

Ep #81: The Grief Spectrum



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With Your Host

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You're listening to Episode 81 of *The Autism Mom Coach*, The Grief Spectrum.

Welcome to *The Autism Mom Coach* podcast. I am your host, Lisa Candra. I'm a lawyer, a life coach, and most importantly I'm the full-time single mom to a teenager with Autism and other comorbid diagnoses. I know what it's like to wonder if you are doing enough or the right things for your child and to live in fear of their future. I also know that constantly fueling yourself with fear and anxiety is not sustainable for you or of any benefit to your child.

That is why in this podcast, I will share practical strategies and tools you can use to shift from a chronic state of fight/flight to some calm and ease. You are your child's greatest resource. Let's take care of you.

Hello everyone, and welcome to the podcast. I am so glad you're here, and I hope you're doing well. I am recording this episode and the next couple of episodes on the day of my son's 16th birthday. Oh my goodness, all of the feels. Disbelief, wonder, sadness, fear, love, pride, admiration, shock, the whole spectrum of emotions, which is exactly what I want to talk to you about today as it relates to grief and loss.

Like I said before, I don't like thinking about grief in stages. I don't think that that paradigm is helpful or really even applicable to our experience as Autism parents. I like to think of our experience more like a spectrum, and how appropriate, right? Because one day or minute you could be feeling fine, even hopeful. Then the next you are hit smack in the face with some reality that stings.

That does that mean you are starting the grieving process over like a board game where you are steps away from the finish line, and now you have to go back to square one. These ups and downs and our emotions are all part of the process of grieving a continuing loss.

That is why for us, parents raising kids with Autism, I like to think about grief as a spectrum comprised of a variety of emotions. Any emotion that

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you feel related to the loss of your expectations related to your child's diagnosis or even related to the victories you achieve as you advocate for them, and you work ten times as hard to achieve, and you and they work ten times as hard to achieve what most kids do with minimal effort.

All of these emotions are part of the spectrum of grief that we experience throughout our journey. Emotions like fear, shock, denial, guilt, despair, anger, resentment, loneliness, acceptance, pride, empowerment, and hope. All of these emotions are part of the grief spectrum.

Now I want you to remember, grief is a very individualized experience. So you may feel some of these emotions and not others. That is perfectly normal. Remember, you can't grieve wrong. There's no wrong way of doing it. Your experience is your experience. It's 100% valid.

Whatever you are feeling as part of this process, I want you to remember that all of these emotions that you are feeling in your body, all of them, are caused by one thing, and one thing only. That is the thoughts in your brain. You have a thought in your brain, and that thought creates a feeling in your body.

When you understand this and when you live your life like this is the fact of the universe, which I believe that it is, this really enables you to bring curiosity and compassion to the emotions you're experiencing versus judgment and resistance. This is the path to creating safety for yourself to experience any emotion, even the painful ones.

In upcoming episodes, I am going to teach you how to create safety for yourself to feel any emotion. But in order to do this, you one, need to recognize that you're having an emotion, and you want to bring some curiosity about the thoughts that are creating that emotion.

Now in terms of this spectrum of grief and all of the emotions that we experience as Autism parents, all of these emotions, again, are caused by whatever thoughts we are having in our brain. So as our thoughts shift and

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change throughout the week, throughout the day, throughout an experience, so will our emotions.

This is important to know because, again, your emotions don't come out of nowhere. I know sometimes it feels that way. That's why I really encourage you to bring more curiosity to the emotions you're feeling in your body so that you can uncover the thoughts that are creating them. The better you get at this, the more you become the watcher of your mind.

So let me give you an example of experiencing the full spectrum of emotions in an experience that I had with my son. So this was in the winter of 2020 right before COVID hit. My son wanted to learn how to ski because he wanted to go on a ski bus. He wanted to be with his friends, and he wanted to be part of the group. I was so excited that this was his idea, but I was also really nervous.

First of all, my son is really rigid, or was, really rigid about homework. So he viewed homework like a caveman viewed a hungry lion. He would get home from school, and he would start doing his homework immediately. It was almost like somebody running through a burning building, doing it quickly while screaming the whole time.

He had so much nervousness about having something hanging over his head that as soon as he got home, he needed to start doing it. I would never even schedule doctor's appointments after school because that, in his mind, interrupted his ability to get his homework done even faster. It became very stressful.

So when he said he wanted to do a ski club, which is exactly after school which meant he wouldn't be doing his homework until later in the night, I was really nervous about is he really going to follow through? Or is this just going to create even more chaos in our evening?

I was also nervous because most of his friends have been skiing for years. He had never been on skis to this point. So I was wondering is he going to have the commitment to follow through. As I'm sure you can relate, there

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are so many things over the years that if he showed even a slightest bit of interest in it, I went all out full in. Then sometimes these things will only last minutes, days, if that, right. Sometimes these things just wait and last.

But in any event, I was excited that he had self-initiated this, and I was willing to go all in with him. So we went to the local ski mountain, and we signed up for ski lessons. As we quickly found out, the regular ski lessons were not adequate for my son. They were very fast paced. There were several people involved.

Even if you got a one on one instructor, they just had a really different style where they weren't breaking things down to the level that my son needed. He definitely needed more one on one attention and people who just had the level of patience to provide him with the reassurance and would know how to interrupt some of his perseverations.

Well, luckily, the mountain that you're at is actually serviced by an adaptive ski club. It was called Strides. Now it's called Summit. They are amazing. They're ski instructors who volunteer to teach people with disabilities, whether they are physical, emotional, mental. Whatever it is, they will teach you how to ski from the ground up.

