

## The Hum Podcast

### Episode 6: I don't live my life in my wheelchair.

**{Theme music begins}**

**{Luke's voice starts to come in over top of music}**

**Luke:** I'm still the same guy. That's what I always come back to and that's what I always come back to and that's what important to remember is that I'm still the same guy. Life is just a little bit different.

**{Music increases in volume}**

**Male voice:** You're listening to the hum.

**{Music fades off}**

**Gilad:** Gilad Cohen sitting here with my co-host, Amar Wala, on another episode of the hum podcast and we are here today with the one and only Mr. Luke Anderson. How're you doing Luke?

**Luke:** I'm doing great, yeah, I'm doing, doing really well.

**Gilad:** So we're really excited to have you here today. Maybe we could uh, we could start with that day that you were riding your bike. Maybe tell us that story of that day.

**Luke:** Sure. You know I think about your question - you asked me how I'm doing and, to be completely honest, I'm not doing all that well right now, this particular moment, because I fucking miss riding my bike. I really do. I miss riding my bike. I miss my old way of life. Because that's what I was most passionate about. Every minute of free time that I had I was on my bike. And in 2002 I bit off more than I could chew riding my bike with a good buddy of mine. I had just graduated from university, went to the University of Waterloo, got my civil engineering degree there. I had fallen in love with the West Coast after spending a co-op term out there. We were living in a, a small town in the interior of British Columbia and we were living the dream, riding our bikes every day on the best trails in the country. And often times we'd bring our video cameras with us and we'd heard other riders talk about this one trail that involved jumping a big 25 foot gap. And so we, we got to the trail and we scoped out the gap and Johnny went first - I filmed him jumping the gap and he, he did it successfully, he jumped it. It was amazing. We'd celebrated it together and it was, you know, that's what adrenaline sports are all about. Just sharing moments like that is adrenaline pumping and, and it's addictive. I wanted to give it a try so I gave the camera to him. You know, 25 foot gap was not something that I'd ever done before, so I was definitely raising the bar. And, uh, I raised it too high, because when I left the take-off platform I left my life as I knew it. I didn't make the landing and, and I crashed. I crashed, I flew over the handlebars and I landed head first and I broke a couple vertebrae in my spine that, in an instant, caused a spinal cord injury. I knew right off the bat what had happened. I blacked out for maybe 15 seconds. But when I regained consciousness I knew that my life was gonna be very different than I had originally intended. I started crossing things off the list right

after, right after the crash. I had visions of, you know, being a parent and how that would probably not happen. In those very, very early moments I thought about holding a job and, and how that probably wouldn't happen. Yeah uh, yeah I knew that life was going to be very different. But, that said, I knew that I wasn't allowed to give up. I knew that life wasn't over and in order to survive I had to calm Johnny down and tell him to go get some help. So he was freaking out. I wasn't freaking out. I knew I was in a really fucking tough spot, but I knew that if I didn't keep myself calm I wouldn't be getting out of there. So, the ambulance came, the paramedics had to cut down trees to get to us and, uh, took me, took me to the hospital where I was airlifted to Vancouver. And I had an eight hour long surgery where they stabilized the bones that I completely obliterated in my upper spine - so my cervical vertebrae 5 right now is a, if you were to look in there it looks like a titanium donut **{all laugh lightly}**. And then I, I started to work with therapists and health professionals that could teach me how to live my new life, how to learn how to be a part of this world in my new physical situation. Yeah, and that, that took a long time. I'm still learning how to do that.

**Amar:** So let's, let's talk about that for the audience, our audience who obviously can't see you. Can you talk about your current sort of physical situation and how life changed for you in the day-to-day?

**Luke:** You mean the leg that's growing out of my shoulder?

**Gilad:** We weren't supposed to bring that up **{humourously}**.

**{All laugh}**

**Luke:** Oh okay, so we won't talk about that **{laughing}**.

**Amar:** Yeah let's not go with that one.

**Luke:** What were we talking about before, my, how my chair is powered?

**Amar:** Yeah, that.

**Luke:** Legumes? **{humourously}**

**Gilad:** Well Luke's on a bean diet we heard **{laughing}**. Strictly beans, chickpeas when he's going crazy.

**Luke:** Yeah my chair runs on flatulence. So, it's a new technology and uh, just means my diet has to be legumes - high, high fiber.

