

Julianne Hazelwood – Bonus Episode Transcript

Julianne Hazelwood 00:00

[bubbly electronic music] My name is Julianne Hazelwood. I am a new mom. My son, Wesley, is 15 months, and in the last year, my life has totally changed in the most beautiful way. Oh my goodness, where to start? Becoming a mom has been such a transformational experience. Becoming a mom is something I have always known I'd wanted to be and it's been a really long journey up until this point.

I was diagnosed with epilepsy when I was a teenager and that was a major-- I don't want to say complication, but a major challenge and something to navigate as I got to this point of motherhood. So, I guess just the feeling of being here and this dream coming to fruition and it filling my heart in ways that I could have never imagined, yeah, it's just... anyways[laughs]—I'm already rambling, but—it's just been a really, really phenomenal past 15 months.

So, my epilepsy journey began when I was about 14 years old, but maybe even a year before that point. That's when I started having symptoms in the sense of I didn't really know what was happening. To be honest, I thought there was something really wrong. I thought I was dying and I wasn't even telling my parents what was going on but, basically, when I would wake up in the morning, I would get up early for choir practice and I would be having these kind of uncontrolled jerks and I thought, "Okay, I'm just tired," but it continued to happen over the span of several months until, finally, I had a tonic clonic seizure where I lost consciousness and had a seizure on my bathroom floor. And thank goodness my mom woke up in the middle of the night, heard me, called 911, and, in the months that passed, I was diagnosed with epilepsy.

I think about those early days a lot in my epilepsy journey because that first seizure that I had, had my mom not woken up, I would have died. I would have choked on my tongue because, when she found me convulsing on the bathroom floor, I was blue, I was gasping, I was losing colour, and she got me upright and made sure I wasn't choking. I think it was a very shocking and, of course, upsetting experience for her, as well, but I feel like my mom, for my entire life, but particularly that point on, has just been this-- she's always there for me. She's kind of like my guiding light throughout my years on this planet and so, yeah, she really saved my life that night and she's saved my life when I've had seizures many times since.

[music continues] So, after I was first diagnosed with epilepsy, I was reluctant to want to go on medication, I remember, at first. It was a scary— I mean, the diagnosis was a scary thing, and to know that I would have to potentially try different kinds of medications and how I would respond to that, the whole thing, I remember feeling just very overwhelmed and scared by the whole thing. But I did start a medication and that ended up being the only medication that I was on for several years, I guess from the time that I was 15 until the time that I was 36, when I changed medications in the lead up to becoming pregnant. [music fades out]

[upbeat electronic music] So, yeah, I remember going on that medication. It was definitely a difficult thing to navigate at first. I remember being on a really high dosage and that really affecting me in numerous ways, so it was trying to figure out the right dosage for me. That was very much a process and a big transition, but yeah, it was just on for many years and, more or less, kept me at a steady level. At different points in my twenties, I had a period where I was having many more seizures. You know, I kind of changed my dosage on the medication I was taking, but overall, it did a pretty good job in keeping me, I would say, relatively seizure-free.

I think I knew that I wanted to be a mom for so long and I also had the feeling that it would happen. It always felt like it was far off, but I felt like, "I need to get my health under control first. I need to be in a better place with my epilepsy," and I also knew that the medication I was on had a higher incidence of birth defects. It was not one that was recommended for women who were of childbearing years, or who could become pregnant, so I also knew that that was a big change that I would have to make. Were I to become pregnant, I knew I would want to at least try to change medications. [music fades out]

So, it was just something that made the whole process feel very far off for a very long time and then the process of actually switching the medications was something that I started when I met Dr Bui. [gentle electronic music] That was one of, I think, our first consultations, she said, "We should switch you off this medication." I knew from talking to neurologists in the past that that seemed to be the consensus among a number of neurologists. And anyways, but it really wasn't until I was under the care of Dr Bui that I felt supported enough that I felt like I could really take that step.

I remember having that first appointment with Dr Bui and I called my partner afterwards and I started to cry because I said, "I felt so heard." I felt so heard in that first appointment, and that was such a contrast to other neurologists that I had in the past. You know, I had been under the care of some great neurologists as well, but I don't think I had ever had the privilege to work with a neurologist where I felt like I was a partner in my care, that we were going to embark on this next stage together, and that my concerns were really being heard. So, I remember just being really moved by that. Like, emotionally, it really affected me that I felt like she was really hearing my concerns, that it wasn't just brushed off, the fear of having a breakthrough seizure or making this medication transition. I really got the sense that she really got how scary that was and that we would take it slowly.

I remember her matching me with past patients who had gone through that journey as well, so I could speak to others, and helping me connect to a community of other women with epilepsy, which I also found really helpful. So, I walked away from that first appointment and from the subsequent appointments just feeling incredibly heard and feeling, yeah, like, supported and safe enough to take those steps – to take the next steps.

Finding out that I was pregnant was just a swirl of emotion in an incredible way. It was also, [chuckles wryly] interestingly enough, that week I had also got COVID. [laughs] So, I think it was the day before, I tested positive for COVID, and then the next day I tested positive for pregnancy test. So, there was an element where I just didn't actually-- you know, we started trying and it happened, thankfully, pretty soon thereafter, so I was surprised by it and I was overwhelmed with joy. I was overwhelmed with joy. [music fades out]

[laidback electronic music] It felt very surreal, in my case, I dreamt of becoming a mother for so many years and then, to go through the process, which was a really challenging one of switching medications and finally getting to that point, and then seeing the positive pregnancy test, I remember jumping up and down. I remember hugging my partner, even though we were supposed to be isolating from one another because I had COVID, [chuckling] but I mean we couldn't not hug when I saw the positive pregnancy test and went and showed him.

