Purple Orange Podcast, Episode 5:

A journey to self-acceptance

**SPEAKERS**

Belle Owen (host), Carey Scheer (narrator), Lauren Spear (guest)

**Belle Owen** 00:00

Hello, and welcome to the Purple Orange podcast where we shine a light on the stories of people with disability in our community. I'm your host, Belle Owen, this podcast is recorded on Kaurna land. This is episode five and today we're going to talk about identity, anger, grief, and the journey to self-acceptance that can come with disability. My disability is genetic. I've had it for my whole life. And so, for me, I haven't experienced grief. Sure, I've considered, you know, what might my life look like without disability? What would my job be if I wasn't a disability advocate? Who would I socialise with? Would my relationships with my family and friends be different? Would they even be my family and friends, but ultimately, I can't separate myself from disability because it's something that's been with me for my whole life. This isn't the case for today's guest. When she acquired disability as an adult, this changed the trajectory of her life, and sent her on a journey of self-discovery and a re-understanding of who she was. Carey Scheer brings us the story.

**Carey Scheer** 01:11

Tell me about yourself. Who are you? At 25 years old, Lauren could answer those questions without flinching.

**Lauren Spear** 01:19

My whole life, everything, who I was, my purpose in this world was, I was a teacher. Second to that, I was a dancer because I did ballet and Irish dancing for most of my life and was still dancing. So, Lauren at 25 would have introduced herself as a teacher and, as a dancer.

**Carey Scheer** 01:39

Lauren didn't just know who she was, she knew where she was going.

**Lauren Spear** 01:43

I thought I was gonna get married soon and then, you know, have a baby and kind of do all those societal norms that people expect after being in a relationship for six years. But yeah, I think I was, I was quite confident in knowing who I was and what I wanted for my future. So, yeah, you can imagine how it felt when it was all kind of taken away.

**Carey Scheer** 02:05

The day Lauren's life diverged from her carefully constructed and planned path started just like any other day. She was teaching reception kids at the time.

**Lauren Spear** 02:16

One of my students was stuck on top of a piece of playground equipment. Not something new to me as my young boys definitely loved to climb. On this particular day, I decided to climb up a couple of rails on the piece of equipment to get a little closer to him. And I was pointing to where he needed to place his foot. He was listening to me and navigating his way down to me safely. I was like, great and before I could climb down safely to return to the ground, he decided to jump off the rest of the way. But as he turned around to jump off the piece of equipment, he had hold of my jumper, and I just wasn't ready for it. I simply lost my balance. Thankfully, my student was fine. He kind of dusted himself off the ground, kind of looked at me strangely because I was still on the ground, and he ran off to continue to play. But I, unfortunately, was still on the ground.

**Carey Scheer** 03:11

Lauren hit her head, resulting in a traumatic brain injury. After leaving hospital, she spent the first weeks mostly in bed, unable to do anything, unable to even focus her eyes on anything. But she didn't yet grasp how serious the situation was. She thought she just needs to get back to work. She'll recover. But her doctor told her a resounding no.

**Lauren Spear** 03:39

And he was telling me that I couldn't go back to doing something that I loved. I was just so mad. I was so mad at him.

**Carey Scheer** 03:46

She had to report to this doctor daily. And even though she was struggling to get out of bed, she was insistent on one demand. Going back to work.

**Lauren Spear** 03:56

I wasn't going to let it go. So, he, in his mind, he's probably like, well, she needs to experience it for herself. And then she'll come back and go, okay, you're right. He cleared me for half a day. And I don't think I lasted 45 minutes in the classroom. I couldn't move. I couldn't do anything. I couldn't talk. I had absolutely no idea what I was doing there. It was like I was hollow. Like my body was there, but Lauren was not there and thankfully, I had an awesome SSO that took one look at me and was like, how about I take over and I just nodded at her and she had to tell me, take a few steps and open the door and I was like, okay, and I left after that. I just cried for the rest of the day.

**Carey Scheer** 04:42

At that point Lauren thought, okay, maybe she needs a few months to get back on track. And first step is working out what's happening with her eyes.

**Lauren Spear** 04:51

I couldn't read anymore, couldn't look at my phone, couldn't watch TV, couldn't look at anything. So really, my eyes were useless.

