

Seizing Life, episode 50
Mourning Your Idealized Life: Resilience, Love and Acceptance
Guest: Miguel Cervantes
(Transcript)

Kelly Cervantes:	<u>00:01</u>	Hi, I'm Kelly Cervantes, and this is Seizing Life, a bi-weekly podcast produced by Citizens United for Research In Epilepsy, CURE.
Kelly Cervantes:	<u>00:20</u>	You stare at the lines on the little white stick and your heart fills with dreams for the life growing inside you. You hold your beautiful child in your arms, and now those dreams have a face. These dreams aren't necessarily extravagant, they could be Little League games, dance recitals, first days of school with a backpack that's too large for their body.
Miguel Cervantes::	<u>00:37</u>	But what happens when medical complexities, in our family's case, epilepsy, begins to steal those dreams. First steps and first words come much later than what is typical or not at all. The future once clear becomes hazy and uncertain.
Kelly Cervantes:	<u>00:51</u>	You fight like hell and love your child with every ounce of your being, but now sadness tinges the corners. You're mourning the life you had envisioned for your child and family. A year before our daughter Adelaide passed away from a neurodegenerative disorder and complications from epilepsy, I invited my husband, Hamilton star Miguel Cervantes, to discuss this process on our Seizing Life set.
Miguel Cervantes::	<u>01:16</u>	At the time, we had no idea what the next year would hold for our daughter. We were just doing our best to care for our family while mourning our idealized life.
Kelly Cervantes:	<u>01:25</u>	Thanks for coming back, babe.
Miguel Cervantes::	<u>01:29</u>	I'm happy to be here again.
Kelly Cervantes:	<u>01:30</u>	So let's throw back, it's 2009. We have just gotten married. You are about to step onto the Broadway stage to do American Idiot, and I'm working in restaurants, and we have our entire future ahead of us. What are you envisioning? What are you picturing our future looks like?
Miguel Cervantes::	<u>01:55</u>	I remember when I was growing up, I think I wanted to have a family, get married, and raise kids. I came from two brothers and so there were always people around. I have a bunch of cousins, so there were always kids around, and I've always felt like creating a family environment and having that of my own was something that I really wanted and was so excited that you thought about that too.

Kelly Cervantes: [02:21](#) Well fun fact, I actually probably could have gone either way on kids. I wasn't entirely positive if I wanted to have children or not, but when I fell in love with you, I knew that your purpose in life was to be a father. If there is a reason that people are put on this earth, they have one purpose, yours was absolutely to be a dad. So I was like well, if this is the man I love, I guess I'm having kids.

Miguel Cervantes:: [02:45](#) Well, that's good. I'm glad it worked out. But I think that was the dream I had when we got married, and at some point there would be kids, and we just had to figure it out. And the actor's life is hard, and we were both actors at the time, and trying to figure out what our life was going to be and how we were going to create our future. And then as one year turned to two, and three, and then I just remember thinking I don't want to wait anymore. I don't feel like waiting anymore. I feel like we're ready. And what did I say? I said we pull the goalie. We pulled the goalie when I was out in California, and we just thought let's see what happens. And that was when I feel like-

Kelly Cervantes: [03:36](#) You were doing Spring Awakening at San Jose Rep, and I came out and visited.

Miguel Cervantes:: [03:41](#) Yeah, and then I got home, and we were pregnant, and I feel like that's when the picture of what our life was began to come into focus.

Kelly Cervantes: [03:54](#) Did it ever even crossed your mind that we could possibly have a child that wasn't neuro-typical?

Miguel Cervantes:: [04:06](#) I mean I guess, but it never felt like we were ... I never had any handicapped or special needs family members or friends really that were in the forefront of my mind. So it really was, I didn't feel like we were in any jeopardy or we need to be worried, and we weren't. And we weren't. And that sense of security, not sense of security, but the assuredness that our son was healthy, we didn't have anything to worry about.

Kelly Cervantes: [04:38](#) And we were also the first of most of our friends to have children too. So we were sort of ignorant to a lot of it.

