



## Transcript of Accidental Intellectual Episode 1: People See the Duck

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[Intro Music]

### **Lee Propp** 0:07

Hi and welcome to the Accidental Intellectual, a podcast where we talk to people working in health related fields and get to know the human behind the expert. I'm Lee Propp, joined today by Ariana Simone.

### **Ariana Simone** 0:19

Hey listeners.

### **Lee Propp** 0:20

In today's episode, we sat down with Dr. Paige Church. Dr. Church is an Assistant Professor in the Department of Pediatrics at the University of Toronto. She's currently on staff at Sunnybrook Health Sciences Center as a staff neonatologist, and is a consulting developmental behavioral pediatrician at Holland Bloorview Kids Rehabilitation Hospital. She's the director of the Neonatal Follow Up Clinic at Sunnybrook Health Sciences Center.

### **Ariana Simone** 0:44

Dr. Church is a graduate of the University of Vermont College of Medicine. Her pediatrics training was completed at the University of Chicago, focusing on inner city medicine and complex care. She then undertook a combined fellowship in Neonatal-Perinatal Medicine and Developmental Behavioral Pediatrics at Tufts University School of Medicine in Boston. She is the first pediatrician in North America to have completed this combined subspecialty training.

### **Lee Propp** 1:10

We discussed how experiences of failure shaped her education and career, her public “coming out” with having Spina Bifida, and her hopes for the future of medicine.

### **Ariana Simone** 1:20

Dr. Church was a real pleasure to talk to. We hope you enjoy this episode as much as we did!

[Interlude Music]

### **Lee Propp** 1:31

Okay, we're recording. Right. So welcome to the Accidental Intellectual. I'm really excited that you're here today. Thank you.

**Paige Church 1:37**

Thank you.

**Lee Propp 1:38**

So we're going to start. We read your bio that you sent over. You have a lot of fancy job titles! It looks like, it seems like you need like more than five days in the week to cover all those positions. So can you walk us and the listeners through what a day looks like in your world?

**Paige Church 1:55**

Sure. So, I am a neonatologist. So that's a doctor who takes care of babies that are critically ill or extremely premature. And in that role, I work in the NICU and I see children with an interdisciplinary team, and we tend to do those in blocks so we do those for periods of time like 2-3-4 weeks at a time and then we take a break off. When I'm not doing time in the NICU, my other training is in developmental behavioral pediatrics. So in that role, I follow children after they've left the NICU and I see them in our follow up clinic, or I see them at Holland Bloorview where I take care of children with Spina Bifida who started off in the NICU and now are at home but in a different facility when they come in for appointments.

**Lee Propp 2:36**

So you really got to follow people from birth all the way through, [I have the best job.] to end of pediatric service? [Yeah.] Is that fair to say? [Yeah.] Okay, I guess that's pretty rare in medicine.

**Paige Church 2:50**

It is. It was an unusual subspecialty to request. So I requested it from the American Board of Pediatrics, because I had had a history of starting off in the NICU in my own medical background. And I was very interested in: how do we take the developmental care and bring it all the way into the ICU, how do we change so the follow up isn't so fragmented? Because as an individual going through the medical system, every time there's a break and care it's a potential for information to not be translated over completely or for mistakes to be made. And for the care, the experience of the person, the care feels fragmented. And so my goal was, meet the families in the NICU, meet their children when they're first born, and then provide that follow up across their childhood so that there aren't so many new moments or new introductions, just to give better continuity of care.

**Lee Propp 3:52**

And then what happens when they become adults?

**Paige Church 3:54**

That's tricky. For the children with Spina Bifida we have established a program. We have an incredible nurse practitioner, who is family medicine based so she starts to meet the children when they're about 12 or 13. And then we co-manage them and then she takes over more and more and helps transition them into the adult world and stays with them until they're about 25.

**Lee Propp 4:16**

That's a really nice model. Yeah, we should bring that into mental health.

**Paige Church 4:19**

Yeah, it's huge. So, the kids are lucky.

**Lee Propp 4:23**

Sounds like it.

**Ariana Simone 4:24**

Would you mind telling us a little bit about your career ambitions growing up and perhaps how you ended up in this field?

**Paige Church 4:29**

Sure. I, well, let me think about that. Initially I wanted to be a nun, because I saw Maria von Trapp. I grew up in Vermont and I saw her all the time at church, and I saw the movie and I thought well that looks pretty glamorous I think I'll be a nun. And then my father clarified that not every nun goes on and marries the captain von Trapp and has this incredible life where they dance around in the mountains and then I was like, oh. But what I realized I really loved and appreciated about the environment, because I was in a school where there were nuns, was the independence and the education of these women. That's what I really loved, was that I was being taught by women that were independent and strong. And so from that crush dream, I switched over to medicine. My father was a physician. So I grew up in a household where that was very common, but the other thing is I grew up in the healthcare system. So I was born with Spina Bifida myself, and so I was in and out of the hospital my whole childhood and adulthood. And at some point very early on it made sense to me that I didn't like some of the things I experienced. And the only way I really identified that I could actually change it was to actually go back and provide different care myself. And so that became a very early drive; very, very early and strong.

