

Episode 4: Make Every Day Count - Makala Castelli

Rebecca Griffin (host) (<u>00:02</u>):

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Rebecca Griffin (host) (<u>00:11</u>):

Makala Castelli, thank you very much for joining us on HealthTech Talks.

Makala Castelli (<u>00:15</u>):

Thanks so much for having me, Rebecca, it's great to be here.

Rebecca Griffin (host) (00:18):

Makala, often life gives us lemons and we have a tendency to feel sorry for ourselves and want to crawl into a cave of self-pity. You were dealt one of the cruelest blows at just 32 when you were diagnosed with cancer, yet you took that experience and turned it into a positive. You've created something to help others who have been diagnosed with cancer. To use your words, you turned lemons into lemonade. So we'll come to that soon, but before we get there I just want to talk a little about your life's journey and what has shaped your career to date. So you studied business at uni and have since worked largely in banking and self-storage. What attracted you to this career?

Makala Castelli (00:58):

I have, I guess I've spent the last 15 years in property and finance, but always in marketing and strategy roles. I really loved economics at school, but I knew I was probably a bit more creative, so business really seemed like the right place to start. I've always been attracted to roles that are underpinned by customer experience and where experience drives advocacy, and I guess bringing my business and health world together.

Makala Castelli (01:26):

I was in my twenties when I was working at Macquarie Bank and I was diagnosed with celiac disease, and that was really my first entree into health, I guess. There wasn't as much awareness about the gluten-free diet or celiac disease at that time, so I joined the board of Celiac Queensland, and that really gave me an insight into the role of health in the not-for-profit sector, and just how important some of those support organizations are in bringing health and economics and policy and community together. And I think I've always tried to balance commercial outcomes with social impact across my career, so I guess even though I have two very separate career roles in life, I always like to bring them together.

Rebecca Griffin (host) (02:09):

So Makala, life was traveling along really nicely for you, you were moving up into senior roles within a national self-storage chain, but then in 2017 your life was turned upside down when at just 32 you were diagnosed with bowel cancer. What do you remember of that day?





Makala Castelli (02:25):

I remember thinking that there must have been some mistake. One week, one day I was just hard at work, I was loving life, I was ticking all of the boxes, and the next day, it was a Friday night, and I was in an emergency department being told that I'd need surgery as soon as possible, that it couldn't wait until Monday. And nothing really prepares you to hear those three words. I remember sitting in hospital a few days later thinking that I couldn't be the only young woman diagnosed with bowel cancer, despite the shock of everyone around me, not just my family and friends, but every doctor, every nurse that would come into my hospital room would pick up my chart and have a look, and just the look of shock on their face, and they would say, "Oh, but you're so young, this doesn't seem right, it can't be happening to you."

Makala Castelli (03:13):

And I think despite being so wonderfully supported by my family and my friends, you couldn't help but feel a little bit isolated and a little bit lonely, because I couldn't see anybody that was traversing that same path, and it wasn't until I made a friend in hospital, there was a beautiful young girl who used to just do laps and laps and laps of our ward, and we connected and something just clicked, and she had stomach cancer. And it wasn't until I had met her, really, that I guess I discovered that finding other people like me, and other people who had that experience, would be one of the keys to helping me navigate all of the fun things that lay ahead, like surgery and chemo, and all of the other countless complications that can come with cancer.

Makala Castelli (04:04):

But I think because I couldn't see anybody like me, I couldn't find anybody who was traversing that same path because there wasn't as much health visibility online back in 2017 as there is today. And I eventually found support, and I found actually lots of other women just like me, but I found them in Facebook groups and in places where you wouldn't naturally turn to for health support or health information. One of the first things you're told once you're diagnosed is whatever you do don't Google, Dr. Google is not the place for you. But if not that, then where? So I spent most of 2018 in treatment, and I guess I really couldn't help but go through treatment with my marketing experience hat on, and to see all of these gaps, and that's really what led me to thinking about ways that I could improve patient experience for people who are living with cancer.