**{All laughing}**

**Amar:** And, uh, on a special day you get to graduate to chickpeas?

**Luke:** That's right.

**{All laugh}**

**Luke:** No, I use, I use a power chair, so my injury is high enough that it prevents me from flexing my wrists. And so I don't have any use of my hands. But I do have use of my biceps, some shoulder muscles, some deltoids, uh, no triceps so I would do really, really bad triangle pushups **{Gilad and Amar laughing in background}**. And yeah, so I use a power chair to get around. With me in it I guess it's about 350 pounds.

**Amar:** When someone goes through something like this is it, is it hard to not sort of think of your life as sort of pre-accident and post-accident? Is that something you kind of think, is that how you see your own life?

**Luke:** Yeah, I do. I refer to myself in a time when I didn't have my injury. And again, I often miss that life. I have to reserve a little bit of energy each day to kind of grieve. But, what I'd like to share is that there are many different ways to live life. You know, there's an infinite number of ways to live life and I've, and I've, I've just been lucky enough to just experience two ways in one lifetime. Because my change has allowed me to shed light on, on a different way, and it's really important to be having conversations like this to share my experience and let people know that it's okay that I have a different way of getting around, you know.

**Gilad:** So, I, I walk around the city and, and I'm, when I listen to music I'm looking down and I see these StopGap ramps all over the place and it turns out that that's you?

**Luke:** Yeah.

**Gilad:** How'd that start?

**Luke:** It's many, many people that are apart of what we're doing. But yeah, those brightly painted ramps, they came about after years of constantly running into barriers wherever I went. Every community that I visited. My office space that I worked for eight years had three steps to get in, and I, I had to, you know, get someone to set up this deployable ramp every time I wanted to get in and out of the building. And my buddy Michael, who I worked with at the firm, the structural engineering firm downtown, he and I would often talk about how ridiculous this was because everybody loved using that ramp and the only why there wasn't a permanent ramp in front of the building was because there was a parking spot **{quiet laugh}** that the building management didn't want to give up. And so we'd, we'd have these really great conversations and these realizations that holy crap, like, everybody wants this ramp left out because they find it easier to get into the building with it in place. So, yeah, parents visiting one of the clinics upstairs pushing strollers, delivery people bringing all kinds of gear in and out of the building. So all of that frustration that I had been harbouring and keeping inside kind of, kind of burst.

**Gilad:** And it's not liking we're talking about one or two places - I read somewhere that we're looking at about 8100 restaurants, bars and caterers that have these stepped entryways?

**Luke:** Yeah, in, in Toronto, there's over 8000 restaurants and bars.

**Gilad:** That's a lot of places you can't get into.

**Luke: {speaking over Gilad}** And I, I can say with confidence that, well more than half of them are not accessible. So, we've got 800 ramps now across the country, but if you were to add up all the inaccessible spaces across Canada - countless. And this problem doesn't just exist here in Canada. This is a worldwide issue. Yeah, so, around, around that time when my frustrations sort of hit, hit the roof, I'd been noticing these brightly painted bicycles popping up around the city. And so these bikes, they're a public art installation and the artists wanted to get a conversation started about urban planning and, uh, community and cycling. And so, so they're using bright colours, these brightly painted bikes to stimulate the conversation and draw attention to the issue. And it was just such a simple, like stupidly simple concept, and I guess it takes it back to why they originally started painting pylons fluorescent orange, right? So you see them?

**Gilad:** Yeah, yeah right.

**Amar:** Totally.

**Luke:** Right? And it worked. Like, tourists would pose in front of them. It just caused a lot of really, really great feedback that made Michael and I realize that, well hey, why don't we paint ramps really bright colours? And so that's, that's really what started it. And so we, we got a bunch of volunteers together and some building materials and we, we built our first 13 ramps in The Junction. We started with an ask for a fee in The Junction. We wanted the business owners to help cover the cost of the materials and we didn't get any, any uptake. There was no, there was no interest, because we'd get - and I still get - responses along the lines of, you know, "I

don't need a ramp because I don't have any customers that use wheelchairs. Why do I, why do I need a ramp?"