**Lee Propp 5:48**

So I do want to talk about that and I do want to talk about your wonderful op ed in JAMA, but I do think that before we get there, I want to talk about sort of your career ambition growing up. And I did listen to another podcast you did with medical students yes at U of T, and I did hear you say that you flunked out, or almost flunked out of nursing school. [I did. Swan dive.] I wanted to hear more about how that experience, and your experiences of a failure, or almost failure shaped your career trajectory.

**Paige Church 6:26**

Yeah, um, it's a good question. Uh, I knew I wanted to do healthcare and I thought I wanted to do medicine. My father's – you know he's older and in his generation women really struggled in medicine. And so I think some of his advice was to try to be protective and he said you know if you're interested in health care nursing might be a more rewarding and more protective field. So part of it was my father encouraging me to go into nursing. And so that's, I listened and I was like “okay, I'll go to nursing,” like, “if you say so.” I think also part of it was, he was very concerned about my medical background, and how much it was going to take of me. And I think he was very worried that the medicine that he knew, the training that he knew, would not forgive my medical needs and that I might fall apart. And after going through residency, I can see why he was concerned because I did fall apart. But at the time, I followed his advice and I went into nursing. But I think it's a combination of things for the failure. And it wasn't something I recognized up front when it happened, but after the fact I did a lot of reflecting and I did learn. I think the first thing was I was not nearly mature enough myself to be in that environment. When I finally went to medical school, it had been -it was another three years later, I had more time to grow up. But even then, quite frankly, I didn't have the insight. It's really as an adult patient that I started to appreciate, to be a nurse is – and I am, I still think my life goal will still be to go back and somehow become a nurse – because to be a nurse is to have the most incredible capacity for empathy and caring. And as a young adult struggling with health care needs that were very stigmatized and embarrassing and very isolating, I didn't have the maturity to tap into that. It was there and I knew I could feel for them, but I couldn't express it, I couldn't deal with it. And so the easiest thing for me was to say, was to – it

didn't work— and the easier thing for me was to say I'd rather be a physician because then I don't have to give that part. There isn't that need for empathy. I get to diagnose and keep moving down the hall because that's what I observed as a patient. You know the physician came in, the physician identified a problem, the physician walked away. The nurse stayed and the nurse watched how that problem impacted a human being. And that, I found very emotional and very hard to deal with. And I think I sort of self-imploded trying. So I backed away and I – and I didn't have the insight at the time to really understand it. It's like, you know, five years ago when I had surgery or 10 years ago when I had surgery, and I saw when I'm in the hospital the doctor stops for 15 minutes. And that's all we have time for like, we have different responsibilities, but it is my nurse that changed my day. It is my nurse that made a lot of my post op-care happen and matter and be really, really nice, or really, really, really awful. And, you know, it was a new friend of mine who was a nurse who helped me recover from my last surgery and made it livable. And that's the skill that, I could appreciate it at the time, but I didn't have the emotional maturity to shelf my own experiences and my own emotional baggage from what I had been through, and be able to tap into that. I just couldn't – I couldn't do it.

**Lee Propp 9:42**

It's funny though that you've ended up in the area of medicine where you do follow people and you're with people for.. [Yeah], and it's, I'm sure an incredible amount of empathy that you do [Yes.] convey. Yeah, as your patients in a different sense than nursing but not that different in the way that it sounds like you practice medicine.

**Paige Church 10:03**

I think – I think medicine is changing. I certainly know as a resident and even as a student, you know, we were encouraged “Don't get involved, be cold, be aloof,” you know, like that was sort of, the mantra was: “this isn't about you, this is about your patient.” And objective detached – detached objectivism or objectivity was what was encouraged and that was really convenient for someone who wasn't ready to deal with anything. You know, so it worked for a while. [Yeah.] I think now it's changing and I think medical students are getting a different experience than what we had, which is good. But it's, you know, it's changed partly probably because of feedback like you know mine and other people's where it just it isn't – it doesn't work. So.

**Ariana Simone 10:46**

So you mentioned that you took three years off between that nursing experience and then going into medical school. [Yeah.] I'm wondering what sort of inspired you or perhaps motivated you to pick yourself up after that and go back to school?

**Paige Church 10:59**

So, when I took the ‘swan dive’ in nursing school I still had to finish out my credits, like I still had to finish the year. I think I had like two non-nursing related credit so I finished those. And then I did finish school and I continued to pursue things, so I didn't ever like completely drop out. But, was I really regarded very well at home. No. And, and I don't really know how I pulled myself out of it. I just sort of, I think, I went back to my father and he wasn't really happy with me and I said, “I really want to go to medical school” and he looked at me kind of like over his glasses like, “are you kidding me, you just finished telling me you withdrew from all your nursing classes because you were getting like a D.” And I said, “I know, but it wasn't the right fit and I've thought about it,” it probably was like that summer and then I said, “but first I want – I want to go to Europe for the summer and study.” And he looked at me like he was ready to shoot me. I have the kindest father though, he was like, “You know what, fine, if this is going to get you on track, then you can go to Europe. And then you're moving home and you're staying in my house under my rules and if you don't succeed, you're on your own”, like, “I'm not paying

