies that show parents of children with Autism experience significantly higher levels of stress, anxiety and depression as compared to parents of typically developing children. And that's surprising said no Autism mom ever when it comes to that. These studies also show that Autism parents are at a higher risk of developing PTSD compared to parents of typically developing children.

In fact, one study found that mothers of children with Autism were up to three times more likely to experience symptoms of trauma than mothers of typically developing children. Again, no surprise here when you consider all of the scenarios Autism parents experience regularly and repeatedly in various contexts, from the medical field to education to social interactions and just the day-to-day experience of parenting a child with Autism.

So let me give you a couple of examples. In the medical context, there is the uphill battle of receiving the Autism diagnosis in the first place. I talk to mothers every day who were put off, who were dismissed, who were told it was something totally different, who were told they were being overdramatic, who were told their child would grow out of it. These mothers were having a very specific experience, a very specific observation, and were being told by other people, "No, you're wrong." That in and of itself is a very jarring experience.

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And then there is the experience of receiving the diagnosis itself, sitting there in the room while the person in the white coat gives you the news. I know for me, I was seeking the diagnosis. I put my son on many waiting lists and we were finally at the appointment and there was something in the back of my head saying, they're just going to say it's a speech delay. It's probably just a speech delay. It's probably not, but it was Autism and it was for sure Autism.

And hearing those words and time standing still and just going blank at the same time and just knowing your life is never going to be the same again, it wasn't going to be anything like you imagined, is a very jarring experience. And then once you get the diagnosis, you continue to navigate the ever changing maze of doctors, specialties, insurance, just knowing that nothing is straightforward, nothing is ever easy, that everything is a production.

I tell my clients, "Whatever you think it's going to be, times it by 10. And if it's a little bit less, bonus and if it's not, well, you're prepared." That is the nature of being a special needs parent. And the educational context, for most of you, I just need to say the three letters IEP and your stomach clenches.

Advocating for your child's educational rights and accommodations, day after day, year after year, with ever changing staff, principals, case managers and schools is exhausting. And it can be quite traumatic when you are listening to people telling you all of the reasons that your child is behind. All of the things that they're not doing. All of the ways that they're not measuring up. Who are denying your experience saying things like, "That's not happening at school. It must just be a home thing."

Or just that feeling of being helpless and unsupported when you're asking people to help you and to help your child and they're not doing it and you feel like they are holding your life and your child's future in their hands. It's a horrible feeling and it's not a one and done. It happens repeatedly. These are ongoing relationships that we have to manage day after day. And that's just part of what we're doing on top of everything else that we're doing with our child.

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I have a couple of clients who were just straight up being gaslit by their school districts. And I'm going to talk about gaslighting in a future episode. But this is something, intentional or not, that Autism parents face all of the time, being denied what's right in front of your face. And even for the most strong willed, self-confident of people, this is something that will make you question yourself. It will make you question your own reality, especially when it's happening over and over and over in and over context after context.

And then in the context of being in the community. There's PTSD that arises from facing judgment and criticism of your child, of your parenting. Dealing with difficult interactions with people in the grocery store, being afraid that people are going to judge your kid, being afraid of just doing the normal day-to-day things because you're not sure how your child's going to react. And if they do react in a certain way, just being so afraid of how other people are going to respond to it.

That kind of stress, that kind of hypervigilance makes day-to-day activities like getting gas and running into the store for some milk and eggs very difficult and perhaps traumatic. And then of course, there is the day-to-day experience of parenting your child with Autism and all that entails.

For me, when I hear the words, "Mom, can we talk?" I feel sick right now just saying it. Because it triggers in me all the times that my son is perseverating over something he has his OCD loop going in his head. And I just go into the, oh my God, if this doesn't resolve very quickly, he's going to get triggered. If he's going to get triggered, he's going to get louder. If he's going to get louder then it's going to progress from there.

And so in that one second from hearing the words, "Mom", I'm already there. Add to this things like self-injurious behaviors, watching your child punching themselves in their face, your child eloping from you, running out the door. Being hypervigilant in your own home or anytime you're out in public with your child because you don't know when they are going to zoom away. Chasing your child into traffic. I have had clients who have done this and it's absolutely horrifying.

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And most of the things that I have named in these different contexts are not a one and done. It's not something that just happens one time and you remember it throughout your life or can get triggered in certain contexts. These are things that are happening regularly, repeatedly. That is going to trigger in your nervous system, the memories of every other time. It's going to put you in a hair trigger reaction. You're always going to feel like you're on the edge.

