

Ep #114: Respite Resistance



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With Your Host

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You are listening to episode 114 of *The Autism Mom Coach*, Respite Resistance.

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. For this week's topic we are going to talk about something that I have experienced firsthand both as a sibling and a parent of a child with Autism and of course now as a coach, respite resistance. So what is this? It is quite simply the reluctance, or the refusal by caregivers to take a break, even when the ability to take a break is available.

I certainly understand that there are constraints to respite that are very real, financial constraints, finding a suitable provider. However, that aside, I am still seeing respite reluctance in Autism moms who have the ability, who have a spouse, a partner, a family member, a team, whatever it is. They have the ability to take a break, but they still won't do it or they hesitate to do it, they resist it. And then even when they do it, they have such conflicting feelings about it that they don't get the benefit of the rest or the respite.

So before we even talk about respite resistance, I want to talk about why it's important in the first place. The ability to take a break, even small breaks from stressful situations is so important for Autism moms because most of us are living pretty intense lives. Our children have big feelings, they have a lot of needs and so often it is mom who takes on the lion's share of all of it.

And my experience from not taking respite for many years or resisting it is that the more you resist it, the less you actually enjoy the time that you do have with your child. You're always on edge, you're irritable. And at some

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point you actually do become resentful of the people who you say that you aren't taking the rest for, they become the reason you're not getting the rest and that can lead to a strain in relationships. Rest is important for us, like it's important for every human being on the planet.

Rest is even more important for us now, given all of the responsibilities that we have and the intensity of our parenting experiences. So with that out of the way, let's talk about some of the reasons that moms aren't taking respite even when they can.

The first thing that I see is the guilt. As women and mothers, we are socialized that good mothers are always there for their children and the idea of taking a break is selfish or somehow a disservice to our kids. And then you add to this the guilt of burdening someone else, whether it's your spouse, whether it's a family member. I've even seen it with people that my clients hire for this very reason.

I have clients who don't ask husbands or other family members not to help out because they don't want to be viewed as not being able to handle everything, or they don't want to be viewed as lazy. I have clients who have hired people to assist in their home and they feel guilty resting or taking a nap while that person is in the home for fear that the person they've hired to help them will think that they're lazy.

There is also that guilt that dad or grandma or the sitter won't do things exactly the way the child wants, or exactly the way the child is used to, that there will be some disruption in their level of service. And the fact is, there probably will be and that's actually a good thing.

It's always a good thing when our children are challenged to have to manage with other people, with different expectations and different styles, all of that creates flexibility. But for the moms, I'm just seeing so much guilt about the fact that they're not going to have it the way they want and they should, and that this is somehow a bad thing.

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The second thing that I see is that there's worry for the child that they won't be cared for at the level that mom would do it. Maybe the dad or grandma will get annoyed faster and they won't know how to deal with the situation. And so I always see the moms worrying about their child not being cared for again at the levels that they think.

And then finally what I see and I have experienced this both as a parent and a sibling of a child with Autism is the fear of taking a break and not knowing what I'm walking back into. I have definitely had those experiences of not wanting to take a break and get all relaxed, only to walk into a screaming child, a distraught family member or sitter, a messy house or not having their routine started. To me that would have just been creating more stress and then the respite wouldn't even have been worth it.

I remember this from my childhood. When my parents were in middle school they won a trip to Aruba and my dad was so excited to go. And I was so excited for my parents to go because my grandparents were set to watch us and my grandma was going to be sleeping over every night. I thought this was going to be so fun and I was so excited for this to happen.

But in the days leading up to the trip, I was really worried that my parents weren't going to go at all because my mom kept on saying, "I don't know if we should go." And she wasn't sure it was a good idea. And this made absolutely no sense to me. I knew how stressed out my parents were. I knew how much they wanted the vacation. So the idea that my mom would say, "We aren't going or we shouldn't go", just blew my mind as a 12 year old.

Now, looking back on that situation and conversations I've had with my mom since. From her point of view, while the vacation would have been great, it was the coming back from the vacation that was creating so much stress for her. The idea of walking into a high anxiety situation, wondering what my sister had done. Perhaps my grandparents being annoyed or being upset or thinking that she was being disrespectful and not listening, created so much stress for my mom that she didn't want to go on the vacation.

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And then when she did not enjoy it nearly as much because she was stressed out about all of these things. So it's like a chicken and an egg thing, too. If you're stressed out about going on vacation because you don't know what you're going to be walking into and you spent all of the vacation being stressed, you're not going to look at vacation as a way of actually getting respite. And again this becomes a vicious cycle but it's not because taking a break is stressful.

The break in whatever form, does not actually cause that exhaustion, it is all the spinning in our brains that does this. And so often this ends up in Autism moms either doing the thing and feeling depleted because they're feeling guilty about it, or they're worrying about their child the whole time, or not doing the thing and feeling depleted.