for anything.” So I think it was a little bit of tough love, and a little bit of also kindness, that he sort of saw that I was struggling. And you know, he is a doctor, I think he could see that there was something very profound that was sort of going on in my head because overall I was a pretty good kid. I wasn't the kind of kid who took advantage of him. And I think he just said, “Okay, go figure yourself out come back.” And it was the first time I had left home without my parents to manage my medical condition, like there was so many aspects of it that were such a hard turn away from everything that he knew me to be that I think he was like, “Maybe she's growing up, maybe this is her way of sort of asserting her independence.” And so he let me do it.

**Ariana Simone 13:00**

And then once you started to experience more difficulty in your residency, what was his reaction?

**Paige Church 13:06**

Oh dear. [Was it “I told you so?”] No. No, he didn't – he never did that. He was always – He's a gentle soul. So I went off to residency, and I chose to leave and go as far away from home as I thought I could, which, I got as far as Chicago from Vermont. That's a good two day drive so that was pretty impressive. But I didn't come home much when I first got out there because you're busy, you're working. And so I flew to meet them for – I had a vacation finally in March and it was two weeks, and I flew to Florida to meet my parents by myself, I think my husband was busy with work or something. And, you know, I got off the plane and I just said to my parents, I said, “I'm so tired. I'm just going to get into bed.” And I fell asleep and, you know, I think he thought that was normal but like on day three, I couldn't really walk on the beach. I was having a hard time – I was walking with my hands out and my feet kind of spaced out like I was – I was staggering. And I was just making excuses, I just kept saying “I'm really tired and my body's just so tired” and, you know, “it's all going to get better, I just need some rest.” And my father just looked at me and was like “this isn't the gate that you left with, this isn't who I saw when she got on the plane to – or when she got in the car to drive to Chicago.” So he, without telling me, called the head of our program, and said, “My daughter came to you, intact and I'm seeing a woman who is neurologically not remotely the same as she was when she left here.” And – and, you know, I had had some medical appointments that I hadn't really followed through with because I was busy and I didn't want to deal with it. And so when I got back, the head of the program, the chairman of Pediatrics, called me into his office and he said, “You know, I understand you had an appointment with this doctor.” And I said, “yeah” and I said, “but I didn't have time to go.” And he was like, “you're going to go, and you're going to go tomorrow.” So all of a sudden he put – I think he realized that, you know, no father calls the head of the program. And so I ended up going to see that doctor and then everything sort of spiraled from there. But it was my father sort of initiating it, I wasn't going to say a word to anybody I was going to continue to fall down the stairs, I was going to continue to pretend I was fine and not and not get help. So.

**Ariana Simone 15:10**

I'm glad you had someone there that was looking after you after he called.

**Paige Church 15:12**

I know, I know. He was a good man. And the chairman of Pediatrics was the scariest guy but such a, you know, because as a resident you're so intimidated right, but he was such a good man. You know, when he pulled me into his office, he was kind. You know, I was like, this little itty bitty fly on the wall to him and he was really kind. He was like, “Listen, this isn't supposed to break you,” you know, “I know you're trying to work hard, but this is...” – and again, that's the beginnings of, I think there was a little bit of greater awareness that the medical system couldn't break someone. Like in the olden days, when my father was a resident, they were on every other night and nobody checked on them. Nobody cared if they were becoming alcoholics or, you know, struggling at all.

**Lee Propp 16:05**

That's the culture of medicine changing people having.. [I think so] more understanding.

**Paige Church 16:08**

And I think, you know, when I wrote the op-ed in JAMA, I think what's happening is, you know, medicine used to be about “conceal anything that was wrong with yourself to your peers to your to your patients to everybody,” like, you were supposed to be a superhuman. And, you know, when you looked around there wasn't anyone who was having – at least to my eyes, everyone looked like they were fine and I was you know the only one that was sort of covering anything up. I think as medicine has embraced that physicians can have physical differences and can have, you know, other differences that may not be as physically obvious and it can contribute to care, I think we're starting to see that medicine is changing. And I think changing for the better. Patients are actually starting to see people with conditions that they might relate to because their physician actually is, you know someone who experiences those. That, to me, makes medicine better, not worse. But it is changing, that was not the culture 20 years ago.

**Lee Propp 16:59**

Yeah, I mean I think so too. Yeah, it's definitely better. I remember after you did write your op-ed in JAMA, I actually reached out to you with an email. And I mean, I'll jump in the vulnerability bandwagon here with you a little bit too, that I shared quite publicly in the Globe and Mail that I was diagnosed with ADHD when I was 19 years old. [Yes, I remember that.] And there was a part of me, among other things that sort of came out of the article there was this sense of relief that I wasn't expecting. [Yeah.] I wasn't expecting – I think I didn't know that I, for so long, had felt like I was like hiding from my expert colleagues and were training to be psychologists. And I was always like, “oh shoot, they're gonna...” [Yeah, they're gonna...] “they're gonna figure me out,” right? You know, “they've caught on to me and then, you know, the jig is up: I'm out.” [Yeah.] And I wasn't expecting that – that big sense of relief and I wrote down what you wrote to me in an email. You said, “it's funny how stepping out from the shadows does conveyed a sense of peace, and I'm so glad it's done that for you too.” I wonder if you can touch on that, that sense of peace that – after you opened up?