Rebecca Griffin (host) (<u>05:03</u>):

And this is what brings us together today, so even though it was an incredibly difficult period of your life, and I can't even begin to imagine, you were inspired by that to, as you say, turn lemons into lemonade, and you've started two businesses as a result, and one is called Oncana. What can you tell us about Oncana?

Makala Castelli (05:22):

I have, Oncana is a digital health and wellbeing platform for people living with, and importantly beyond, cancer. So we blend evidence based resources and apply modern wellbeing principles, and we deliver





personalized support. And we have coined the phrase whole-being care with hop, because for us treatment for cancer means so much more than that medicine, and it's really about supporting the whole person as they go through their treatment.

Rebecca Griffin (host) (<u>05:49</u>):

And is it any kind of cancer?

Makala Castelli (05:51):

It is any kind of cancer, and that's something that I'm really passionate about, and I really wanted to make sure that Oncana was cancer agnostic, I guess we would call it. There are so many inequities in the cancer landscape. I remember I was in hospital once and I had a new nurse come to administer my chemo, and if you spend long enough in hospital you get to know the nurses and their colored shirts and who does what, and I hadn't met him before and I said, "Oh, what's your role here? Tell me more about you." And he said, "I'm a care navigator, I'm a cancer care nurse," and I shot up in bed and went, "Oh, you are exactly the kind of person that I need. I've been sitting here trying to figure out how to put all of these puzzle pieces together and really bring together a support team to help me. Tell me more."

Makala Castelli (06:42):

And he looked at me, and he looked at my chart, and his eyes just fell. And I said, "Oh, what's wrong?" And he said, "Oh, I'm so sorry, but I'm only funded to help people with blood cancer." And at that point I couldn't help it feel like not only could I not find the support that I needed, but I couldn't access it just because I'd been diagnosed with, in this scenario, the wrong type of cancer.

Rebecca Griffin (host) (07:10):

And at what stage in a person's cancer journey should they access your website?

Makala Castelli (07:16):

Yes, I would love to say all stages, but I think something that I'm learning is you can't do it all at once. So Oncana is really designed for people who are having treatment currently, or nearing the end of their treatment and are really looking for what's next and how they go about pulling together life after cancer. You need a different type of support when you're newly diagnosed, and hopefully at some point we will be able to offer that as well, but there's so much acute medical care that goes into those first few weeks and few moments that at the moment we are really focusing on how can we help people live well with cancer once they're over that first hurdle.

Rebecca Griffin (host) (<u>07:57</u>):

Did you feel that some of this, or all of this information that you are now giving people ready, easy access to, was missing on your journey?

Makala Castelli (08:06):





It was. I think there are so many great resources out there, but they're so incredibly hard to find, and they're hard to find at a time when your whole life has just been turned upside down. I think for many of us it's so hard to ask for help in so many situations, let alone in these sorts of times, and I think one of the hardest things about being diagnosed with cancer is so many people want to help, but you don't know what kind of help you need. You don't know what to expect, you don't know what to ask for. So many people say, "Oh, if there's anything I can do, please just let me know, I'm more than happy to help, I would love to help." But as a patient dealing with this for the first time, you simply don't know what you don't know.

Makala Castelli (08:54):

So I think bringing all of these resources together and helping people navigate their care, and pull together this practical support in a care team is really what Oncana is about, but I think the other missing piece for me in my experience was really the patient voice. It's one thing to hear something from health professional, or from an oncologist or a nurse, but it's entirely different when it's coming from someone else who has tread that path. You have so many questions and you'd never dream of asking your oncologist some of them, and even practical things like how much do you share with your kids? Or how do you tell your boss you have cancer? You need life experience and you need to be able to understand how other people have processed and worked through some of these scenarios, and it's simply care that doesn't come from a medical team.

