

Ep #80: Ambiguous Loss



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With Your Host

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You're listening to Episode 80 of *The Autism Mom Coach*, Ambiguous Loss.

There are losses where life dramatically changes while staying exactly the same. There are losses for which people do not send sympathy cards or flowers. This does not make these losses any less real. It makes them more painful. The Autism diagnosis and life parenting a child with Autism is one of those losses. Stay tuned to learn more.

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 podcast on September 2, which is exactly 10 days from my son's 16th birthday. In fact, this episode will air the day after he turns 16. Right now, in this moment, my biggest wish for my son's 16th birthday is that he is accepted to a residential program that can help him.

Never did I ever imagined that that is what I'd be wishing for my son's 16th birthday. I had plans for when he turned 16. I thought we would actually take a trip abroad. He was always fascinated by France and Germany because of his interest in World War II. I thought this would be the perfect time to do that, a high school student, 16, going abroad. How amazing would that be? Yet, we can't really walk five steps out of our house these days without overwhelming anxiety and OCD derailing us.

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I'm at the point where we've done so many things. This time last year, we moved to Rhode Island for four months for an intensive OCD program. We tried a boarding school in Utah for children with moderate Autism that only lasted eight days. Then from that point on, my son's been hospitalized for the bulk of the last six months, which has been excruciating.

Excruciating in a way that I can't really describe because on one hand, it was a bit of a relief due to the safety issues. On the other hand, this is my child who I adore, who I love, and who feels lost to me. The stages of grief don't really even begin to describe this roller coaster of emotions of living with a child, raising a child, advocating for a child who was still alive, obviously, and who you want so much for and still accepting where they are in this moment.

For me, this has been a really difficult journey because I really thought that my son was higher functioning than he actually is. That is because he quote unquote looks that way. Or I should say he looked that way. We used to get he doesn't look autistic before, but I'll tell you we don't get that anymore because of the severity of his anxiety and his perseverations at this point. But for a long time, he looked better than he actually was.

So coming to terms with how severely impacted he is and acting on that information has been really difficult. Although I accept it, it still hurts. I still feel sadness and anger about how hard everything is for him, about how he seems to be imprisoned by his own mind, and how I'm unsure of my own safety around him because of his low impulse control and the fact that I'm his person. I'm the primary caregiver.

Life with Ben has always been challenging, but I never imagined it would be like this. With all of my focus, all of my hyper vigilance on him, I really rarely thought about my own experience. Until about a month ago. I was on one of many calls with an extended team that included my son's educational consultant slash clinician.

During that call, she referred to me as a grieving mother. This stopped me dead in my tracks. Am I grieving? What am I grieving? As I thought about it,

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the answer was obviously yes. But up to that point, I had been so busy being on doing everything that I could for my son that I never even realized it. I was and I am grieving.

So one thing led to another, and I was googling all of the articles and all of the studies that I could find about grief. None of them resonated with me. They all involved what I would crudely refer to as a more concrete loss. A death, divorce, loss of a job, and lots of talks about the stages of grief. First you're angry, then you're bargaining, then you land somewhere in acceptance.

Again, this really just did not resonate with me, with my experience of raising a child who you're working so hard for. Accepting their limitations but at the same time you are trying to work for them to be the best version of themselves. At the same time, realizing that this is not what I expected, or I signed up for. Like I thought parenting would be much different than this. A really complex set of circumstances that really I don't see captured by the literature on grief.

So as I dug deeper though, I came across the work of Pauline Boss, and I will link this in the comments, who wrote a book called *Ambiguous Loss*. This theory resonated the closest with me as an Autism mom. Although it still falls way short, I think, of what our experience is, but it does give voice to some of the ambiguity that we experienced grieving the loss of a child we expected to have and, at the same time, raising the child that we do have, wanting to accept them the way that they are, and at the same time holding out hope.

