VOA Ep 4 featuring Claire Smith: Redefining Strength - Life After Disability Disability

[00:00:00] Welcome to Voices of ABLE2, where we share real conversations about disability inclusion and community. I'm Emelou Porquez, and today's episode is called Redefining Strength: Life After Disability. Sometimes life changes in an instant, and everything we thought we knew about who we are is suddenly rewritten.

For today's guest, that moment came after a devastating fall ended her Olympic equestrian career and changed the course of her life forever. But what followed wasn't the end of her story. It was a powerful beginning. In this episode of Voices of ABLE2, we speak with Claire Smith, an active contributor to the disability community, as well as being a member of the Leeds and Grenville Accessibility Committee.

She's a board member of the Ontario Brain Injury Association and of ABLE2: [00:01:00] Support for People with Disabilities. Her memoir Falling into Now stories her life as a 1996 Olympian, a 1997 severe head injury survivor, and a 2010 PhD graduate.

Welcome to our podcast, Voices of ABLE2 Claire, thank you so much for taking the time to, uh, chat with us today.

Thank you very much for asking me.

Um, so first of all, I just wanted to say that, I finished reading your book a few weeks ago as I was preparing for this interview, and I just wanted to say that the book is just so well written, was reading, reading it felt like you were taking us along with you through the emotional journey, your thought processes as you were dealing with many life transitions.

And I'm, I'm the type of person who is, you know, very easily attached emotionally, so I felt like I was in there with you as well. So I just wanna say that it's just wonderfully [00:02:00] written and yeah, overall, your memoir is certainly an eye-opener and really takes its readers on this journey to your self discovery and acceptance, like the title implies, ‘Falling Into Now’, your life, now living with a disability.

Yeah. Well, thank you. Well, uh, it's funny because, um, when I first got hurt, and thanks for saying all those nice things about my book, when I first got hurt, it was not, um, a visible disability. Mm-hmm. Um, and we can get into that later. But, um, uh, the initial thing was when I fell off, uh, in, uh, on September 13th, 1997, it was, I had a severe head injury and, uh, yeah.

So before we get into that, I wanted to start with your past. What led you to a life of horse riding and then to competing as an Olympic equestrian?

Oh, gosh. Um, because I'm very, I've always tried to reach the best for things. [00:03:00] And that was kinda the first thing I grabbed onto was, was the horses, right?

Mm-hmm. And doing as much as I could with the horses. So, so, um. And then after that, then I went back to school and got my PhD. I grabbed onto that, um, or grabbed onto the idea of getting a PhD. Um, but yeah, I mean, I, I just, I, I love the, I love working towards a goal and for me, riding through the woods on a horse does nothing for me.

Um, it's, it's, I mean, I, I love to ride, but it's the fact that you can, you can. Use it to get some, like you can reach goals within that. Yeah. And perhaps I would've done something else. I mean, that, that also was something that was goal similar. Yeah. Throw out what that would've been. But, um, yeah. Yeah.

So was it like, in speaking about your identity, have you always been, you know, competitive? Have you always been like, goal directed throughout your life?

And that's, that's actually a long story and that comes [00:04:00] out I think in the last chapter in my book. Is that, um, you know, I, I, I did the horses and reached the top of that sport and got hurt badly and couldn't ride anymore. And so I grabbed onto the other thing that was available to me.

I was always very good at school and I never really followed that. And so I grabbed on the idea of getting, um, um, pursuing education to the highest level I could. Mm-hmm. You know, I did.

So, let's talk about when you had the life-changing brain injury. Can you recall the moment when you realized that your life was going to head into a completely different direction? What was that like for you?

Oh gosh. Well, I, so I had post-traumatic amnesia for the first four months. So I really, I don't remember that ton at all. So post traumatic is when you have no, you can't build memory. Mm-hmm. So I remember up to 30 seconds before I fell, and then I remember nothing for four months, nothing.