**Gilad:** Right. Well maybe because they can't get in there, right? **{Luke laughing softly in background}**

**Amar:** I think there's a chicken and egg thing going on there

**Luke:** Exactly.

**{All laughing lightly}**

**Luke:** So we, we had to go back to the drawing board and, and get some, some partners on board to help us with the materials. And then some friends and, and other volunteers to help build the ramps. So once we got those pieces of the puzzle together we went back to the business owners and asked them, "hey, we're back and we're here to offer you a free ramp." Their answer changed. And so that's, that's what allowed us to gain some, some traction when we first started. And yeah, we got a lot of traction, to the point where we're now in more than 30 communities across the country with more than 800 ramps on the ground. And a lot, a lot of those are here in Toronto - I think there's just over 500 ramps here in Toronto. I just got an email, though, from a group out of the Czech Republic **{laughs}**. They're going to be taking on a ramp project in..

**Gilad:** Amazing.



**Luke:** Yeah, in the next year.

**Gilad:** Wow.

**Amere:** Nice:

**Luke:** Yep. And so we just, we just launched our New York project and so we'll have our first New York ramp on the ground in a couple months

**Gilad:** That's when you know you've made it.

**{Luke laughs}**

**Luke:** You get into NYC?

**Gilad:** Yeah **{laughing}**. So we have something here called the AODA, and there's this plan to try to make Ontario, Ontario sorry, barrier free by 2025, correct?

**Luke:** Mm-hmm.

**Gilad:** Are we finding that, are we hitting the mark?

**Luke:** I don't think so. I don't think so and we do have a mandate to become a fully barrier-free Ontario, yeah by 2025. So the AODA was passed in 2005, with, with a mission of creating a barrier-free province, but there's 34 of the 69...?

**Gilad:** Yep.

**Luke:** Subway stops have an elevator. And in some cases it takes up to eight years to install one elevator.

**Gilad:** Shout out to Lawrence West Station **{humourously}**.

**Luke:** Exactly, there you go. And so start, it's easy to do the math. We've got less than ten years to go and we're just talking about one issue we're, we're talking about elevators in the TTC stations. The list of barriers that exist out there, it surpasses just the physical space, it's the digital space. So making sure that companies' websites are available in alternative formats or in formats that everybody can access, whether they may have low vision or hearing loss. There's many, many different barriers. Barriers can present themselves in many different forms.

**Gilad:** Amar and I were chatting earlier and I think this is a good segue to maybe, to maybe get to that question. But we, we got feedback from someone on another episode of the podcast that's hearing impaired and she had suggested making some changes like adding a transcript to the website and all that so, maybe Amar, maybe you can transition into...

**Amar:** Yeah, I mean I think that, this is something that we, Gilad and I have just started thinking about and that's why we really appreciate you sitting down with us because I think being able-bodied is something that most of us don't even think about. It's something that those of us that able-bodied take entirely for granted...

**Luke:** I know I did.

**Amar:** Yeah, and while we live in this community - Gilad and I talked about this in our last episode - we asked each other do we live in this progressive bubble as like young Torontonians who are constantly talking about all these progressive issues? But, you know, one thing, like access and having sort of like a barrier-free community is not something we talk about very often. And even when we were sort of, I would say, called out a little bit on our podcast for, "hey, you know you guys should have a transcript up so people who are hard of hearing can actually enjoy your podcast as well," our first reaction was to sort of be a little bit defensive and say "well we didn't, we didn't you know mean for it to be sort of like not accessible for people who have hearing impairment." And I think that that's often the reaction people have the first time that they're kind of called out on some of these things.

**Gilad:** And it's even, it's even like, do you know how much work goes into putting this? Do you think I could have placed more time...

**Amar: {talking over Gilad}** Yeah, and so, so that was our first reaction, which I'm kind of embarrassed by. And that's, and it, luckily we've gotten to the point now where we kind of, you take a, you take a step back and you, you learn from your reaction. I guess my question is how

do you, how do people who are working with you, how do you guys get past that first reaction from people have of “oh, I don’t want to have to do work to actually deal with this” or “oh, it’s not my fault,” that kind of thing? That defensive reaction that all of us have when we’re confronted with these sort of new issues or confronted with thinking about things in a new way for the first time? How do you...

**Luke:** That’s a, that’s a really good question. And, well, we - in a number of ways, and I’ll maybe explain it in a few different examples. I was watching a movie the other night and there was some issues with the volume, there was some background noise, and so I just flipped on the captioning. I have pretty good hearing, I don’t have hearing loss, but having captioning available really, really helped me out. And I think a similar thing happened at a conference that I went to and there was captioning available on another screen and I found myself looking at the screen quite often just to, to get all the, the parts that I missed. That just spoke to me. That just said when you provide something for someone with a disability all of a sudden that works for everybody, that works for everybody else. It’s a universal design, right? And...