**Paige Church 17:59**

Yeah. I think, I mean, my partners here had a fairly good idea of what was going on because I had to, again, it was always the surgery. The surgery was always the outer, you know, that would always be the thing that would make me have to come out. In residency I had to come out that I had something wrong because I had to have surgery and everyone had to cover me. But you worry because your peers are covering you and that's always awkward because you don't want them to resent you for doing work that you're not doing. And so my partner's knew and they have been incredible. But, more or less, a lot of people didn't know. And it was over Christmas break and I sat at our cottage and I just sat and wrote in like one – a couple of hours, I just sat at the counter and wrote the editorial because I just was fed up. I felt like I had become a game of lies. You know, we'd sit down for noon conference and I might leave four times because I didn't feel well. Or, you know, I had to go the bathroom. And, you know, I was jokingly identified as having ADHD: she can't sit still, she's always up on the move, you know. And it worked for a while but it was so dishonest and disingenuous because that wasn't really what was going on. What was going on was I was eating like 10 crackers and in the bathroom five times. I was tired, I was rundown. I had a splitting headache from not having enough to eat. Like over time it just got so much and it was extending, it was, you know, at work it was happening and then in our personal life it was happening. You know, we were going to go to Hawaii and my husband was like, you know, “oh well,” – we were going with some of his work colleagues – “they're going to want to go on a hiking trip

and what do you want me to say, because I don't think you should go.” And I was like, “we'll just say that...” you know, but then I became this person I wasn't, this brittle woman who wasn't interested in nature, meanwhile I walk in the woods every day, like, it's my favorite thing to do. I'm from Vermont, like I love hiking. And so I was becoming more and more of a person I didn't recognize, and I didn't like, and what I saw other people seeing. And I just think I just snapped. I was just tired. And I felt so isolated and alone. And so I wrote it and then I was like, “What did you just do?” It was like those crazy moments where you're like, “forget I ever did that.” [Yeah.] So I put it away and I hit it. And then it came out when a colleague of mine, I couldn't go to a meeting and I had sort of begged to come to the meeting. And I think I annoyed them because I was like, “I really want to be on this project, please, please, please, please.” And then they set the meeting up and I was like, “oh, but I can't come that day.” That's obnoxious. But I couldn't go because I was asked to do a consult for Spina Bifida, which I didn't really want to do. I really wanted to be at the meeting and I didn't really want to deal with the Spina Bifida because, again, it was in my face that this was one more time that I couldn't go because of something with that. And so I finally said, you know, “You have no idea how much I'm regretting that I'm missing this meeting” and she sent me an article about counseling women was Spina Bifida and experiences and I was like, “okay, wow that's really cool” and I really liked the article. But then I was like, “I think it's time that I...” – so I returned with my editorial and said, “Well, this is why I find it difficult, I actually have it.” And she responded – and I'd never met her – and she said, “this has to be published immediately.” And it was this external validation from someone who wasn't trying to be nice to me, didn't know me. And it just was like, “How could no one know this story?” And all of a sudden it was like a voice that I that I hadn't ever relied on or asked anything of that gave me the nerve to say “Okay, I'll send it.” And then it was published shortly thereafter. But it's so interesting to me that a stranger someone I respected very much, and I still do academically, but I had never met was the one who set off the cascade that made it happen.

**Lee Propp 21:40**

It's funny because I mean, I find that sometimes that feels the most, I don't wanna say genuine, [Yeah!] but like people you know closely, they're going to say nice thing.

**Paige Church 21:47**

Exactly. I always worried that they're going to be like, you know, “Oh, of course you're nice and of course this is an important story,” like this to me felt like someone who didn't know anything and everything she's written academically is so profoundly important and interesting that I was like, Okay, if you think it's worth publishing then I will. But if my husband or my friends told me to forget it because they're just being nice to me.

**Lee Propp 22:11**

Exactly, yeah. Yeah, I think that's – for me actually was that it was a close friend who said, “You gotta send this somewhere.” Yeah, it did it sat on my desktop, [Yeah.] I guess gaining virtual dust [Yeah.] for a very long time. [Yep.] And I think, to me, posting it was – I don't know if you felt the same way but it was sort of like, “if I could change even one person, one little kid's trajectory, if they don't have to feel the same I do.” And then I think the relief and all the other things, that came after, but the initial motivation was, I hope that I can make things better for one small kid.