Mm-hmm. Um, which is [00:05:00] probably a good thing 'cause I was not in in good shape at all. Um, so it only really, and then. Afterwards, I went back to North Carolina where I'd been for a long time with the horses. And I, I was determined to make my horse world work. And although the experts and my family thought this was a terrible idea, they realized they had to let me try it, to let me realize it wasn't gonna be possible.

Mm-hmm. Uh, so, so it took a long time and it took, it took gosh, and then I came back up here in like, at the end of 1999. So I, it was two years really of, of before I finally realized that, um, I wasn't gonna be able to ride like I used to.

Yeah, and I really like that part too, where your family, you know, let you make that decision for yourself and let you, you know, decide what the next course of your life was gonna look like.

Well, what, uh, I think what, what [00:06:00] happened too was my therapist at the time, we, uh, my parents were actually horrified that I wanted go back and ride some more, but my therapist at the time said, you gotta let her do it. You gotta just let her go and, and see that, that, um, find out for herself. Mm-hmm. You know, that, that life was not, not gonna be available for her anymore.

Yeah. And what stood out to me in your book also was how honest and vulnerable you were about those early days, you know, the grief, the frustration, and the long process of coming to terms with this new reality. Um, so what did coping look like for you and how did resilience, uh, show up for you during those days?

Coping. I, I think both of those things, I was totally unaware that I was doing. I think resilience is part of my character, part of my makeup, and that became more clear as we would go on and we talk about dystonia. That, that [00:07:00] I really had to resilient and literally plow through the crap around me, the crap of my life before I could come out the other side.

And, um, I think you're, you're born resilient, you know? And the other thing is that everyone, other people can help you and a lot and I had tons of family supporting show support. But unless you want to do it, it's not gonna really work. And I'm lucky too because some head injuries, what happens afterwards is people are, are they, they're apathetic.

They lose their, their any sort of, um, zest for, for achieving things. Something that I, I still had, um, thank goodness. So,

Yeah, and you went on to accomplish all the things that followed after your PhD, your master's degree or PhD, and then this book, which is really, you know, admirable like the, your resilience and how you pulled through out of all of it.

[00:08:00] Um, so you, in your memory, you also talked about, wrote about the relationships around you and how it shifted after the head injury. And I appreciated actually reading the chapters from the point of view of your parents because it really shows, you know, how disability has also impacted the people around you.

Well, it's funny, just say just to umm. It says in the beginning of the book that I wrote the chapters of my parents, so many people said, oh, it's so neat that your parents wrote the chapters too, because they saw my mother and they saw my father. 'cause they're very, like, I made them the way they are. Right. And so they didn't realize that I, I had written them. Um, so that was kind of funny. Yeah.

Either way it really showed, you know, this perspective of your parents. Um, so can you talk more about, about how your relationships changed after your injury?

Oh, sure. Well, I went back to, um, North Carolina to do the horses about two years after I fell off, which, which, um, we already talked about was not a good [00:09:00] idea in the long run.

And there I was still recovering. So everyone saw me with head injury in my forehead and they treated me differently. And as I got better, I started realizing what was happening and I was more and more uncomfortable and more and more sad, um, and realized more and more that my old life was not gonna work for me.

So, so, um, I think I didn't, you know, that's really when it hit me, that I was not gonna be able to ride anymore. And that was 2000, like, that was two years after I got hurt. Yeah. It took that, 'cause I came back home, um, just before around

Christmas of 1999. So that was like, uh, more than two years after I was hurt, uh, until I realized that, you know, it, it, it wasn't gonna work.

Yeah. And so. How, how did you come to terms with this, you know, shift in dynamics of how they treated you like after injury?

Well, I, like I said, well, I was not [00:10:00] well enough to realize that they were, and then, yeah, I mean, it, yeah, it's like you were in any situation and you're, you're in an unhappy situation. Maybe you're being bullied, maybe you're in an uncomfortable work environment, and, and you, you're just unhappy. I mean.