**Carey Scheer** 04:58

She was sent off to a neuro optometrist.

**Lauren Spear** 05:02

He told me that the way my eyes and brain communicate with each other at the moment was not, they weren't working in sync anymore. As we were leaving he, he tapped mum on the shoulder and said, give me a call when she's fully recovered, because I'm really interested to know when that will be. And he said, I don't think it's going to be for a very, very long time. And I overheard.

**Carey Scheer** 05:27

That was the first moment where Lauren understood. This isn't just a little hurdle; this is a life-changing event. A unique kind of loneliness took hold.

**Lauren Spear** 05:40

I could have been surrounded by, you know, five of my family members and still felt completely alone. It is a very different type of loss and type of loneliness and type of isolation.

**Carey Scheer** 05:52

Did you have any kind of social life at that time?

**Lauren Spear** 05:56

No, I tried. I was trying. And if I knew that there was something that I wanted to go to, even if it was just like a coffee, on a Friday, I knew that I could not do anything for the entire week leading up to it. I'd probably be in bed unable to move because that simple coffee catch up, just took everything out of me. Kind of get to a stage where you do have to ask yourself, who's worth feeling crap for in your life? When you go through something like this, you do find out who your true friends are. One pivotal moment was I met this group of people for a breakfast, and I remember walking in and everyone was there already. And I sat down and it's like, oh hi, you know, hi, yeah hi. And then you continue the conversation. Everyone was, you know, laughing their heads off, you know, talking. And I sat there and not once did anybody ask anything about me or check in or ask how I was going. And then you're in two minds, you're like, well, not everything is about you, Lauren. But, on the other hand, I just, I wanted to cry the whole time I was there. I just felt like I was not a part of any conversation. I felt really numb and just disconnected. I was almost starting to have that out-of-body experience again, where my body and brain just, you know, we're going to shut down because this is not good for us. And we're just going to leave your shell of an outer person here.

**Carey Scheer** 07:27

It wasn't just friendships that were lost. That future of marriage, house and babies she had envisioned with her boyfriend, that also didn't survive.

**Lauren Spear** 07:37

I don't think we, on both sides, handled things very well and I didn't know who I was anymore. So how was I supposed to be there and connect with somebody else in my life where I felt like a broken shell of a person.

**Carey Scheer** 07:56

At some point, Lauren did return to work, but not to teach. She was at the school doing small ad hoc tasks.

**Lauren Spear** 08:05

People would leave me little jobs like cutting up visuals and laminating things for them, which I absolutely hated. I knew that these jobs were only temporary, it would help me get back into the classroom, but I hated every second of it. I didn't want to do it. I had no interest. So it was almost like my heart and my brain were telling me two contradicting things. Like my heart was telling me this is the right place for you, don't give up and my brain was telling me, like this is absolute crap. Let's get out of here as quickly as possible. Let's hate everyone, let's hate everything. And then you can imagine feeling those things and then having to do small talk in a staff room.

**Carey Scheer** 08:46

As much as she hated being there, it was this one tiny, fragile thread connecting her to her old life, and she was holding on to it. But one day, it snapped. She was in the staff room and suddenly she was struggling to form any words. Her colleagues called an ambulance.

**Lauren Spear** 09:09

I think maybe I had a TIA, a transient ischemic attack, which is like very short, almost like stroke-like symptoms that are temporary and go away. I guess it was my body's way of saying, no more, Lauren. And I never went back.

**Carey Scheer** 09:25

Who are you? Tell me about yourself. Those questions felt very different to Lauren at 26, 27, 28, than to Lauren at 25.

**Lauren Spear** 09:38

I couldn’t answer that anymore. Well, I lost my career. I lost my hobbies. I lost friends. I lost a relationship. I lost my ability to socialise. I lost some of my independence. Not being able to drive myself around anymore or just complete new daily ordinary tasks independently. I lost my sense of self, like my identity. And I grieved, it was probably two or three years, if I'm being honest, of grieving and trying to come to terms with accepting my life as it was. People go, you know, it could have been worse, you're here, you're doing a good job. You know, embrace this part of your life, or whatever they're going to say and it's, you can't get to acceptance without grieving first and people just needed to let me grieve.

