

Ep #79: Grief Myths



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With Your Host

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You are listening to episode 79 of *The Autism Mom Coach*, Grief Myths.

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 and other comorbid diagnoses. I know what it is 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 hope you are doing well and I am so glad you are here. Like I said last week, we are going to be doing a deep dive into grief. And I know that sounds miserable, but I urge you to stay tuned because it won't be. I have done a deep dive into the topic of grief and I'm going to talk to you about it in a way I bet you have never heard before, and one that I think will deeply resonate with your experience. This is not going to be a cookie cutter recitation of the so-called stages of grief. This is something specifically tailored to you and your experience.

I think this is important because grief is an issue that is always creeping just below the surface for us and it needs to be understood in the unique context in which we experience it. And I'm a fan of facing things head on. I think this is especially important with grief because ignoring it or resisting it is not a strategy or a solution. That's because it's still there and the more we resist it, it persists. It does not go away, it remains, it festers and it usually explodes out of us in a way that feels all of a sudden or out of nowhere. This is because it is a pent up emotion that has not been released.

So we're going to talk about it. We're going to shine a light on it and we are going to normalize it. We're also going to create safety for ourselves to

Ep #79: Grief Myths

experience our pain so that we can move forward. But before we talk about grief in the way that I want to talk about it for Autism moms, I want to spend this episode talking about the misconceptions around grief because there are a lot of them. And these misconceptions may be getting in your way of understanding your own experience and validating it for yourself.

So I'm going to share with you five myths or misconceptions about grief that you may have heard somewhere, read somewhere or they're just in the air. And these misconceptions might be getting in your way of understanding or validating your own experience.

First, grief only relates to death. Well, that's not true, grief isn't exclusive to death. Grief is a natural human response to loss, any loss including death. Over the course of our lives, we experience all sorts of losses, relationships, jobs, our health, experiences, life taking a turn that we did not expect. In fact, in some ways I think death is easier to grieve because the loss is so tangible, a person was alive and now they're not.

And when I say easier to grieve, I don't mean that the death is easy. I mean that the concept of grieving around death is so expected and validated by those around us. There are books about it. There are support groups. There is a general societal acceptance and expectation of mourning a person who passes. By contrast, there is not much guidance or support about the process and the experience of grieving a child who is still alive. How do you grieve for a person sitting right in front of you?

It seems strange and counter to what most of us think about when we think about grief. And if this is you and you're associating grief with death, you might not realize that you're actually experiencing grief related to your child's diagnosis or their struggles. You might not even realize that you are experiencing grief related to your child's diagnosis, their struggles, how you expected life to be and how it is.

Myth number two, grief follows a linear path. One of the most prevalent misconceptions about grief is that it's a linear process with distinct stages that people move through in a predetermined order. This belief originates

Ep #79: Grief Myths

from a misunderstanding of the five stages of grief model created by Elisabeth Kübler-Ross that was based on her study of terminally ill patients. The five stages model is a theory and it's a very useful one, but it's not prescriptive as in every person has this exact same experience of grief.

It's just the opposite, grief is non-linear and it is an individualized experience where individuals may revisit various emotions and stages over and over. So while it may be comforting to have a general idea of some of the emotions and experiences you may have during the grieving process, the five stages, they're not a checklist that you need to complete to end at acceptance. Moreover, I don't think the five stages of grief is a helpful theory for Autism parents, and I will tell you why.

First, as I have said, the theory was built around an actual death. It is not based on the lifelong experience of Autism parents raising children with an invisible disability. Moreover, the loss we are experiencing is not one and done. It's more like a loss by a 1,000 paper cuts, all of the daily big and small experiences we have or don't have related to the Autism diagnosis. Every meltdown, every therapy appointment, IEP meetings, sleepless nights, Instagram posts of our friends' kids doing 'normal things'.