Miguel Cervantes:: [04:46](#) Yeah, you don't think about it. It's not something you want to even bring up into the world, into your psyche. So I don't remember being overly nervous, especially when the initial tests came back and everything looked fine, and there was never any problem, and that's how it was. And I was making plans for our family and for our son. And as my career, I guess, was moving

along, and we decided to buy a house, and everything just felt like we were moving in the right direction. And even though times were hard financially, acting life is a tough way to raise kids, it felt like we were going to be fine. It felt like we were going to be fine, and our cute little family was going to be okay. And as we ended up moving to our little suburban house in New Jersey, and I had my yard, and we were doing the housework, and we were pregnant again, and then all of that.

Miguel Cervantes:: [05:50](#)

And then I think when we moved out to New Jersey is when reality started to creep into our lives. We had the pregnancy that we lost in the middle, and all of a sudden complications that are terrible came right into our front yard, into our life. And that was the first time that I began to think of a different version of life, but at the same time, the way that doctors made it sound is everything was fine and things just randomly happen. And so we got pregnant again, and it was a girl, and all of a sudden life's back on track and we're going. It's going, going, going. And then so new expectations of life. And my son's going to have a baby sister, and I'm going to have a daughter, and she's going to get married one day, and we're going to have this storybook life, and everything's going to be great. And that's what I dreamed of. That's what I thought of. That's what was going to happen. And that's why I had no reason to think that that was not going to be the case.

Brandon: [07:04](#)

Hi, this is Brandon from Citizens United for Research In Epilepsy, or CURE. For the 65 million people worldwide living with epilepsy, progress is unacceptably slow. At CURE, our mission is to find a cure for epilepsy by promoting and funding patient focused research. Learn more at cureepilepsy.org. Now back to this episode of Seizing Life.

Kelly Cervantes: [07:24](#)

At what point did you realize that our life was not going to be that idealized version that we had pictured?

Miguel Cervantes:: [07:41](#)

Even after she was born and things weren't quite right with her, any parent would hear about this situation, and get all the information, and still think that everything could still end up being okay, that everything still could make its way out of this terrible news, and you go down these internet search holes to say that oh, there are stories of recovery-

Kelly Cervantes: [08:08](#)

Positive outcomes.

Miguel Cervantes:: [08:08](#)

Positive outcomes or something.

Kelly Cervantes: [08:09](#) You called it our cone of possibility.

Miguel Cervantes:: [08:11](#) Yeah. I think in our situation, you get bad news and you see all of these outcomes that are spread all over the internet, and some of them are, "Oh yeah, everything was fine. And at the end of the day, I have a healthy baby, have a healthy child." And the other end is the worst terrible news you can get. And so that's a big cone. And I thought we're way down here at the beginning and where our end is, is not known.

Miguel Cervantes:: [08:41](#) And no doctor was telling us, "Oh, this is how it's going to be." So I didn't put all those ... I didn't put all of the dreams and stuff to bed, it was just a hiccup, a bump in the road, and I think it was easy to stay there for a while as more and more information was coming. And you ask about when it happened, I think it's happened, she's three years old, Adelaide's three years old, and I think it's finally happened, finally, within the last six months or a year. She's been sick for three years and only now do I really look at her and look at our family in a way that's resigned.

Kelly Cervantes: [09:36](#) Or accepted.

Miguel Cervantes:: [09:36](#) Accepted. Yeah, I accept our role, I accept what our family is, I accept what my daughter is and is not. And it took a while because no matter what information you get, no matter what you're seeing with your own eyes, the hope is always going to be there to have that life that you dream of, or some version of it, or some even small sliver of that.

Kelly Cervantes: [10:05](#) And what emotions did you go through to get there? Because I feel like we processed Adelaide differently, and I don't know if it's a man and woman thing, you are far more optimistic than I am in general, so there's definitely more personality traits at play as well, but in those earlier days, we've moved to Chicago and problem after problem arises, setback after setback, regression after regression. And our response to that early on was very different. I think it's come closer, we've come together more now that we have gotten to a place of acceptance, but those earlier days when we were working through that, and mourning, and those emotions, do you remember the path that you went through?