**Paige Church 22:40**

Yeah. Yeah, I think, I think so, you know. And I think the other interesting thing was when we, when it did get accepted. I remember sitting down with my husband and he hadn't read it and I let him read it. And he sort of read it and then he put it down on his lap and he looked at me and he said, “This has been ours for a long time.” And I said, “Yeah, I know.” And he's like, “Are you ready for it to be someone

else's?" He's like, "Because once this is out it will no longer be our story." And – and I said, "Well, I think I am but I don't want to do it without you." And he's like, "Paige." He's like, "I've always been the keeper of it." He's like, "It's not mine to tell." He's like, "That's your story." So, you know, that was really nice but it also made me realize how incredibly isolated the two of us have become with these lies and this story. And I think it kind of gave him some freedom because he no longer has to like tell 1000 stories to his colleagues at work, he can just be like, "Nope, Paige has a medical condition and she's just not going to do that." So I think for everybody, it's just sort of lightened the load of it and made it fresher.

**Ariana Simone 23:48**

What was the reaction from the professionals you work with and perhaps the patients that you work with?

**Paige Church 23:54**

I don't think that many patients have, read JAMA so I don't think it crossed over into the patient sector that much. I mean, I did get a couple of emails, but not many. I would say that professionally, what was really interesting is, you know, most of my colleagues sort of knew and they actually had a preview screening of it so they had read it before it came out. But the nurses and the people I don't work with every day, you know, that I see when I'm on service but not necessarily when I'm not, many of them came down and they were like, "Holy cow, we never knew." The other great comment was apparently my nickname had become "your highness," because they thought that somehow I had sort of – because I was so royal – that I had demanded that the partners not let me do certain things that everyone else was doing and it was really because of medical reasons that I wasn't doing them. So I, you know, I think for the most part it was quite positive. I think, you know, there's other interesting pieces of it though is there's some people that I think enjoyed having the story be their information and not have been known by everybody else. And there's people who have never acknowledged that the paper was published, [Really?] which I think is really interesting. And I also think that's sort of tells about, the story was conveniently theirs and not to be shared, you know like, they enjoyed that power of having the story.

**Lee Propp 25:13**

In what way, expand on that a little bit.

**Paige Church 25:16**

I'm not sure, this is all conjecture, [Yeah.] but my thought is that when the story was so secretive and so stigmatized, there was sort of a there was sort of a privilege to knowing it, which there – I think there was, you know, I trusted someone enough to share it. But when it became public information, that privilege was taken away. And I think people some people didn't like that they didn't have that privilege anymore [Hm, yeah. Okay.] Like it felt a little bit like it was taken from them instead of... And it was surprising, I was surprised at some of the fallout from it.

**Lee Propp 25:48**

So they weren't the only ones privy to that very intimate detail about your life.

**Paige Church 25:52**

Yeah. And some of them have never acknowledged that they haven't read it, which I think is really so interesting because I see them all, you know, a lot. [Yeah, that's a little strange, yeah.] So.

**Ariana Simone 25:59**

But the neonates, have they acknowledge that they read it?

**Paige Church 26:01**

No, my little babies, it's like padding their isolette, probably in the inside of their diapers. That's, uh, they're definitely not going to read it. But, you know, I think the JAMA piece was really also written to my colleagues to say, you know, because I think to some degree my counseling had fallen under some criticism of being not recipe enough, not consistent enough, like it was too individualized. And my pushback was, it should be. And it is never going to be black and white, I'm not going to come up with an absolute "yes or no" on these answers, it's me teasing from them what their answers are and then helping them find them. So, I hope it's provoked that. I really hope it's provoked that you can't go in and do a 'one size fits all' consult for whatever the condition is.

**Lee Propp 26:52**

Do people ever question your judgment?

**Paige Church 26:54**

I'm sure they have in the past. Yeah, I'm pretty sure. I know that they have questioned it, yeah. You know, because the way we were taught in medicine was, you know, decisions were really clear. And significant disabilities were going to be things that were – not correctly– but in our common, what we thought to be true, was that they were associated with qualities of life that were less fulfilling, that there were more problems. The more medical problems you had, the more it chipped away at your quality of life, was the, is sort of a common misunderstanding. So when you enter in with that proviso or that mindset, and then you go and consult a baby who has had a significant bleed in their brain and they're going, they most likely will have some outward effect of it, you know, my job is, I think, is to present the range of possibilities to explore with them how they feel about handling those possibilities and then help them find the right answer for them. You know, if it's something that I think is going to have a significant impact on the child's day to day living I will say, you know, "I'm going to tell you that within the range of options available to you would be that some families would say that my baby shouldn't have been born by now, that they that they, you know, are being supported artificially, and that I think that my baby's trying to tell me that they've had enough and that I want you to stop providing this intensive level of care for my baby because this isn't what I wanted for them. This isn't what my family can handle." There are other families that will say, "I love my baby and I want my baby no matter what condition they're in and I want this intensive care support as long as it's not causing harm to my baby and let's keep going." And my job is to help them get to that place, but not to tell them what that place is. And I've had families with the same, virtually the same likely outcome, choose very different paths. And I'm not to tell them what to do. And I try very hard not to go in and give them the value to it. Their job is to find where that makes sense for them, not me. My job is to guide them and give them real life, "This is what it could look like. And tell me how you deal with that, tell me how, you know, how, how can you handle that day to day is that something that you have the means, or the family structure, or the ability to handle." And if, if the answer is "Yeah, we thought about it, we can make this work", you know, "It doesn't matter." Then we go for it. If the answer is, "Oh my god, we're here by ourselves. It's only the two of us in this country. We can't afford to miss a day from work, we're financially so strapped." On top of that, "This isn't a life that we would dream of for our baby, we think our baby is going to have a life that's really, really hard," or "We know someone who has this –you know, has a similar condition and it's really been hard for them." It's a chance for people to talk in a way that they're not going to be judged and that they can make important decisions. That is where we've done a good job. But that has fallen under judgment if my colleagues don't like the final result of the family.