All right, so let's talk about what ambiguous loss is. Ambiguous loss is grief with no definitive boundary or closure. Boss coined this term from her research on families of soldiers who went MIA after the Vietnam War. So unlike the families who knew that their kids had been killed, the MIA families were essentially frozen in unresolved grief because they never truly knew if their loved one was gone, or if they would ever just walk through the door one day.

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So as Boss was doing this research, she realized that this limbo of loss was not limited to people who were physically missing. It also applied when a family member is physically present but emotionally absent. So for this, she looked at people with Alzheimer's, dementia, addiction, mental illness, or even a parent or a spouse that was preoccupied with work or kids. So they were physically there but emotionally absent.

The common thread here is the lack of clarity about the nature of the loss and the uncertainty about how or if the loss will ever be resolved. So all of this makes ambiguous loss a uniquely painful form of suffering. But still with ambiguous loss of a person who is physically there but emotionally absent, you're grieving the loss of someone that you knew, and you're almost wanting them to be back to who they were.

So if someone has a newly diagnosed mental illness, and they're evolving into a different person, you want them to be the person they were before. Same thing with a drug addiction or Alzheimer's. So you're mourning the loss of a person that you knew, the person that you did lots of fun things with, and life as you knew it.

But again, for us, we are mourning the loss of life being nothing like we expected it, and, at the same time, raising a child who we love unconditionally, but we're still holding out hope for the best outcome possible. So while I think ambiguous loss is really a helpful framework for us, I want to acknowledge there's still really nothing out there that captures our experience.

I say this to you because I just want you to know that however you are experiencing the loss, the grief, there is no shame in this. Just because you can't google it and find something that resonates with you, it doesn't mean that what you're experiencing isn't real, isn't valid, and that you don't have a right to feel it.

I will get into that more and more as these episodes go on. But for right now, I want to talk about the five factors that Pauline Boss identified when she was studying folks with Alzheimer's and the impact of this loss on the

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family and why the loss was so significant. Because I think that these five factors are very much aligned with the experience that we have as Autism parents.

So I want to share this with you just because I will say for me, the better I can understand something, the less shame there always is in whatever I'm feeling. So I always like information and frameworks and just perspective so that I can take myself out of my personal experience and see things from a broader view. I find that helpful, and I hope that you do too.

So the five factors. First, lack of clarity regarding the diagnosis. Well, I think that this applies to Autism way more than an applies to Alzheimer's because I think once you figure out that a person is suffering from Alzheimer's, there's a pretty clear trajectory. There are ups and downs, but the outcome is usually the same. Not so much for the Autism diagnosis.

Now we know there's no blood tests for Autism. So getting the diagnosis is not a straightforward game. It usually includes several iterations of a parent raising concerns, being dismissed, rinse and repeat. So there's always that question sometimes even after the diagnosis is this Autism, or is this just toddler? It would be so much easier, right, if there was a blood test that was like your child has level two Autism. Then there was a printout of here's all of the things that you can expect throughout the course of their lifetime. That does not exist.

Number two, the difficulty in predicting outcomes. Now we've all heard the expression. If you have met one person with Autism, then you have met one person with Autism. This is so spot on. The presentation of Autism takes on as many different forms as there are people with Autism. So you get the diagnosis, maybe you even get a level, but the level is a blunt assessment at a point in time. It is not predictive or prescriptive. You simply do not know.

Of course, all of this ambiguity can be amplified by the advice slash warning given to all Autism parents that we should do as much as we can as fast as we can so that our child can have the best outcome possible.

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Number three, day to day variability in functioning. I can't tell you how many times I hear the following sentence from clients. But he was doing so well. Yes, our children have great days. We get lulled into this idea that every day should be like this. Because if they can do it some days, then they should be able to do it every day.

I can't tell you how perplexed I was by my son at the age of 10, seamlessly moving from New Jersey to Connecticut. But if I came home from work 20 minutes late because of a meeting or traffic, holy smokes. It was like the world ended. Look, as parents, we see other people's kids and maybe some of us even have our own neurotypical children. So then we always have that nagging question. Is this because she is eight or 16, or is this because of the Autism?