That is why I think it's important to focus less on the stages and more on the fact that grief is a non-linear and individualized experience. This means however you are experiencing grief, you aren't doing it wrong. You shouldn't put pressure on yourself to experience an emotion like anger or acceptance at any certain time. You could feel hopeful one day and angry the next, or even the next moment. Whatever it is, your experience is completely valid and there is no way you are doing it wrong.

Myth number three, time heals all wounds. Grief doesn't adhere to a schedule. The notion that time heals all wounds oversimplifies the grieving process, especially for us because we are not dealing with a one and done loss as crass as that sounds, we are dealing with loss every day. While time can and does ease the intensity of grief, it doesn't change the fact that we continue to experience loss associated with our expectations versus reality.

Ep #79: Grief Myths

Myth number four, grief has an expiration date. It does not. Grief evolves over time, but it doesn't disappear. Rather, we find ways to adapt and live with a loss by integrating it into our lives. And for sure, if grief had an expiration date, I would say that 10 years needs to be it. And I will tell you I have been raising a child with Autism for 15 years and I still grieve.

Things like the first day of school, that one really gets me. It's all of the pictures on social media of my son's peers doing things that he's not going to do or may never do. And that's a loss and it hits me every time, it doesn't matter that he's been diagnosed for over a decade. It doesn't matter that this isn't the first time I've experienced this, it still hurts.

Myth number five, grieving is a betrayal of your child. Now, this one is for us. Some parents do not allow themselves to grieve or even acknowledge their grief because they view it as a betrayal of their child. That somehow if they have sadness about how their child is or isn't, that this flies in the face of unconditional love. To this, I say both and, you can both love your child endlessly and feel sadness and loss.

Another reason Autism parents may struggle to acknowledge loss is because of the messages we get from society, messages like, God only gives you what you can handle. You are so strong. You're so good with him. You are such an inspiration. All of these sentiments are well meaning or honestly, they're just clumsy things people say to us because they don't know what else to say or maybe they've actually said I'm sorry, who knows.

But the message that I get, at least when I hear all this is like I've been awarded a prize and I don't have a right to grieve. When you hear things like, God only picks special moms to be special needs kids and you're like, "Okay, now, I need to live up to some ideal of this very special hand-picked person who now needs to navigate all of this stuff without a handbook." That is just way too much pressure for anyone to bear.

The fact is, is that we do experience grief and it is different and it's a little bit uncomfortable that we are in some way grieving the child in front of us, the child that we love. And I think it's really important for us to break our own

Ep #79: Grief Myths

rigidity, our own all or nothing thinking in this respect and just think both and, two things can be true. I can love this child. I can advocate my heart out for him or her.

I could walk in front of traffic for them and I can still be a little bit sad that they're not going to graduate from high school. They won't go to college. They struggle to make friends. They're not invited to birthday parties. Whatever it is, it's not a betrayal of your child and in fact, you pushing down your own grief, the only person you're betraying is yourself. You're creating more pain for yourself and let's face it, we don't need more pain, we've got plenty of it to deal with.

And remember our experience as Autism moms is unique, it does not conform to stages or tidy theories. So don't ever judge yourself for feeling bad, don't ever tell yourself that you should be finding a silver lining or making lemonade out of lemons or any of that. Feel as bad as you want to feel for as long as you need to feel it because that is the pathway to healing.

Alright, that's it for today's episode. I hope this was helpful and I hope it helps you open up to the loss that you may be experiencing in a way that promotes healing. Next week, we are going to talk about loss and grief for Autism moms in a way that I bet you've never heard before and in a way that I think will really help you process some emotions that you might be pushing down.

Until then, if you are struggling with how things are versus how you expected them to be, if you are struggling to find joy in your parenting experience, I want to help you with that. Schedule a complimentary consultation for my one-on-one program and let's talk about whether it makes sense for us to work together to improve your parenting experience. Alright, I will talk to you next week. Have a great week.

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

Ep #79: Grief Myths

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.