**Lee Propp 29:45**

It's, it's funny because listen as you're talking sounds like a lot of our therapy training, right. People are often surprised when I'm like, "I'm not really in the business of advice giving here." [Yeah.] I'm just here

to, sort of, be there to sort of walk you through as you make the decision. Which to me sounds like a great place to be. So, in some respects is a little bit surprising to me that the colleagues would, you know, only be judgmental when they don't really like the place that your patient has gotten to. But the cynic in me is not surprised, [Yeah.] I should say. But yeah, I mean I'm hopeful that it keeps changing for the better.

**Paige Church 30:27**

Me too. But, we'll see.

**Ariana Simone 30:29**

That counseling with the family seems like it would be emotionally taxing on the average physician, and perhaps even especially for you, having been that baby once upon a time.

**Paige Church 30:40**

Yeah, I do struggle with that. And it's interesting because you know my parents didn't have the benefit of any antenatal identification. I showed up and they were stuck with, you know, what they what they got and there was a lot of chaos. To this day, they don't agree on what they would have done if they had had antenatal counseling, particularly because of the language that that was used after I was born, you know, it was very, "This is a very bad outcome. This is going to be very bad, this is..." you know, it was all these words that made my mother feel like there was nothing that was going to be positive that will come out of my existing. If someone had just said to her, "This is the range of what could happen," and, you know, "this is, this is the things she might run into," but without using all these words my mom might have felt differently. But what she heard was: bad, horrible, severe. And for her that wasn't something she could handle. You know, it shows you the strength of our words. Our words really can shape what someone sees. So I try to be very mindful of the impact of that on families and they're – what they're hearing is overwhelming enough. They have the right to then assign where they think that value is, not me. You know, that's their right, is that they have the right to say, "This is what's important to me, this is what's not. I think that's actually really bad, I think this is actually okay." That's not my job. That's, that's very important but medicine has a very strong opinion that it is something we convey. And we do it all the time. "Oh, the results were so bad, her chest X ray was horrible, it looked awful!" You know, like we have all these adjectives, "Her chest X ray had infiltrates, it showed", you know, "this." We need to back away from our conjecture and just offer the facts and guide them but not fill them with our own opinions.

**Ariana Simone 32:34**

And I liked what you said in your JAMA article about disability being a spectrum. [Mhm. It is.] What you just said, it speaks to that.

**Paige Church 32:40**

Absolutely. And I think the other thing is, you know, if you got me on Tuesday I might have had a totally different answer for you about what I think about day to day life. I think that's the other piece is that it's a spectrum, but it's also – it's also something that at any given moment, you're going to have very divergent opinions about what it means to you and to try to wrap that up into a simple conversation is really, really hard. So instead, you know you offer the spectrum, you talk about the fact that your child may feel good about something one day, and bad about it literally 10 seconds later and that's going to be part of the existence but there is there is joy that does come out of a lot of these challenging conditions. And there's a lot of learning, and there's a lot of opportunity. So, but I do find them incredibly hard.

**Lee Propp 33:26**

So I want to pick up on what you said about, you know, “if you asked me on Tuesday I would’ve felt very different.” And I think in reading things like, you know, like the article that you put out or other people reading stories about people have a personal perspective on disability. We have this, at least to my mind, there's this sort of, in society, we like happy endings right we like it when things and very clean and we like it when you know someone prevailed against all odds. We love the movie about the underdog that succeeded. And I think to some respects, your story can look like that from the outside. Right? You know, you went through the medical system, you still experience the medical system and your doctor and you're changing people's lives and it – it looks like it has all these sort of neat bows tied around it. [Yeah, I was gonna say, put a bow around it.] In reality, I can imagine, it's entirely not like that. How do we...