**Amar:** Kind of like your ramps?

**Luke:** Yeah, yeah and the engagement piece can happen just out of an organic place, like that conference that I went to where it just, I just happened to naturally gravitate towards the captioning. But, we’re using some strategy with the ramps. We use these vibrant colours that are playful and fun. And to get engagement, to get people to understand that a barrier-free amenity is not institutional - it’s not that sterile, kind of stainless steel grab-bar in a bathroom. It’s something that can be sexy, it can be uh, a universally designed bathroom that looks really

great and a grab-bar might be integrated into the design in a way that doesn't stick out like a, like a sore thumb. So the bright colours are strategic in that we want to use them to, to add a really playful element. To let people get curious about them and not be put-off or have those ramps be invisible.

**Gilad:** I want to, I want to maybe go into another part of conversation here. How have you found that your relationship with people has changed at all? Like, we were talking earlier about dating and intimate moments and, and things like that.

**Luke:** Yeah. Yeah, yeah, that changed, a lot actually. I was living, I was living a pretty selfish life I think. I mean I was bike riding for the sake of getting that adrenaline rush that I, I so wanted to experience. And, once that was taken away from me, there's a big void. Yeah I, I truly believe that I've filled that void with the satisfaction that comes with helping others out **{pause}**. My life has changed in that sense with the relationships that I have. There was, you know my buddies in high school you know that I partied with and spent all my time with - a lot of them are not as, as close as they once were. And that's, that's fine, that's part of growing up, but I'm convinced that there was some difficulty in, in coming to terms with, with what happened. And it's a big change, yeah. It's a big change. There's a lot of **{quick laugh}**, a lot questions, that come with me. Like you guys are probably wondering, okay Luke, your chair doesn't run on flatulence, but...

**Gilad:** What? **{speaking over Luke, laughing}**

**Amar:** You dashed our dreams so quickly!

**Luke:** But how do you, how do you get it on? Like how, how do you, how does that work? And the answer is that it still works, but it's, it's just a little bit different. And that's not an easy thing to communicate to a, to someone you're meeting on a first date. Because that's what's going on in their mind, so I have to be, I have to tread lightly with that one and introduce little tidbits.

**Amar:** So you don't sit down and go "It still works, I swear..." **{Gilad laughing in the background}** "Nice meeting you."

**Gilad:** Prove it **{laughing}**.

**Amar:** Like that's not how we get the first dates going?

**Luke:** No, that, well I've tried it.

**{All laughing}**.

**Gilad:** You talk about, like, well you talk about your experiences, and I just met you about an hour ago and I'm in a new experience with you as well. Uh, for example, offering you a glass of water and, you know, holding it so that you could, you could drink from it. And I'm finding, my question I guess would be, when you're around new people is there an awkward moment where you have to sort of help them understand that this is how they need to help you, or are people open, uh, to asking?

**Luke:** People aren't always open to asking. But I think it's important to ask how you might be able to help someone with a disability. And it's just asking, just "how can I help you?" And if that person needs help they'll inform you. If they - if they don't help they'll let you know. But if they do, then they'll say, "yeah, if you wouldn't mind lifting my glass up to my mouth that, that would be sweet."

**Amar:** And things get pretty intimate with you pretty quickly right?

**Luke:** Yeah.

**Amar:** I was also holding your glass up for you while you drank and I'm sure even just things like, you mentioned putting on your jacket, you get, people get physically very close to you very often. And so, what was that like in the first, when you were sort of getting used to using a wheelchair and that life sort of post-accident. Was that awkward for you as well or...?

**Luke:** That's a really good question. Like I was a proudly independent guy. I loved working with my hands. And I loved, I loved my, yeah I loved my independence, and so it was a long road to being cool with asking other people for help. Because the alternative, not letting people into my life in that really intimate way, meant staying in my apartment. And that, that wasn't a healthy way to live. So when I realized that okay, well, if I just carefully describe how to put my jacket on - if I carefully describe how my neighbour can help me put my jacket on then, then I'm good and I can get outside and have a fulfilling day, right? It's given me the opportunity to meet a lot of cool people. Yeah, and, and it is a, it's a different way of life and, and disability was so far off my radar at one point that having someone, just trying to describe how to put my arm through a

sleeve would never have crossed my mind. And that's where most people are coming from when I approach them. I'll get you to help with my sweater when we leave and you'll have to let me know how I direct you.