And so these are just some of the contexts in which the trauma can arise. And so the fact that this stress, this trauma is chronic it's a little bit different in the way I think about it from post-traumatic stress disorder. The idea of something happening at a fixed period in time being triggered thereafter, because this is happening on an ongoing basis. And this is what is actually referred to as complex PTSD.

This is not a distinct diagnosis from PTSD, but it is used to describe the effects of repeated trauma exposure, which is exactly what I just described above. And it's so interesting because the symptoms, the key features of PTSD line up perfectly with what I have experienced in my life as a mom with Autism and what I see in so many of my clients. So I'm going to list off these features for you and just ask yourself, is this me? Does this sound familiar?

Number one, difficulty regulating emotions. Chronic stress can lead to heightened emotional reactivity, making it harder for us to manage our feelings of anger, sadness or fear.

Changes in self-perception. Prolonged trauma exposure can lead to feelings of helplessness, shame or guilt, and a negative view of oneself. I have had this experience so many times, just feeling like I was helpless to do anything about my situation. And I'm feeling a lot of shame about that and doubting my own competence as a parent.

Disrupted relationships. Chronic stress can strain personal relationships and lead to feelings of isolation and distressed.

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Number four, loss of meaning or purpose. The relentless demands of Autism parenting can leave us feeling depleted and questioning our own sense of identity. I've had this experience so many times in my own life, and I'm seeing it with my clients too. You just don't know who you are anymore because you're used to working hard.

If you're used to getting results in certain ways and now it feels like everything you do and you're working so hard, you're working harder than you've ever worked for anything in your life and feeling like you're not getting the results that you want. It really makes you question yourself and second guess yourself. It makes you doubt yourself and it is exhausting.

And then finally, there's all the somatic symptoms of chronic stress. There are disruptions in sleep, if you're sleeping at all, headaches, gastrointestinal issues, chronic pain. All of these are symptoms of complex post-traumatic stress disorder. And the reason I bring this up, it's not to slap a diagnosis on to the symptoms that you are feeling, but it's to highlight to you that they are real. The experience you are having is real and there's a name for it.

We're not having the experience of being a bad mom, ineffective mom, the crazy mom, the drama queen, none of that. The symptoms you are having are the result of the chronic stress and trauma you are experiencing. And I think this is important to know, because when you are in a continued state of chronic stress, you are not going to see this for what it is. And the go to of so many mothers is to blame ourselves, is to think it's a deficiency with us, that there's something wrong with us, and there's not.

You're having a very real response and that's just not the case. And in fact, that's really an example of this entire experience of having an experience and then having it being denied at the same time. This happens to us all the time in the context of being a woman, of being a mother and then being a parent of a child with Autism, where you're being told that the thing that you are seeing so clearly is not a big deal or it's not the case, or that you're wrong.

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We experience this all the time and then we double down on it when we're doubting ourselves, we're questioning ourselves or we're dismissing ourselves as being drama queens or crazy. That's just a way of us doubling down on our own experience of trauma and it leads to more feelings of helplessness and isolation. And so it becomes a vicious cycle, that we can interrupt. And I think that starts with noticing your experience and validating it. You might not get that validation anywhere else. It has to start with you.

So take a listen to this episode again. See if what I've described resonates with you. Are you having these experiences? How is it showing up in your life? And validate yourself. And if you want to join this conversation with me and other moms like you, you can join my Resilient Autism Mom Facebook group. We're going to continue the conversation in that group.

And then finally, if you are struggling with these symptoms, if you are struggling with your own chronic stress and the way that it's showing up in your life, the self-doubt, the anxiety, all of that, I can help you with that. In my Resilient Autism Mom program, this is exactly what we target. The realities of Autism parenting, what it is actually like, the things that you can do to take control of your parenting experience.

We can't control our children, but we can control ourselves. And this starts with understanding and appreciating what is happening for us on a day-to-day basis. And all of the things that we can do to interrupt the patterns that are keeping us stuck in that cycle and to create new ones. And this is exactly what I do in my one-on-one coaching program. If you are ready to break this vicious cycle and to feel better, more confident as an Autism mom, schedule your consultation now using the link in the episode notes, go to my website theautismmomcoach.com.

Alright, that is it for this week. Have a great week and I'll talk to you soon.

Thanks for listening to *The Autism Mom Coach*. If you are ready to apply the principles you are learning in these episodes to your life, it is time to schedule a consultation call with me. Podcasts are great but the ahas are fleeting. Real change comes from application and implementation and this

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is exactly what we do in my one-on-one coaching program. To schedule your consultation, go to my website, theAutismmomcoach.com, Work With Me and take the first step to taking better care of yourself so that you can show up as the parent you want to be for your child with Autism.