**Paige Church 34:08**

Well, I mean I think in putting out the paper I think I was trying to sort of shed a light on the charade. You know, like, I know this is what you see, but you didn't see that I got up at 5:30 and that I had to do 15 things before I even got dressed. Like, that's the part that isn't seen. And I wanted to put an ugly light on it and say: it all looks nice and fine, but there's a lot of work here. Because it isn't perfect and it isn't, you know, totally happy all the time and there's a lot of, you know, there's a lot of down moments. That being said, I hope that that paper and that these conversations will sort of draw the draw light to the fact that, with those with every horrible thing that's happened, there's been something that I can't say I wouldn't sell my soul for a million dollars to get rid of the horrible thing... But I've come to realize that that would then sell away all the lovely things that came with it. So, you know, if I hadn't had, you know, guys in university either not date me or dumped me quite quickly, then, you know, I probably wouldn't have met my husband. And I might have married this really, really, you know, other guy that I thought was really good looking and I really had a crush on and I probably would have sold my soul for but it didn't work, and I didn't have a choice and I was really angry about it. But then, I'm matched to this incredible man who is loving, and kind, and supportive, and yet doesn't baby me or treat me like I'm fragile or, you know, it's a very even relationship. And I don't think I would have found that if I hadn't had all the horrible things happen. So, you know, if you're on a good day, you can make that a happy ending because yes he's, you know he's the white knight in shining armor and he's fantastic and he really is. But, we wouldn't have gotten there without all the horrible stuff that happened so, you know, this doesn't resonate very well with my girls in Spina Bifida clinic right now but I'll say to them you know it's really bad right now and I get that. But out of this you will learn incredible things about people and about who you are. And that will help guide you to the really good people that you'll end up with. You won't – your peers who look like they've got everything much easier for them might make some less successful choices because they aren't getting these hard lessons early. You're not being given a lot of choice but there's some hard lessons with that that might serve you well later. So, yeah, it's not perfect, but...

**Lee Propp 36:34**

Yeah, I mean, I yeah I'm on the same page with you there. I think I haven't personally done any like sort of counseling with any clients or patients in that manner. [Yeah.] I can imagine maybe sometime down the road when I'm a little bit more established, that could be part of what I do. But I have, you know, spoken to some people who are younger and they see they're like oh you're in a PhD program or, you know, teachers, friends of my parents. And they're like, “Oh, you worked it out,” right? [Yeah.] “You're not this ‘all over the place’ student anymore,” right? “It's good now.” And it's still really hard! On the days where I have to just sit my ass down in the chair and get that writing done, that's not happening, right? I'm up. I go for a walk my dog, I get a snack. I'm all over the place still, I just, there's other things that work. And you look on the outside and it just looks like she's this successful PhD student. And I try really hard to say, “It's still hard.”

**Paige Church 37:35**

It's like a duck, you know, on the water's surface [Exactly, yeah.] you look perfectly calm [Yeah.] and then underneath it's like, "brrrrrr" (noise imitating fast movement).

**Lee Propp 37:40**

Frantic paddling. [The feet are going.] Yeah, exactly. [Yeah.] Yeah.

**Paige Church 37:45**

But people see the duck.

**Lee Propp 37:46**

People see the duck. People like the duck, I think.

**Paige Church 37:47**

They do like the duck, it's cute.

**Lee Propp 37:48**

People really like it, it's cute and it makes them feel a little bit better.

**Paige Church 37:49**

Yep! And it simplifies it right, this is the problem. People want life to be simple. I mean, we can talk about some of the successes of our current political environment in the US and the use of Twitter, like, brevity is good. Simple as good. It's what resonates, it's not necessarily what's real.

**Lee Propp 38:07**

I was thinking actually a lot about that recently because I think people like to say, you know, we like that like the Twitter culture or the – the short snippets and things, but they're thinking about like things like binge watching, right? And these dramas. And people still have this, like, human craving for stories right? We love stories and we love messy stories and the story arcs and the complicated characters. [That's true.] Something about me wants to bring that into healthcare but I, how do we – how do we sort of make people see those really messy human stories and be okay with them. That's – I think about that.

**Paige Church 38:51**

Yeah, and I'm not so sure. I mean certainly there is no program that I'm aware of, yet on television that sort of done it, you know. I mean, there's the drama part that everyone likes like the, you know, train crash with multiple fatalities and whatever but, like, that's not really life. I don't think we've quite hit it. You know, it's, but the richness in people's stories is. I mean every day that's all I do is listen to stories. It's unbelievable. You know, it's such a privilege. And I think what also I've learned from perhaps coming out of the closet, releasing that JAMA paper is that my story wasn't obvious to people. So my instinct, historically, was to sort of sum it up and be like, "Eh, She's fine. They're fine." That story, you know, I kind of would wrap the story up ahead of time. And I've now learned to stop and to go in and be like, "Okay, so tell me what's going on." "Tell me how your family works," "Tell me," you know, "how you get here during the day," like, you know, if you're not here until two o'clock in the afternoon, "tell me what it means for you to get here" and just learning people's stories. Often, it's not nearly what I thought it was and, of course, it's not nearly as simple as I made it either. But it does provide a deeper understanding and I think it makes me a better provider because of it.

**Ariana Simone** 40:07

So, as a very highly regarded professional. We are wondering if you could do something over in your career, what would it be and how would you change it?