So yeah, I was just... [exhales, happily] I was filled with so much joy in finding out that I was pregnant. I remember hearing about The Lullaby Project in one of my appointments with Dr Bui. She had mentioned it and it really grabbed my attention, and it was something that, when I became pregnant. I recalled that

conversation and the wheels started [chuckles] going into motion in my own mind of, "Oh, my goodness. I wonder if this is something that I could take part in," and then, "Oh, my goodness. I wonder if I could document this," which I ended up doing as part of a documentary and, in recording the entire process of me being in The Lullaby Project, so it was something that just clicked as soon as-- yeah, I would say within the first few weeks of finding out that I was pregnant, I thought back to that conversation I had with her about this project that she was launching, and then asked her if I could take part.

The Lullaby Project appealed to me because music has always been a very core part of who I am. Growing up, singing has always been a love of mine, from those early days around my diagnosis where I was always in multiple choirs, I was getting up early, as I had mentioned, but yeah, just throughout my entire life, I've loved music so much and like, I'm sure, so many people, singing, making music, listening to music has helped me get through different things, help me process different things. So, I thought, "What better way to navigate this journey than by getting to actually channel all of what I'm feeling into a song?" It just struck me as such a beautiful, poignant act. [music fades out]

[gentle music with soft vocals] The Lullaby Project is a program where it connects women with epilepsy who are pregnant, in my case, with songwriters to write a song for our babies to be, and I think there's a really wide scope of what you can put into that song. Maybe it's messages that you want your baby to know about you in the world. In my case, it was a song about my journey up until that point that I wanted to share with my son and, through the course of several weeks, you meet with the songwriter. I would come to our sessions with poetry that I had written and we would take those words and make it into a song and a melody.

And so, my experience was incredibly positive. It was a really satisfying, moving, awe-inspiring process to bring to our sessions poetry or reflections about what I was going through, and then the very talented songwriter that I was working with, artist that I was working with, to be able to kind of, yeah, transform that into a beautiful song. I'm almost at a loss of words for how to describe it because, when I think back to the months that I was pregnant, that was a really foundational experience in helping me even kind of understand what I was going through. I think just the act of, like, creating the song, it was such a wonderful way to kind of, yeah, for me to process what was going on, for me to kind of put into words what my journey up until that point to have been, it really got me even more excited to meet my son, to get to sing this song to him. So, it encapsulated so much.

My song is called The Road to You and it's about, yeah, my journey up until [chuckles] that point of being pregnant, really, and just also, it was partly that – kind of talking about my journey up to that point. And then, my other aim in the song was just to really pour so much love into it and into Wesley every time I sing it to him. So, yeah, it's been such a special thing because I have sung it to him so many times. It's probably, since he's been born, something that I've sung to him practically every day. [music fades out]

[uplifting electronic music] Becoming a mom, it has been transformational in a lot of ways and I also feel so grateful because, in those early months of my son's life, one thing that I don't know if I anticipated would be the case as much as it was, is how scared I was because of sleep deprivation. In those early months with the help of Dr Bui I was, you know, taking higher doses of medication just to make sure that I had my seizures under control, but what I was so grateful for was my mom was staying with me a few nights a week to make sure that I was able to get through that period of time safely, as well, and I've reflected on that so much over the last year, just how grateful and how full circle it has been.

I'm so grateful to my mom because she saved my life so many times when I had seizures and then, for me to be a mom now and for her to be there by my side in those early months when my son was a newborn, and to make sure that I could be there for him and care for him, she was right by my side, as well. So, yeah, I don't think I'm fully answering your question, [laughs] but let me try to answer it a different way. My mom and I are so close. She's always been like a best friend to me, and she has been so important in, I guess, keeping me safe, making sure that I have always felt, I don't know, that she has my back, that I've been able to navigate my life so much more smoothly and with grace because of my mom and because of my mom's incredible love and kindness.

And so, for me to become a mom, I think that was an incredibly special thing for her, for her to see me go through that process and knowing that that was something that I always really wanted. And, a few days after my son was born, we took this photo of my mom holding my son, Wesley, and it was just such a beautiful moment. My mom was smiling, and Wesley was just looking up at her, and I thought, "Oh, my gosh, just like the two loves of my life – my mom and my son." I feel so lucky to, I don't know, be surrounded by that love and to have had her support all through my life and particularly through this journey of becoming a mother.

The term "music as medicine" very much came to life for me during my experience with The Lullaby Project. I think it was the act of really getting out what I was feeling, processing my experience and emotions as I was going through my pregnancy, which was such a vulnerable time for me, and I remember just coming back from my sessions with the songwriter, just feeling lighter and then the act of getting to sing this song, which encapsulates so much of who I am to my son, night after night. [music fades out] [bubbly electronic music] It has been this incredibly therapeutic process, so I feel like, yeah, the phrase "music as medicine", it just hits home, for me, with The Lullaby Project in such a big way. It was very much that and more.

I think, for other women with epilepsy who are hoping to have a family one day, I would just say that, "Keep going. It is so possible." I wish I could give them a hug [laughs] because I see them and I feel them. I know how scary it can be on the journey to get to that point. But I'd say to them, "If that is something that you want, just keep going." [music fades out]