**Amar:** Okay {laughing}.

**Luke:** And let me know how you feel with the experience, because it's not, like you said lifting the cup up to my mouth was an experience that you'd ever had before so...

**Amar:** No, yeah...

**Luke:** {music starts coming in as Luke speaks} So yeah, there's intimate moments in my day that happen all the time that aren't typical.

**{Soundbite overlaid on top of theme music begins}**

**Man's voice:** Imagine a world where all of us have equal access to each other. Imagine a world where there are no physical barriers. Can you imagine that? Can you see a world like that? Who can see it?

**Woman's voice:** {cheers}

**Crowd:** {cheering and clapping}



**Man's voice:** Yeah? Yeah! Well you know what? Congratulations. You've just received your device. So go and have fun making this world a better place!

**Crowd:** {cheering and clapping even louder}

{Music and soundbite end}

**Amar:** Do you feel like we as a society need to do a better job of recognizing and being aware of people with disabilities and, you know, barriers to access in day-to-day life? Do you feel like it's a thing that's starting to become a, a mainstream topic or do you feel like we still have a long way to go?

**Luke:** Yeah I think it's, it's a topic that's getting more press and getting more attention. It's really important for people to understand that there's many different ways to live and {pause} what I would love to see one day is that word disability not exist. We all have different abilities, right? It's not a disability. What I truly believe is that it's, it's our buildings, it's our transit system, it's our websites that are disabled. It's not us as humans that deal with disabilities but it's the places that we live and work and play in that are disabled. So {pauses}, yeah I would love for one day to see that, that word disability be removed.

**Amar:** I think that's really important. I think I just learned something really important from you just now and I think that, um, this kind of brings us to that thing we were talking about before we were rolling tape which was the importance the importance of language and that's something that you focus on quite a bit.

**Luke:** Yeah. Um, that's low hanging fruit.

**Gilad:** But even signage, we were discussing?

**Luke:** Yeah, hmm, have you ever navigated the path **{laughing softly}**?

**Amar:** **{chuckles}** I think I tried once and gave up and just looked for the first exit.

**{all laughing}**

**Luke:** The signage down there is garbage. I think it's an important thing to talk about because it's really easy to start removing barriers right now, just by using language that's empowering and that puts the person first and not their disability. So, I'm not a wheelchair person. My friend David is not a blind person. He's a person who is blind and I'm, I'm a wheelchair user. I use, this is just the device I use to get around. It doesn't define who I am, it's just a device I use to get around. You know I'm not confined to my wheelchair, it's - I'm not bound to it. I don't live my life in my wheelchair, I get out of it at the end of the day. I don't live in my wheelchair. I don't sleep in this thing. It'd be the most uncomfortable sleep ever **{laughing softly}**.

**{Amar laughs}**

**Gilad:** Are you finding that people are, are better with that language over the last, let's say ten years?

**Luke:** Umm.. no **{laughing}**. No, we, we hear it every day on the radio, references to, just reporters using antiquated language that isn't empowering.

**Amar:** Like, can you tell us, give us some examples of, of terms that they still use?

**Luke:** Well, "in a wheelchair" reference, or "confined to a wheelchair" reference is used a lot, yeah. And I, I make a point of, of making sure that, uh, that I tweet it, or.. And I think we can all help in that effort to get people more educated on the use of proper language. Because it is really easy. It's a lot easier than building a ramp, but it can be just as impactful. It can really empower people and give people opportunity to focus on, on the person and not the disability. So it's people-first language that we want to be focussing on.

**Gilad:** While we're on the note of empowering, I was on your website today and I noticed that you're also making it incredibly easy to replicate what you're doing here across the country and you're also putting the power in other people's hands to be able to build these ramps themselves. Is that correct?

**Luke:** Yeah. Yeah we share all of our resources. We don't want to hold all this secret. This is really important work that we want other people to take on and use and, and really find enjoyment doing, because it is, it's a lot of fun. And it engages a community to work together, to empower and let people reach their full potential, right? Because uh, there's a lot of communities out there that, that have a ton of barriers and, and that barrier might just come in

the form of a two inch step, **{theme music starts to come in as Luke speaks}** but that two inch step is the same as five steps for a lot of people.

**{Music gets louder as speaking ends and continues for about five seconds before trailing off}**