Miguel Cervantes:: [11:05](#) I just always remember thinking that it felt like there had to be a reason that this was happening, because we didn't have a reason that this was happening.

Kelly Cervantes:	<u>11:21</u>	A diagnosis.
Miguel Cervantes::	<u>11:22</u>	A diagnosis that all this was going bad, that there had to have been some reason why she was as bad as she was. And if we could just find the door into thee puzzle, the key to the puzzle, that though typical and normal probably wasn't on our ... there was always something else. There was always some other ... There was always some other way to get into her head. I guess it was denial. It wasn't even denial. It was hard for me to give up hope. Any little glimpse of anything, I kept always saying, "Well, what if we try this? And what if we try that? And we're going to try that. And I would do this. And we can maybe try that. And then why don't we do this?" And I feel like it was always a constant hope that we just hadn't found it yet. We hadn't seen it yet. And I think that still is the case now.
Kelly Cervantes:	<u>12:21</u>	It has to be.
Miguel Cervantes::	<u>12:25</u>	And we always do that. And I got mad, and I got sad about-
Kelly Cervantes:	<u>12:28</u>	And I remember you turned inward a lot.
Miguel Cervantes::	<u>12:30</u>	Yeah, I did.
Kelly Cervantes:	<u>12:31</u>	You didn't really want to leave the house. And of course, my response to all of it, I felt so helpless in being able to help Adelaide that I jumped into volunteering and fundraising with CURE because I needed to see results, I needed to feel action, I needed to feel like I was doing something because nothing I was doing was helping Adelaide, so I had to get out, and you didn't need that. I had to pull you behind me kicking and screaming at first.
Miguel Cervantes::	<u>13:03</u>	Yeah, I guess in the first year that we were here, the Hamilton experience, it was so much, it was so much, so much was happening. And at the same time, we were also trying to find out what was going on with Adelaide and with our daughter. And I kept thinking how is this even possible that we can have these two worlds happening at the same time. And then, we got involved, and it was this really weird place of really wanting to be involved and understanding how important it could be for us, and for the epilepsy community, and everybody to put my face out there and say stuff. And at the same time, I hated every thing about it. I hated everything about it. I didn't want to talk to anybody about it. I didn't want to see ... Because it felt like if we have to deal with this, we have to focus on our child, and all

of that's a distraction. And this is the most important thing, and it was really hard to step out of our own bubble of pain.

Kelly Cervantes: [14:26](#)

Our own crisis.

Miguel Cervantes:: [14:27](#)

Yeah, and say that maybe helping out and maybe saying stuff about it, maybe talking about it and finding out more would help us, but to understand that our situation was as dire as it was was really hard to accept for me, for her, for Jackson, for our son. And I think I didn't want to talk about it. I didn't want to share our story with people. I didn't really want to get involved with all of the outside world, because it was-

Kelly Cervantes: [15:13](#)

It was emotional.

Miguel Cervantes:: [15:14](#)

It sucked. I mean as the dream of our life and our future was crumbling around us with every doctor's appointment with her, and every failed treatment, and every failed drug, and every new cluster of seizures, I said, "What the hell are we doing here? Why are we even trying? What's the point of any of this?" And I still get that way. I still feel that way all the time. I feel like it stays there. That feeling never stops.

Kelly Cervantes: [15:47](#)

And what's interesting is that I think I finally got to that place. It took me much longer, but it wasn't until we had to resuscitate Adelaide for the second time. So October of 2017, her heart nearly stopped and the doctors had to resuscitate her, but I was still able to push through that. It was the second time when I was like okay, we could feasibly lose her that I started to feel that desperation, that not being able to talk about it in a way that I had been very open to, but it took me two years to get to the same place that you had been where talking about, it wasn't helping. I was able to come around, but it was a whole new ... I feel like we mourn different things at different stages.