**Paige Church** 40:16

That's a good question. If I could do something over my career... [Would it be to be a nurse?] It might have been, I mean certainly, it might have been. It maybe it will be still to be nurse. Maybe I'll switch over. I think it might have been to appreciate that I had no business trying to be a nurse. That I was so out of my league, in every way. So, probably, that's one life lesson. And I think the other one is that, I think because I always felt this incredible responsibility, because what I couldn't do or what I wasn't able to finish because, you know, either – you know, now I don't really do nights that much, and I don't really do weekends and that comes with a package of guilt that you feel like you're constantly trying to make up for what you're not able to do. And I think, and I'm still not sure I've got it yet, but what I would love to get to is a place where I'm not apologizing for what I can't do. Because, you know, I'd sell my soul to be able to do what other people can to, in some ways, you know if I could do those things, it would be really nice to have that capacity. So I think that's probably the thing I still struggle with is to stop apologizing for what I can't do. I'm not there yet.

**Ariana Simone** 41:25

Yeah, that's a really strong message that you're sending to lots of individuals younger than yourself.

**Lee Propp** 41:29

A lot of good lessons to be learned here.

**Paige Church** 41:31

I hope so. Thank you.

**Lee Propp** 41:32

Thank you for being here.

**Ariana Simone** 41:33

Yeah, thank you for so much for joining us.

**Paige Church** 41:33

Thank you.

[Interlude music]

**Lee Propp** 41:42

That was really wonderful conversation that we just had with Dr. Church. I appreciate how she challenged us to – how she challenged us to think about the complexity of the field of medicine and how we as clinicians, think about our patients and our detachment from them.

**Ariana Simone** 42:02

Yeah, and she talked a lot about how the culture of medicine is sort of changing and how doctors are no longer these robots that don't have their own human lives, aside from their jobs as doctors. And I really like how she mentioned how when she was in med school it was sort of the mantra of like, “be detached, be aloof, be cool,” “It's about the patients, it's not about you,” and she's so humbly alluded to the fact that it's people like her, who are sharing their stories that are really changing that mantra.

**Lee Propp** 42:32

Yeah, a hundred percent, I think it'll inspire I think a lot of people to challenge themselves to be better clinicians, to be better scientists, to be better researchers in this field, but I think it'll also inspire a generation of young clinicians themselves, perhaps those who have experienced disability, and I mean, I think the field will be richer for it. And I think it comes down to the same thing, like, if you can't see it, you can't be it, right? Like all these young people are going to be like, you know, it's hard for her too but she's still doing it. Maybe – maybe I can do that too. Maybe I can help people. Maybe I can change things.

**Ariana Simone** 43:12

For sure. I think she's empowering a lot of young people and I too really enjoyed that conversation with her.

**Lee Propp** 43:17

Her candidness towards how taxing and how difficult it can be to work as a clinician day in and day out. I mean, I try and be honest, I think those are the most exhausting days I have the ones where I'm working as a clinician. And I – I always appreciate when someone who's established in the field, let's you in on the fact that it doesn't really get easier you just need to get better at it.

**Ariana Simone** 43:38

Yeah. We certainly don't hear enough of that. So it was really refreshing to have her talk so candidly about that.

**Lee Propp** 43:45

Yeah, and how, you know, some days can just be difficult and you just – you just kind of power through them and you – you learn, you learn how to make them... I don't want to use the word “easier” because I don't think that's the goal of it, you don't want it to be easier. You just want to, you know, fill your toolbox with things that can help you cope a little bit better.

**Ariana Simone** 44:06

And she made that really cool metaphor about the duck in the water, [Oh yeah.] and how her coming out as having Spina Bifida was a little bit about letting the people see what was underneath the water and that the ducks feet are going so quickly, right? People only see the duck on top of the water who's chilling and looking happy and looks like they're doing everything so easily but there's a lot that goes on to being a clinician that's not seen under the water.

**Lee Propp** 44:30

Yeah, I think that's important for the patients but it is so important for trainees to be able to get a glimpse of that because I think so often, I mean, this is to allude to what we said before, like the hope of a culture of healthcare and culture medicine is changing but you still get... I think she may be at one point mentioned you know sort of the ‘old dinosaur’ of saying like, “this is not how I did it,” you know, “I walked there uphill both ways, barefoot in the snow.” And I think there's no use in that, right? We want to make things better and it's, I mean, I think people like her are really putting us well on our way to get there, but it's – we still have a long way to go, but that candidness I think is going to take this huge way of the way. [For sure.] All right, well, we really hope that you enjoyed and we – I learned a lot from that conversation. [Totally. Me too.]

**Lee Propp** 45:23

All right. Until next time.

**Ariana Simone** 45:24

Until next time.

[Outro Theme Music]

**Lee Propp** 45:58

Thanks for listening to the Accidental Intellectual. Today's guest was Dr. Paige Church, interviewed by me, Lee Propp, and Ariana Simone. Our podcast is produced by Bronwyn Lamond, Rachael Lyon, Harrison McNaughton, Stephanie Morris, Lee Propp, and Ariana Simone. Our theme music is by Alexandra Willett and our branding by Maxwell McNaughton. You can check out our Twitter @accidental\_pod and on Instagram @accidentalintellectual. Our website is [accidentalintellectual.com](http://accidentalintellectual.com). We'll be back next time with more stories from the humans behind the experts.

[Interlude Music]