**Carey Scheer** 10:44

Early on in Lauren’s rehab, she kept a log of her symptoms and fatigue levels. But as time went on, the simple log evolved into a journal of her thoughts, feelings and experiences as she navigated this new path. And she began sharing her writing with her family and friends. Her brain injury is invisible to those around her, so this helped them better understand. And she got great feedback. And so, one day, she decided to turn the journal into an online blog. Very quickly, she realised just how needed it was.

**Lauren Spear** 11:22

I remember one girl, I think she was the one from Ireland saying that she was sitting in an airport and came across my blog, and was reading and she just started crying. She goes so many people were looking at me in the airport, like, why is this girl crying? But she was like, it was the first story or I was the first person she'd ever come across that was going through the exact same thing that she was. Or I had family members go, like, I've been struggling to understand what my son was going through and now thanks to you and your story, I better understand. And it opened my eyes to a whole world, a whole brain injury community online that I didn't even know existed. So I started to meet new people, connect with people who were encouraging each other. It was awesome.

**Carey Scheer** 12:08

A common experience shared amongst this online community was the sense of loneliness and isolation after a brain injury. This motivated Lauren to start a local meetup.

**Lauren Spear** 12:21

I run it once a month, called Butterfly Hour, and it's just a chance for people in the brain injury community to come together in the Botanic Gardens. We’re two and a half years in to Butterfly Hour now and there's people there that haven't missed one, which is awesome. And so, you get the regulars and when a regular doesn't show up, everyone's like, oh, where's, you know, where's John? And it's like, oh, I'm gonna check on him. So that's really nice, like, we're building friendships and relationships, and people can check in on each other. But then you have people coming up and like tapping me on the back and turning around and going like, I just wanted to say, thank you so much for putting this on. And, you know, grown men starting to cry telling me how much it means to them. That's why I keep going. I know how important it is.

**Carey Scheer** 13:06

Today, Butterfly Hour isn't just for people with a brain injury.

**Lauren Spear** 13:11

I'm so sick of having all these important conversations about things and we're all sitting around a table going, yes, yes, it's so important, let's tell everyone. But nobody in the non-disabled community is actually in the room to hear and to listen and to learn and grow with us. So, Butterfly Hour is not just for the disability community, not just for the brain injury community, it's for the entire community. Like, why are we, why are we all these tiny little communities? Let's just be one.

**Carey Scheer** 13:42

Today, Lauren is 31. She works in a part-time, casual capacity at Purple Orange, teaching businesses and organisations how to be more inclusive to the disability community. She also teaches a tutorial at Flinders University about disability. She's also found love, and she's got loving and supportive friends and family. She still has impacts from the brain injury, she accepts that this will likely always be a part of her.

**Lauren Spear** 14:15

I still have moments of being heartbroken, and I still have moments of grieving. My life definitely has its big challenges and hard moments. Like, I don't think I'll ever be able to work full-time again. Yeah, and I'd love to go to a wedding or a party where I didn't have to worry about how I'm going to feel over the next day, five days, week after, recovering. You know, my life doesn't really have that spontaneity anymore. But I think about all the people that I've met and all the things I've learnt and all the experiences that I've gained because of the work that I'm doing now. I love it even more than what I was doing before and I know, I couldn't have imagined doing anything else with my life five years ago, so that's really awesome. And then I guess everything that I've built with the Orange Butterfly, that's been a massive, positive thing that's come out of my accident and one that I definitely would not be involved in if my accident didn't happen.

**Carey Scheer** 15:16

To read Lauren's blog, or to find out more about the Butterfly Hour, head to www dot the orange butterfly dot blog.

**Belle Owen** 15:27

While life with disability, whether it's lifelong or acquired, can present unique challenges and barriers, it doesn't mean it's less than, it's just different. Life might not always look the way that we expect it to, but that's okay. If you have a story you'd like to share, or feedback on the podcast, please get in touch. You can reach us on Facebook, email us at stories at purple orange dot org dot au or call 08 8373 8388 or visit our website at purple orange dot org dot au. I hope you join us next time for episode six. It's a really important one about the right to inclusive education. I'm Belle Owen, thanks for listening.