Makala Castelli (09:49):

The other thing that I found that was missing as I went through my treatment path was that I had noticed that I had taken all of my corporate skills and really helped to build my own care team and connect all of my clinicians together and made sure everybody was talking to each other, and if I needed solutions I went and researched them and found them. And it wasn't until I started supporting a lot more people online that I came to realize that not everybody has those types of skills and that not everybody knows how to advocate for their own care, and really nor should they have to, but this is the system that we are working within, and not everybody knows what type of Allied Health or complimentary care is out there, or the support from other amazing not-for-profit organizations that they can access. So I think Oncana is really about taking people's hand and helping point them in all the directions that they need to be able to live well with and beyond cancer.

Rebecca Griffin (host) (<u>10:45</u>):

What's your aim with Oncana, what do you hope it can achieve?

Makala Castelli (10:49):

I really would love Oncana to help people be able to integrate their own care and for them to be empowered, to be their own advocates. We can curate the best evidence based resources, and we can connect the people to the support that they need, but at the end of the day I think I'd really love to develop this new language around cancer, and it's not a language, it's a language that I see and speak and hear every day when I talk to patients, but it's nothing that I see in the medical landscape, or the healthcare





system as it stands. So I think my aim is really to, there's a lot of talk in healthcare about patient centered care, but really I think this whole-being care notion is so much more powerful than that.

Rebecca Griffin (host) (<u>11:38</u>):

You're listening to HealthTech Talks, a podcast series delivered by Lumina. To find out more about Lumina visit the website LuminaGoldCoast.com.au and sign up today to receive your Lumina opportunities pack. Along with on Oncana, Makala, you began a second business as a result of your experience of having cancer. You began designing adaptive clothing, and now sell this clothing from your website, Limonata. What is adaptive clothing? I've not heard of that before, and how did the idea come about?

Makala Castelli (12:16):

Yeah, well, everything changes when you're diagnosed, and that includes your body, and it includes your sense of self. And I spent so long in hospital tangled up in IV lines, and with port-a-cath, and all sorts of things, and getting dressed and undressed and dressed again, and needing help to do all of that, that I became really frustrated with that experience. And I don't mind admitting that I love a bit of retail therapy, and I definitely tried to buy some control in this situation, but I couldn't find anything when I went looking. So I designed a range of functional fashion, which is another name, I guess, for adapt clothing.

Rebecca Griffin (host) (<u>12:56</u>):

Love it.

Makala Castelli (12:56):

And it's about garments that are easily accessible. They're comfortable, flowing styles, they're all clinically compatible and scan friendly, which is really important in hospital environments. And so the sides and shoulders of all of our garments open with some unique snap fastness, so no more dreary unforgiving hospital gowns, and they're all in bright, beautiful colors and prints, because being a patient doesn't mean that you have to forgo your sense of style and your sense of self, and I think that's really important because we know, and there's certainly lots of evidence to back it up, that when we feel like we look good, we feel better too.

Rebecca Griffin (host) (13:35):

Makala, last year was a huge year for you, you were appointed CEO of the Self-Storage Association of Australia. In addition to that, you were a participant in the HealthTech accelerator program LuminaX. What were the tangible outcomes this program brought to your online cancer support business Oncana?

Makala Castelli (13:54):

LuminaX was such an incredible program and really delivered such an impact for me in a short space of time. So much knowledge came through those few weeks that we had down here, and knowledge that isn't easily accessible elsewhere, certainly coming from outside of the health sector I found that really, really powerful. The contacts and connections that came with the program and that have lasted long beyond the program have been absolutely amazing, contacts that I would never dream of having had





access to. And also for me, structure and accountability. I like to wear a lot of hats, and sometimes that means I need a little bit of help making sure that I'm on track.

Rebecca Griffin (host) (<u>14:37</u>):

Meeting those deadlines.

Makala Castelli (14:39):

Meeting those deadlines, and so adding somewhere to come to each week, and themes to focus on, and homework, really made sure that we could power along our startup journey.

Rebecca Griffin (host) (<u>14:51</u>):

So if you hadn't been a participant in LuminaX, where do you think you'd be with Oncana?

Makala Castelli (14:57):

Oh, I'd be so much further behind. I think LuminaX really helped me flesh out the opportunities in the sector, the commerciality of the sector, which is really important, particularly in cancer care, because the funding structures probably aren't where we need them to be to be managing survivorship care as part of a funded process, so I found that really helpful, and really just fast tracked some of those thought processes and the progress piece for me.

