

## Survivor Stories: Kayleigh and Cassidy

### The limitations of public healthcare and private science-based options

Cassidy: Drives me crazy that, you know, people take the doctor's advice as the gospel in Canada. Like we're taught that, you know, the doctors obviously know best. Not everybody responds to their advice the same way, but I would say the majority of Canadians are complacent in taking the doctor's advice until the point where, you know, they're out of options. and they're just blissfully unaware that there's alternatives when it comes to, you know, critical illnesses like cancer. To go and try to find those private services though are, it's not easy to understand what is reliable. We've already talked about how, you know, there's all this snake oil out on the market and there's so many people that prey on people that are desperate to spend money for better care. That's something that I've become an advocate for is, is making sure that people understand that it's not a, you know, a blanket, a broad brush where everybody outside of the public healthcare system is predatory.

Cassidy: You know, there's people that are out there actually trying to do good and have, have research to back it. And it's not the Canadian mentality to think of private options. but that's what I'm hoping will change. You know, people will see more and more of the benefits. I have no doubt that the future in 10 years are hopefully less of cancer diagnosis and treatment goes straight to individualized next generation sequencing. Hopefully we don't have to call it next generation anymore, but I don't like how long that might take. You know, I want the option, you know, they say one in two, people will have cancer in their lifetime, in our Canadian framework, and probably most North Americans, you know, I would say at least one in three. so, you know, when the time comes for most people, it's a matter of what you know, when not if you want to get an accurate diagnosis.

Cassidy: I don't wanna have to pay out of pocket, you know, half my life savings to get the kind of treatment I need. I, and I think most Canadians would agree if they understood how much more effective this type of testing is in, in getting a) the diagnosis right And b) exploring all possible treatments, that may have the, you know, most minimal side effects for maximum treatment efficacy. And yeah. Anything we can do to make that more of a reality sooner than later, I think is something we both wanna do.

Kayleigh: Yeah, definitely.

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Cassidy: Yeah. You shouldn't have to do 20 hours of literature searches to know if this is the right way to do it.

Kayleigh: Yeah. And I'm proud that we have free healthcare in Canada. We couldn't afford it to pay for my ICU stays and all that time in the hospital. Don't get me wrong, I'm so grateful for that. I just want to see some of this more the next generation sequencing put into practice in our healthcare system somehow, instead of reactive healthcare system, a proactive healthcare system. And I know that we're not the only ones that want this. We're just some that have now seen it in action and kind of got the bad end of the stick - I don't know how that saying goes. But I truly believe if we were focusing on stuff more like this, like next generation sequencing or prevention, we could actually save money in the cancer care in Canada on a whole, for example, with mine, if I had just done that chop chemotherapy and it hadn't have worked, even though that was the cheaper option, if it didn't work, I would've just had to go to the brentuximab because that was a second line treatment.

Cassidy: Yeah. It wasn't approved for first line treatment for her, which was something that really blew my mind that these options, even though they're a little bit more expensive upfront, that are known to have higher treatment success are reserved for second, third, fourth line treatments. It's so reactive. I mean, it's the story of public health, not all public health systems, but ours for sure is so reactive, the lack of proactive treatment, when we know that the cost savings is there in the long run, just it makes physical sense. It makes so much sense for physical wellbeing and quality of life for people. I mean, our eyes were truly open that at how shortsighted the system is operating right now. And it's not that people don't want it to work the other way, it's just, you know, there's so much to do and everybody can only react to the most emergent situations, and it's a hard pattern to break and I don't know how to do it other than, you know, showing that it works and showing those cost savings, and life savings and suffering reduction, if that's something you can quantify, like it's insane.

Kayleigh: But if we can kind of be the poster child for it, you know, I had to relearn how to walk. Now we go hiking every weekend, and I'm not saying I'm in the same shape I was, I'm gasping fair a lot more than I was before.

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Cassidy: The doctors told you you would be on oxygen for the rest of your life, that you may even be in a wheelchair the rest of your life. Mm-hmm. You know, we go on hikes every weekend. Now we're working out every day. We're actually back to some level of...

Kayleigh: Normalcy. Yeah, I'd say some level of normalcy. In 2019 before all this happened, we were so healthy and active that we actually went to Peru and did a four day hike of the Inca Trail, and then went traveling around the Atacama desert in the Salt flats in Bolivia.

Cassidy: And just a few months before she was in the coma

Kayleigh: So we were in, like, when I say I was in good shape, I, I was in very good shape, which is why my heart was able to handle it. And then to be told, oh, you're not gonna be able to do any of that anymore. You're going to be in a wheelchair with an oxygen tank for the rest of your life, to getting the good treatment. And if we hadn't advocated for ourselves, if Cass hadn't done, and my family and friends hadn't done what they did while I was sleeping, I probably wouldn't be able to, you know, we're planning on doing the West Coast trail hopefully this summer. I couldn't do that. I would be sitting just sitting out watching other people live their lives and,

Kayleigh: Yeah. And with CTOAM , we actually know my line of treatment if I, if it returns because we have the genetic sequencing. we don't just have option B, we have option B through F, I believe. Yeah. and then some, that's not the end of the story if none of those work. The nice thing about it is I don't think any of those until we get to like f I don't think any of them involve chemo.

Cassidy: No. Most of them are...

Kayleigh: I can keep on growing my hair .

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Cassidy: Yeah. Most of them are immunotherapy. And kind of the cool thing is, you know, I've been doing a lot of the middleman stuff between her oncologist and, you know, the research team at CTOAM, Alex specifically, trying to figure out if we needed that next treatment. What does it take, right? Like what, who do we have to talk to, is it approved here you know, what do we have to pay for that you know, do we have to do more fundraising, et cetera, et cetera. and I'll bring, you know, like this, ALK inhibitor "alecensa" that was recommended as our next line of treatment, in the case of relapse to her oncologist. And she'll say, well, let's not worry about that till we get there. Which makes sense from, you know, her time management and her resource availability.

Cassidy: She can't, she can't go there. She doesn't have the purview to do that. But she also said, you know, there's not enough evidence. I could not prescribe this if I wanted to, even though the research now shows it's the most effective treatment. Interestingly, since we brought that up towards the end of her first line of treatment last year, it was just this past fall that it got FDA approved for her specific type of cancer. And has been showing, you know, much higher success treatment rates, in patients with later stage, lymphomas, specifically her T-cell lymphoma. and there's been some really interesting studies that have shown that the standard of care should change over to that specific treatment. So it was just reassuring to hear that, you know, when I, I already had trust in Alex's research capabilities, and I know that he's got the knowledge that most people won't on where the direction of treatment needs to go. But having our oncologist say, my hands are tied, I kind of agree that this could be a good treatment option, I couldn't prescribe it if I wanted to, because there's not enough data to support it. And then literally, you know, six months later having this research article come out and say, this is our new best line of treatment. That says a lot to me from a scientific, perspective on the competency of this approach to cancer treatment.