It was not gonna work for me. I, I was at that point cognitively aware enough to realize that it, that life was not gonna work for me anymore. Mm-hmm.

And that you had to do something about it.

Yeah.

So, in your book, you also talked about coming to terms with dystonia or the chronic illness affecting your ability to walk, and you talked about finally coping and accepting your new reality after the head injury and that being kind of slapped on with this new disability that took over your reality, the dystonia. So looking back now, how has your perspective on success, identity, and purpose evolved since dealing with dystonia?

So there are two things. [00:11:00] First of all, um, you know, I was halfway through getting my PhD when I started dragging my foot. So I was, at that point, I halfway through getting my PhD, so I'm, my brain's working just fine. And so my injury was really invisible.

Mm-hmm. Except maybe people that had known me for a long time and knew that I was a different person than I was before I was injured. But, um, I think, um, I think the, the, the hard part was, I've written several academic articles about this, is the wheelchair makes your disability visible. Right. Like—

And that's why I still make a point to this day when I, you know, I unload my wheelchair and I wheel into chapters and someone holds the door open and I have a conversation with them to, because they immediately, people tend to immediately see the wheelchair and think there's something wrong with the person in the wheelchair.

So, so, um, I'm fine with it now. I mean, I, you know, it is what it is and, and, uh, you can't do anything about it. So you, you, um,

Just live with it?

Well, yeah. And, [00:12:00] and you're happy despite it. I mean, I think that was a big thing too, is um, I graduated from my PhD and, and all of a sudden I was in a wheelchair.

Mm-hmm. And graduating PhD was not a happy event because it takes forever to get it. And then you gotta decide what you're gonna do, once you have it. So that's an unhappy event anyway, and then all of a sudden I face this disability. I had a most fantastic psychiatrist who actually just retired less than a year ago, and he was fantastic about, um, helping me to, to, um, learn to cope and teach and guiding me through the process of grieving, which is really what it was grieving for the loss of my identity

Yes.

Of all, but at that point I already was okay with that, but it was a lots of being able to walk. Um, yeah, that was, that was pretty tough.

Yeah. Um, I imagine.

Yeah. But, uh, yeah, but you know, and also the, the thing, I think I talk about that this is my book is I have the [00:13:00] most amazing family. I had the most amazing help.

I had the most amazing therapy, friend. But unless you, yourself make the decision to be happy, no one, no one can do it for you. Right. Hmm. And, and that's the hardest thing. And, and I think now I think people don't necessarily know what my head injury, well they do. 'cause I talk about it a lot where a long time wouldn't even talk about it.

Um, but other people see me through the head injury lens still, and that, that is not, that's not cool. Mm-hmm. But, you know, I can't, I can't change that. They, they, um, that that's something that, that, that I live with is that I know that they see me as different.

Yeah. Yeah. And that, that seems to be like a barrier for many, you know, people with disabilities, is that the mindsets of other people who see them, who immediately see their limitations, who immediately assume you know that there's something wrong with them, and they can't see past that. And I, I guess that's what we're trying to do at ABLE2 is to, you know, [00:14:00] to remove those barriers and make sure that the mindset is changed to celebrating people with disabilities rather than seeing their limitations.

Well, and that part I was saying earlier about the wheelchair, right? Mm-hmm. Visible and making a point of talking to people. Just to make sure that people are comfortable with someone in a wheelchair and to realize that they're probably cognitively just fine. Yeah. They may not be able to walk or whatever, but they're cognitively just fine.

Even if they're not, they're still people. Yeah. Ability to talk to them, right? Yes. So, um, yeah.

Yeah, absolutely. Um, so something towards the end of the book of your book that really struck me too was that moment when you were driving, I think it was downtown Ottawa, somewhere that, and, and you saw those people walking along the streets, you know, and you, you said that they seemed like they took walking for granted and you were taken back to your life before the head injury, and you [00:15:00] said you were unintentionally unaware of the realities of many people living with disabilities who had come to terms with illness or disability and had no choice but to choose how to live their lives. And you had no idea until you became someone with a disability yourself.