Rebecca Griffin (host) (15:26):

What's been the greatest challenge for you as an entrepreneur in the health industry, and as you said, an industry that you hadn't really had that much experience in?

Makala Castelli (15:34):

You're absolutely right, and for me personally it is being a bit of an outsider. Every day I work with highly experienced clinicians and leading experts in their field, they all have many letters before and after their names, and so for me it's really been owning the fact that I'm a patient and that I'm doing things a bit differently, and that that's okay. And I think it's certainly my greatest challenge, but it's also probably my biggest opportunity.

Rebecca Griffin (host) (16:03):

What's your advice to other entrepreneurs and self-starters thinking to enter the health industry?

Makala Castelli (16:09):

Oh, this is a good one, and I've probably got a few gems to share that were shared with me at the start of LuminaX. I think the first is probably becoming a student of the sector. HealthTech is such a great industry in Australia, and there's so much happening here at the moment, particularly in southeast Queensland and on the coast, so really become a student of the sector and learn what's happening, connect with people. Something I have found in health is that people are so generous with their time and their insights, it's not always the case in the corporate sector, so it's been such a pleasant surprise here.





Makala Castelli (16:44):

And you'll receive tons of advice. Everyone will have a thought or an opinion or a suggestion on a way you should do something, but I think something that I was told at the start of LuminaX was remembering that you're the one who gets to decide what you take in and what you put aside. You're the domain expert in whatever your field, so take it all and then process it, sit with it for a while. Don't be too precious, be prepared to pull it all apart and put it back together, but just take the advice and run with what works for you at that time. I think the other thing, if people are considering either a career in health tech, or as an entrepreneur, starting something themselves, please jump in. There's so much change that is required to improve patient experience in this system, there are so many other opportunities in health here in Australia, and we really need some passionate people to do it.

Rebecca Griffin (host) (<u>17:38</u>):

Makala, how do you do it all? I mean, you're a CEO, you've got two businesses on the go, a lot of other hats, no doubt. How do you do it all?

Makala Castelli (<u>17:47</u>):

Well look, I'm not sure I do it all particularly well, and certainly not all at once. Cancer is such a life defining moment, and it gives you so much more perspective, and I am just so grateful to be here, and I have so many wonderful friends who haven't been given that opportunity that I have no choice but to make every day count, and I'm so motivated to help others. One in two Australians will be diagnosed with cancer in their lifetime, which is a staggering statistic, so if I can just help improve their experience by a fraction, it will have all been worth it.

Rebecca Griffin (host) (18:32):

Makala, we're doing this interview from the Lumina development here on the Gold Coast. How do you think Lumina can support other HealthTech entrepreneurs like yourself?

Makala Castelli (18:41):

Oh, Lumina is such an incredible precinct. I think to have everything in one place here on the beautiful Gold Coast is just a joy, it's a joy to be here, it's great to be around so much innovation, from a health perspective you're so lucky to have this great congruence of private and public and academia altogether, and then there's this great artificial intelligence and machine learning community that's growing, and they're doing some really cutting edge work here, and really using incredible technology to save lives, which is incredible. So I think from here, Lumina, this amazing community, there's such a passionate team here in Ben and Ariana, they really get behind you, and I think having that confidence and enthusiasm for HealthTech has been such a boon for the project.

Rebecca Griffin (host) (<u>19:32</u>):

Before we let you go, what are your websites?



Makala Castelli (19:35):

Oh, absolutely. You can find Oncana at www.oncana.com.au, that's O-N-C-A-N-A, and then you can find Limonata adaptive clothing is www.Limonata, L-I-M-O-N-A-T-A.com.au.

Rebecca Griffin (host) (<u>19:55</u>):

Makala, you're an inspiration and it's been a privilege talking with you, thank you so much.

Makala Castelli (<u>19:59</u>):

It's been wonderful, thanks Rebecca.

Rebecca Griffin (host) (20:03):

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