Kelly Cervantes: [16:44](#)

In the beginning, I mourned Jackson having the sister that I wanted him to have, I mourned her being able to lead a full life, I mourned being able to plan a wedding with her, or watching you two have a first dance at a wedding, and sending her off to prom, or all of the things that you look forward to with your daughter. And then because Adelaide's condition is so severe, there was almost pre-mourning her life. You watch your daughter be resuscitated twice and you start to realize how fragile life actually is. I don't feel like the mourning stage ever is over. We were in a constant state of mourning of the life that epilepsy took from us, but I also feel like with each of those mourning phases, I do come to a place of acceptance. How have

you been able to find acceptance in this life, and accepting our new normal?

Miguel Cervantes:: [18:11](#)

Acceptance is such a crazy word for it because people say all the time, "You guys are so strong. You're such strong parents. What you do is so amazing." And I said, "Well, we don't really have much of a choice. We don't get to say, "You know what, we're not going to do that today. I don't feel like it."" No parent has that option, especially us, you and the care that she needs. We don't get to say, "I don't have the strength today."

Kelly Cervantes: [18:38](#)

I don't feel like giving her her meds tonight. I'm just really tired and want to go to bed.

Miguel Cervantes:: [18:41](#)

I don't accept this today. So it's forced acceptance. It's shoved down our throats whether we like it or not. And it's a day-to-day battle, it's a day-to-day struggle. I'll hold her hand now and feel so sad for the little girl that is not there, the little girl that I wanted to be there. I look at her and I look at Jackson hug her, and I'm so sad for him and for his sister that he wanted, and the life that he envisions, and even still does, and that makes me sad too, because he doesn't have the same understanding. And then it doesn't take it away to say that I understand that through her illness and through her situation, we have helped people, and we are helping people, and we continue to help people. And I get it, and I accept that as well. So to put those two things on a scale, sometimes it doesn't balance.

Kelly Cervantes: [20:09](#)

But I see them as two sides of the same coin. I think that the advocacy that we're able to do, and being out there, and talking about it, and fundraising, that helps me accept it, that Adelaide's life is not in vain, that we are able to take her story, and her life, and our story, and do something with it. To me that helps me accept it.

Miguel Cervantes:: [20:36](#)

Yes, but it sucks. And I think that's the other part of this that we don't talk about as much, and we don't get to talk about, because through this struggle, we are making good, but I would give up the struggle and the good to have my daughter. And so is that fair? No. Does that make me less excited about all the help that we have raised and all the money we've raised for CURE and research? No, I think it's amazing. The sweat and the hard work that we've put into this organization, it's amazing. Would I give it all back? Yes, absolutely. And so we are forced to find meaning in what we do, and we are happy to use our pain and grief to do good, but it doesn't make me happy for my daughter or for our family.

Kelly Cervantes: [21:59](#) And I don't think that acceptance has to mean happy, acceptance means this is the situation that we are forced to live with, and you can either live in despair and mourning or you can accept the situation for what it is, because we can't change it, and make the most out of it, and love her, and accept who she is, and love the disabled little girl that she is, which of course we do, but in accepting her circumstances, we can also let go of those idealized dreams that we had for her, and just live in the moment, and love the daughter that we have.

Miguel Cervantes:: [22:46](#) Yeah. I mean that's what mourning is. I think that's the mourning process, to go through all the steps. And it's not gone, it doesn't go away, I think. Most days, I feel that way. Most days, I look at her without a lot of pain or without pain, and more just love. And I try to just make sure she knows that we're there and knows that we care about her. And that's most days. Some days I am much more aware of the mourning and the loss. And then somebody will write a Facebook post or something about how much what we do means to them and how much we have helped. And you can put it back in your pocket a little bit and say, "Yes, wouldn't that other life have been grand." But we don't have that life, and any anger and resentment just fuels. It just is going to ... It's going to eat us up, you and I. And so I'm able to put it away.

