

Ep #15: I Need to Live Forever



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With Your Host

Lisa Candra

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You are listening to episode 15 of *The Autism Mom Coach*, I Need to Live Forever. Whether your child is verbal and capable of completing the activities of daily living or has an intellectual disability and requires 24/7 care, the physical, mental and emotional demands of caring for a child with special needs are significant and never ending. Perhaps this why as early as diagnosis many special needs parents find themselves wondering, what will happen to my child when I die?

For some special needs parents this question is so paralyzing that they avoid the topic altogether by telling themselves, I need to live forever. If this is you, you are not alone. Stay tuned for this week's episode where I will talk about why telling yourself, I need to live forever is not helpful and what you can do instead.

Welcome to *The Autism Mom Coach*, a podcast for moms who feel overwhelmed, afraid, and sometimes powerless as they raise their child with Autism. My name is Lisa Candra. I'm a certified life coach, lawyer, and most importantly I'm a full-time single mom to a teenage boy with Autism. In this podcast I'll show you how to transform your relationship with Autism and special needs parenting. You'll learn how to shift away from being a victim of your circumstances to being the hero of the story you get to write. Let's get started.

Hello and welcome to the podcast. I hope you are doing well and enjoying the first few weeks of summer break. Let me start by acknowledging that today's topic is a heavy one. If you don't feel like you're in a place to listen any further I understand. You can always come back to this episode another time. So let me just give you a bit of background. Today's topic was inspired by a recent interview I did with my friend, Emily Wood.

She is a partner at Connecticut Wealth Management which is a registered investment advisor that provides financial planning and asset management to individuals across Connecticut and nationwide. Now, to be clear I am not offering financial advice or making any financial recommendations. I will however leave you links to Connecticut Wealth Management and the

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resources that I reference in this show in the show notes. So, you are free to check them out on your own.

So, Emily invited me to participate in a content series produced by Connecticut Wealth Management focused on parents or guardians of a loved one with special needs. This series includes an interview with me about how to navigate fear in special needs planning as well as interviews with a local business owner about enrichment opportunities through inclusive employment and an attorney about estate planning and special needs trust.

If you are interested in watching the interview and I highly recommend that you do, stay tuned to the end of the show where I will provide the information about where you could watch and get a copy of a free worksheet I created to go with the interview.

Okay, on to the topic for today. Almost immediately following my son's diagnosis I started having the thought, I need to live forever. And I know I'm not alone on this one. I hear it in my clients, and from the parents in the support groups I lead at work and in the community. And of course, I see it online all of the time. So, let's just backup a second. When we decided to have a child we knew that they would be human beings subject to all the ups and downs that come with being a human, joy and sadness, health and illness, love and heartache and ultimately, death.

Still, we had them, maybe not thinking of any of this, or maybe thinking if we love them enough and did all of the right things, or at least none of the things our parents did that they would be okay whatever okay means to you. Then the diagnosis, or diagnoses and everything changed. We no longer believed that they would one day be okay or at very least we had our doubts. So, let's talk about this thought, I need to live forever. First, this thought is a fantasy. No surprise there. Human beings don't live forever.

Second, this is a loaded thought, on the outside, five simple words, on the inside, painful thoughts like no one will care for my child when I am gone. No one will care for my child like I do. No one understands. My child will

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suffer. My child will be alone. My child will be unloved. Five words hiding a lot of grief, fear and anxiety.

Third, I need to live forever is a cover thought that enables us to cover over and avoid the pain by the thoughts lurking underneath. As unrealistic as this thought is we prefer it to thoughts like, no one will care for my child like I do. So, we use it to avoid the pain we would feel if we looked under the cover. Finally, the thought, I need to live forever, it's just not helpful, or let me just put it this way, it's not helpful to me. Maybe you think this and it has inspired you to be super healthy and it has set you in exactly the direction you want to go.

But this has not been my experience. What I see for myself is this thought produces a lot of avoidance, and spinning, and inaction. Now, I'm going to give you an example from my own experience. Until not too long ago I didn't have a will. And this tormented me. I knew better. I'm a lawyer and a single mom. I need a will and I wanted one. And I also wanted to create a special needs trust for my son. But I did not want to think about the details, things like naming a guardian. I did not want to think about my son and his life without me.

My thoughts were, no one will care for him like I do. I am the only one who understands him. He will be lost without me. These thoughts created feelings of fear and anxiety. So, what did I do? Well, I avoided it for years. I told myself, I just need to live forever. It was not until I started coaching as a client that I discovered my own model and what it was creating for me. And I want to share this with you. My model was, first the circumstance which was a will. And my thought, no one will care for my son like I do. And this thought produced fear.

My actions, I did not make an appointment, I did not fill out the paperwork, I did not talk to family or friends. What I did do is I spun in fear picturing a terrible life for my son and catastrophizing about what his life would look like without me. And here was the result. I didn't make preparations for my son's care. So, I want you to notice this. I was essentially making my thought come true. My thought, remember was, no one will care for him like

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I do. And my actions were to not do anything to prepare other people for what I wanted when I'm no longer here.

I want you to notice that this result of not making preparations for my son's care was proving my thought true. No one will care for him like I do. Well, what that was producing is a lot of inaction for me, a lot of me not making the preparations that would enable someone to maybe not care for him exactly like I would but at least to have a roadmap. When I saw this on paper, when I saw the result I was creating, what my thought and what my fear was producing for me it was a big aha moment. This thought was standing in my way of creating any measure of security for my son.

So how did I go from this model which resulted in me not making the preparations that I wanted to make, to the model that resulted in the creation of a will? First, well, instead of focusing on my default thought, no one will care for him like I do, I brainstormed some thoughts about creating a will that were more neutral to me. And the thought that I came up with was, it's better to have a will. And this was a thought that I certainly believed and it was not so personal, not so scary, and when I thought it I felt confident.

And when I felt confident I took the productive action. I had some conversations with close friends. I made the appointment, I filled out the paperwork. I made some decisions. And I created the will that I wanted to create. I'm not saying it was easy and there were not tears because there were a lot of them. But I was no longer stuck. I was moving forward. And I felt really accomplished once I executed the documents.

So, let's sum up. I need to live forever is a fantasy. This thought is loaded with thoughts that we find too painful to look at. So, we cover them up by telling ourselves, I need to live forever. In doing so we may also be blocking ourselves from taking the productive action we want to take to support our child and provide for their best interest. That may be a will, that may be a caregiving plan. It may be teaching life skills. It may be letting other people into your child's life.

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Maybe it's being open and honest with your family or your friends about your struggles, about your child and coaching them on how they can be supportive now and in the future. But to do any of this you first need to be willing to take a look at the thoughts under the hood and the uncomfortable emotions they create.

If you want some help working through the thoughts and feelings you are having about financial planning, or any other decisions related to your child and how to create a model that supports you, I have a free resource I want to share. Now, I made this resource specifically for the Connecticut Wealth Management collaboration so it is specific to financial planning. But really you could use it for anything. Here's how to get it.

So first to listen to the interview that I did with Connecticut Wealth Management go to the show notes for the link. Then to get a copy of their free worksheet go to my website theautismmomcoach.com. And after about two seconds on my website, you will see a popup to enter your email address. Once you do the worksheet will be sent to your inbox.

Okay, that's all for today. I hope that this episode was helpful and I hope that you enjoy the interview along with the free resource. Thanks for listening and I will talk to you next week.

Thanks for listening to *The Autism Mom Coach*. If you want more information or the show notes and resources from the podcast, visit theautismmomcoach.com. See you next week.