And so often people don't really grasp the, the idea that disability can happen to anyone at any point of their lives. So. Um, for others who might be navigating a sudden change or dealing with a new reality of living with a disability, what would you want them to take away from your story?

Oh, I think, you know, everyone, everyone goes through life having to deal with good things and not so good things. And you can't do anything about the changes. They're there, they're gonna happen. Mm-hmm. It's how you deal with the change that's important. So if you, if you deal with the change in your life in a, in a positive [00:16:00] way, um, that's obviously better. And also, I think the happiness thing's a big thing too, right?

Mm-hmm. People, people see you smiling and they're happy, and they're not, they're not. I mean, my friend, friend base has completely changed from when I was riding horses. I mean, I have a couple of really good friends, so from that time, but mostly I've got completely new friends and stuff because they don't, they didn't know me how I was before and I was different.

I mean, everyone changes right after a head injury and they didn't, they don't, they don't know the old Claire, so they have nothing to compare it to, but uh mm-hmm. So, yeah. So I think it's important for anyone, not just physical or illness changes is how you deal with a change in your life. Mm-hmm.

That's really true. Uh, life transitions changes, these things are really inevitable, and it's how we really show up for ourselves that matter. So thank you. Thank you for that, Claire. [00:17:00]

And so before we end, what is something that you would like people to understand or know about living with a disability?

You know, it's funny because when I was doing show horses, you always have riding times, right? So I was always like always on time for everything. And that's the way I always was for everything. And, um, now, everything takes longer 'cause you, because I have a stairlift in my house, so if I forget something upstairs, I'm gonna go all the way up the Stairlift.

And so I tend to be five, five minutes early for everything, 'cause I've built an extra five minutes in case something happens, which often does especially 'cause I have a little puppy, which, who right now I don't know where he is. Like that is another complication. And so, so you, you know I built in more, I built in extra time for everything. Um, and. I think, I think what anyone who's dealing with a disability has to, has to, um, accommodate that disability.

I think accommodating, that's a [00:18:00] good word for it. You have to accommodate what's in your life. Right. Whether it's a disability or something good or 10 kids or whatever you have. Right? Yeah, absolutely.

If you would like to share more about what your book is about and where people can purchase your memoir, where can they get a copy?

I think it's on Chapters still. Um, I have copies myself. Amazon has, has them if Chapters doesn't. Um, and, um, I mean I wrote the, the book for me, there's a theorist, um, in the States who wrote that um, writing is a complicated and tangled method of discovery. And it is. You write things, you discover things about yourself, right?

And I think writing the book was part of my healing process as was doing the PhD was 'cause I studied people with head injury for my PhD, so that was part of my healing process. Writing the book was part of my healing process because all the time you're figuring things out and you're, you're discovering things about yourself [00:19:00] and, and, um, so yeah, I mean, I think, I think a lot of people journal for that reason, right?

Because, yeah. It helps them figure things out. So yeah. That's amazing. You know? I wish I could write more. I've just been got so much going on right now and I really would like to write more and write about the next space of my life. But then it hasn't happened. It may never happen, who knows.

Well, we are looking forward to your next book, and it was, it was truly a pleasure, you know, getting to read about your, your story and your experiences.

So thank you so much for writing your book and thank you for uh, coming on to Voices of ABLE2.

Thank you very much for talking to me.

Claire's story is such a powerful reminder that disability does not replace identity, and that people with disabilities are more than just their limitations. Claire has redefined what strength looks like, not only through her achievements, but through her [00:20:00] courage, resilience, and determination. Claire has turned some of the most difficult and vulnerable moments of her life into opportunities to grow, to lead change, and to give back to her community.

Thank you, Claire for sharing your story with us and for continuing to shape a world as it should be inclusive, accessible, and grounded in lived experience.

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