Kelly Cervantes: [24:11](#) How do you do that? What techniques do you use to process those emotions?

Miguel Cervantes:: [24:18](#) I'm very lucky. I'm a very lucky person in so far that when I go to my job, I have to pretend to be somebody else, and so I can make my brain go into different places, but also at my job, I'm asked very specifically to cry a lot.

Kelly Cervantes: [24:41](#) It does help.

Miguel Cervantes:: [24:44](#) So there are times every day that if I'm really feeling some sort of terrible emotion that I can release it enough to feel like the dam can break a little bit, and it doesn't shut me down. In fact, it probably makes the show better.

Kelly Cervantes: [25:00](#) But I think that's a valid point is giving yourself permission to release those emotions. You get paid to do it, not everyone else does. I find our shower is a lovely place to release those emotions for those of us who don't do it in front of thousands of people every night.

Miguel Cervantes::	<u>25:18</u>	I really do feel though that it's about accepting the mourning. It's accepting the loss, making sure that you give yourself permission to be angry that this was the card that we were dealt. That doesn't make what we do with it any less important. And I have to remember that myself. I have to make sure I remember that despite how I feel about our situation from day to day, from one day to the next, that on top of it all, we really are helping people. We can really make people ... We can make change happen.
Miguel Cervantes::	<u>26:02</u>	And it makes it much more palatable to say, if this is the life that we have, and this is the life that my family has, then we accept the responsibility that we've been given to take care of her and then to do what we can beyond that. And I see a little girl running down the street and I wonder. I see a little girl in a wheelchair that's smiling and acknowledging her parents, her brothers or something, and I wonder. And then I go home and see my daughter, and she doesn't do those things, and yet I hold her and kiss her face.
Kelly Cervantes:	<u>26:59</u>	She's really good at cuddling.
Miguel Cervantes::	<u>27:06</u>	She's a good cuddler. And I think everybody's got problems. And I think that any family is going to have problems, and we have our problems, and we have learned how to deal with them. And I think too, we used to talk about Jackson a lot and say, "Wouldn't it be nice if we could always see the world through a six year old's eyeballs." He doesn't see a disabled child, he sees his sister. He doesn't see loss, or grief, or-
Kelly Cervantes:	<u>27:46</u>	What she could have been.
Miguel Cervantes::	<u>27:47</u>	... what she could have been, he only sees what she is. And he wrestles with her, and he kisses her, and he attacks her, and he plays with her.
Kelly Cervantes:	<u>27:56</u>	He's accepting of her without even knowing that that's what he's doing.
Miguel Cervantes::	<u>28:02</u>	And I think we are not allowed to live that way, but if only we could. If only we could just for a little while, just forget about all of that, the rest of it, forget about what our original dreams were, and what that would be like for one day. And I think that's kind of how we live anyway. We live that way now.
Kelly Cervantes:	<u>28:31</u>	As much as we can.

Miguel Cervantes:: [28:33](#) Yeah.

Kelly Cervantes: [28:34](#) Well, we probably should have given everyone the forewarning that they should have passed Kleenexes for this episode. Apologies, but thank you for opening up, and being vulnerable, and sharing our journey through our mourning into our constant state of mourning and phases of acceptance. I love you a lot.

Miguel Cervantes:: [29:04](#) Emotions around grief and loss can be complicated and contradictory, especially when you are grieving dreams or someone who is still alive, which is why it is that much more important to have these often uncomfortable conversations with those we love.

Kelly Cervantes: [29:17](#) There was little we could control when it came to Adelaide's seizures, and it was easy to feel helpless, hopeless, but in supporting Citizens United for Research in Epilepsy, CURE, I was able to regain a bit of control. By raising money for their patient focused research grants, we could help push science forward.

Miguel Cervantes:: [29:34](#) Science wasn't able to catch up to our Adelaide, but we firmly believe that answers and cures are out there for the other 1 in 26 that will be diagnosed with epilepsy in their lifetime.

Kelly Cervantes: [29:44](#) To help us achieve this goal, please visit cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.