So I was so grateful. I was so excited. I signed my son up for the lessons with this program. We were so lucky because they actually had a spot for Ben. They don't have many spots, and they had a spot for Ben. I was so excited. I decided we would just double down on this for a few weeks. If we did that, he would be ready for the ski bus. All good, right?

Until they told me the price difference between the adaptive ski lessons and the regular. It was a pretty big jump. It was a big investment. Well worth every cent, but still Ben had started and stopped so many things before that going all in on skiing, I mean it is so expensive. I justified it to myself in every way because he's not doing travel, soccer, basketball, baseball, any of that. He's never done any other sports. This was the thing that he was into. He was showing interest, and it really had the potential.

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So we're going all in. But in addition to feeling gratitude that this program existed, I also felt frustrated because everything in special needs is more expensive. Then on top of feeling the gratitude and their frustration, I felt the fear. What if he doesn't go through in this? I will not get this money back. So that's a lot of money to invest.

So for this one decision of deciding to sign up for ski lessons, there was gratitude, frustration, and fear all at once. So then the lessons began. It was amazing to watch. My son going down with two instructors by his side. They had straps, they had harnesses, and they worked with him for hours and hours over the weekend.

In not too long of a time, he was gliding down the mountain on his own. Now, it was a little bunny mountain, but he was doing it, and he was able to stop. The pride I felt for him. I was just so proud of him. I was so excited. I was in tears. This was so huge. 13 years for my son to find his sport, all of the work, all of the effort, all of the hope. This was life changing. It had such a huge impact on his self-concept. So it lit him up, it lit me up. All good, right.

It was until we got into the lodge. So after the lesson, my son comes into the lodge, and he is in line waiting for food. I say I'm going to go, and I'm going to scout out a table. So while I was doing this, I saw four of his classmates, and they were together, and they were laughing. One of them told me that they had been dropped off by one of the boy's parents, and they were all there together for the day.

My heart sunk. The first thought I had was this will never be Ben. It will never be that easy for him, or for me, to just drop him off with his friends and let them go about his way. I was feeling a lot of jealousy and sadness at the same time, and some fear because I'm like oh good, Lord. If Ben sees these boys, he's going to want to ski with them. He can't manage the trails that they can, and they're not going to want to go on the bunny trail.

I'm playing out this whole dynamic in my head that never actually happened. When Ben came over to the table, the boys were so sweet to

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him, and they were congratulating him, and they were cheering him on. In that instant, my fear went to just such love and appreciation for these kids and for their kindnesses, and hope for my son of having really good friends and having these experiences.

So by the time we actually sat down for food, all of these emotions that had been shifting and changing and building throughout the day, I was a mess. I was just crying. So I excused myself to the bathroom. I just cried. I wasn't happy. I wasn't sad. I was just a little bit of everything.

There's not a stage for this. This is just the human experience. All of these different emotions in one day. It was a lot. It was overall just a really good thing. It was a good experience. But it was just so clear to me like how tightly I was holding to his experience and making sure he had a good experience, and how much fear that I had around him and his experience, and all the different experiences that we had had over the years building into this one day.

So I let myself cry it out. But then I was trying to explain to a friend later on like yeah, I was in the bathroom crying. To explain why I was crying, to explain why I was having all of the emotions that I was having, the answer is the thoughts that I was having. Autism, skiing, ski lessons, my kid's friends. None of those circumstances caused me to have the emotions that I was having. It was my thoughts about all of them.

My thought we are so lucky this mountain has lessons for special needs kids created the feeling of gratitude. My thought everything is so much more expensive caused me to feel frustrated. My thought he is crushing this, he is so resilient created feelings of pride and joy. My thought that his friends might not want to ski with him created sadness. My thoughts that he'll never have a day like this with friends or things are so much harder for him caused sadness. My thought that these kids are supporting Ben caused gratitude and love.

This was the spectrum of emotions I experienced in just a few hours, all related in some way to the loss and grief of parenting a child with special

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needs. This is what I mean by the spectrum of grief. The variety and variability of the emotions we experience on any given day.

All of these emotions are created by the thoughts we are having. These thoughts, the sentences in our brains are the interpretations that we have of life happening. Part of working through our grief and our loss is the ability to recognize that when you are having an emotion, there is a thought that is creating it. To recognize this thought and to be kind to yourself.

This is how you process the emotion. This is how you experience the emotion versus staying stuck in the emotion. This is a topic that we will talk about a lot more in coming episodes. But for now, I want you to start to become aware of the spectrum of emotions that you experience related to your child's diagnosis, your child's experiences, or your parenting experience, and validate those emotions as part of the ongoing process we all experience in our unique experience of grief and loss at Autism parents.

I really think that once you become more aware of the thoughts that are creating your emotions, the more aware you will become of the grief and the loss that you're experiencing that maybe up until now, you didn't even realize. Because let's face it.

It's a lot easier to be frustrated that things cost a lot of money or to be angry or to compare and despair. It's a lot easier to do all of those things than to get in touch with like the actual loss and the actual grief that we are experiencing. So get curious with yourself. Be compassionate towards yourself, and get under the hood a little bit of your experience and see what you find.

All right, that is it for this week's episode. As always, if you are struggling with your emotions, if you are resisting them, if you are being controlled by them, I can help you with that. You can schedule a consultation for my one on one program, and we can figure out whether it makes sense for us to work together. All right, have a great week, and I will talk to you next.

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Thanks for listening to *The Autism Mom Coach*. If you're 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 ah-has are fleeting. Real change comes from application and implementation. 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.