In order to shift from this respite resistance, I'm going to share with you the work that I've done and the work that I do with my clients. And this might surprise you, but I'm not going to tell you how to take respite, what you should do or how you should do it, because taking the respite isn't actually the first thing that you need to do. Because you could take the break technically and spend all of your time during the break being stressed out about it so you don't get the benefit.

So in order to get the benefit of whatever breaks that you can take, it really starts with shifting how you think about respite in the first place, flipping the script. When we're thinking about respite and all of the ways that it might disrupt, annoy or inconvenience other people, it's always going to be stressful for us. So I want you to think about this in terms of the think, feel, act cycle. We talked about this in episode four or five and I will link it in the show notes.

Think, feel, act cycle is simply posits that the thoughts in our brain create feelings in our body and those feelings fuel our actions. So if we are thinking that taking a break is stressful and we're feeling stressed when we actually take the break. Our actions of spinning and worry and guilt and checking in on the child, all of that is not going to result in us feeling

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refreshed. And so we really do need to look at how we're thinking about the respite in order to shift our experience.

And so that is the question you need to ask yourself. How do I need to think about respite so I can actually enjoy it and reap the benefits of it? For me, my default thought about rest or before even when I could do it, it was something along the lines of, it's not enough or it won't matter anyway. And when I was thinking it wasn't enough or it won't matter anyway, I was in no way motivated to actually make it happen so then it didn't happen. As a result, I'm not getting rest, I'm getting more stressed, I'm not having a break, I'm more irritable.

And I really needed to check that thought, it's not enough or it's not worth it because it wasn't helpful for me. So when I did go from, I don't think it's enough to it's enough, no positive affirmations, no trying to convince myself of something I didn't believe quite yet. But what I did believe about respite was that it was important. I believe that rest is important just generally speaking, I can get behind that.

And so just that thought, this is important, focusing on it being important and then focusing on it being important to me and focusing on how it was important to my child that I got this rest. By being able to shift myself and my thinking to the benefits and to why it was important, it felt so much different for me. It no longer felt like a nice to have or a luxury, it felt more necessary.

It was part of just my daily life, my medicine, being able to have food, to being able to hydrate myself, to being able to have rest and respite. These were all of the things that actually helped me and enabled me to support my child. And just that shift in thinking made the experience of taking the rest, restful. I actually took a break.

But when you're looking at taking a break as being an inconvenience to other people or something that you shouldn't be doing because you're making somebody else suffer, it's not going to be a break at all. And it also requires you to really check-in with some of these thoughts that you're

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thinking. When I hear the word guilty, I think of it in terms of we feel guilty for things that we've either done wrong or go against our morals and our values. And do you really want to feel guilty?

Do you really want to believe that you have no right or ability to take rest for yourself? Would you really want to feel guilty about that? Do you think that you're wrong or you've done something bad? And most of my parents will say no, they don't feel like they've done something bad, but they do feel uncomfortable. That is normal when you have been socialized to believe that being a good mom means being completely selfless, being essentially a martyr, doing something that benefits you will feel weird.

And what I want to encourage you is to let it feel weird, it will feel weird to shift your thinking. It will feel weird to create new patterns. That's not a problem. That's actually part of the process. Your ability to notice that it feels weird is part of the process. It's not a reason not to do it. And so when it comes to respite, when it comes to rest, it's really important for us to get clear on the value of it.

What do you believe is the value of you having rest and respite both for you, your child, your family, both today, tomorrow and in the long term? When you start focusing on thoughts like, for me it helps me stay calm. I am responsible for taking care of myself. This is my responsibility. When I feel calm, I'm able to model calm for my son. All of these thoughts, all of these beliefs that I have about rest, make taking the action of creating time for myself feel very necessary. I feel determined. I feel motivated. I don't have a moral judgment about myself because of the rest that I take.

And so when you can take that away, when you can take away the judgment, when you can take away the guilt, when you can take away the should, you can actually get the benefit of the small breaks. And so again respite doesn't mean a vacation. Respite means small breaks. And those small breaks can go a long way when you're not beating yourself up, when you're not telling yourself you shouldn't be doing it, when you're not telling yourself that you should be doing something for other people, or that you're failing other people. You can get the benefit of even the smallest of breaks.

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So that is what I encourage for all of you, take a look at your thoughts about rest and respite. If you see the thoughts that aren't serving you, that are making it harder, check-in with yourself, are these thoughts true? Do I want to believe them? Are they helpful? All of this is part of the process of creating new patterns for you that will help you stay regulated, that will help you stay present and will enable you to navigate the ups and downs, the roller-coaster of Autism parenting with so much more grace.

Alright, that is it for this week, I hope this was helpful and I will talk to you next, take care.

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 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.