So when our kids are inconsistent in how they handle certain things, it really makes us question is this because they can't do something, or they're unable to do it, or are they just being willfully difficult?

Number four, appearance of health. We all know this one. She looks so normal. Are you sure? Maybe you're just going overboard with all of that therapy. Yes, we all get some version of this at some point or another. Autism is an invisible disability. This creates a lot of uncertainty for parents first coming to terms with the diagnosis themselves, but then when we are deciding how to approach the diagnosis with other people, do we tell them? Do we out our child? Do we risk that our child's behaviors will be misperceived? Do we risk the judgment?

Number five, the loss of relationships. This happens on several levels with Autism. Maybe you are experiencing the loss of the relationship you envisioned or wanted with your child. I have clients whose children who are non-verbal. So although they know that they are connected to their child on some level, it feels more transactional and more caregiving to them because they never get to have a conversation, or they never get to have a conversation in the way they envisioned it.

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Maybe you're experiencing the loss of the relationship you hoped your child with Autism would have with their siblings, other family members, and friends. Or maybe it's the loss you're experiencing about how you believed your child would participate in family events.

You may also be experiencing loss in your relationships with your other children, family members, and friends as a result of all the time and attention spent on your child with Autism. The isolation that comes from maybe not wanting to go to certain events or take your child out in public because of certain behaviors.

Or maybe it's the isolation that comes from feeling like the other people in your life or in the world just don't get it or won't understand. All of this is a loss. It's a lot of loss. Not one and done loss, continual loss, lingering loss. Not one and done loss, but continual loss, loss that lingers.

So what does all this mean? Quite simply, it means you're not crazy or alone. If you ever find yourself stuck in fear, sadness, or even rage, I am betting it is some form of loss that you're experiencing but you didn't have a name for it.

That is why it is vital to name the losses we are experiencing. Naming is to recognize it, to validate it, and to remind yourself you are not alone. This is the first step in normalizing the experience. You are having a very normal reaction to a very abnormal situation. It is also a step in the direction of acceptance. Not one and done acceptance because that's not a thing. Acceptance in any given moment for however you feel.

When you are able to recognize and name how you were feeling then you are able to process the emotions instead of staying stuck in them. That is the key to being sad, angry, or afraid versus staying sad, angry, or afraid.

All right, that was a lot for this week's episode, a lot of deep stuff. So let me summarize. As Autism parents, we're all experiencing some form of loss. You might not even realize this because there really isn't a name or paradigm to describe the loss we experience raising a child who is alive

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who we are working hard for their best outcome. So it's not loss that happens once. It's loss that happens all of the time.

So much of the roller coaster of emotions that we experience, I think, are actually tied to the loss that we are grieving, whether we realize it or not. We probably don't because there really isn't a paradigm. I think that when we think of the Autism diagnosis, we think okay, we grieve the diagnosis. But it doesn't end with the diagnosis. That's really just the beginning.

So it's not as if you get the diagnosis, and you come to acceptance about the diagnosis and then life goes on. Yeah, life goes on, and there's still loss that we are experiencing.

That's how I came across this theory of ambiguous loss. Because it's a loss that's different. It's a loss of somebody who is physically with us, but emotionally not, or emotionally we're not having the experience that we imagined having with our child. That is all a loss.

I think it's a loss that we need to recognize. I think so many of us don't, or we just breezed past it because there's so many other things to do. But I think our ability to support ourselves in whatever feelings and whatever emotions that we're having, and to realize that this is a normal reaction to a very abnormal situation is just a way for us to validate our experience so that we're not shaming ourselves on top of everything.

All right, everyone. I hope that you found this episode helpful, and I will talk to you next week. Have a great week.

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

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better care of yourself so that you can show up as the parent you want to be for your child with Autism.