

Survivor Stories: Kayleigh and Cassidy's Lesson

How to Get the Right Treatment the First Time

The big kind of light bulb moment for me was how long the diagnosis process took and how quickly she was degrading. That's when my mind said, "There's definitely gotta be a better way." Like I know there's been enough progress made in genetic profiling of different cancers and different diseases in general. That there's no 'one shoe fits all' solution and if we're dealing with a cancer this aggressive, we better be damn sure we're getting the treatment right the first time, because there's no room for mistake with her case. Right? She's so advanced in the disease progression that one failed line of treatment could, could be it. So I got on the horn and I called around to as many places I could in Canada trying to find some private consulting. Michelle was able to respond within a business day and say, "yeah, let's set up a call." but she actually gave me Alex's number and said, "You know, text Alex and see when he can talk in the next two days."

I think it was two days that I had to wait, which was-- I was expecting a week to get somebody on the phone. And he said, "Okay, yeah, this is a pretty intense case." He's like, "You know, you guys don't have a lot of time to figure out what to do. And you know, I can't do much until you guys have an oncologist, but, as soon as you get that diagnosis, let me know and I'll do a little bit of reading on where the cutting edge research is." But he gave us a one pager and said, "Look as soon as we got that diagnosis this is the best treatment available that you guys can get in your hands in Canada today." So of course, I brought it to the newly assigned oncologist, who is an expert in blood cancer.

We were lucky at the Tom Baker Center that there was, somebody that actively researches lymphoma. She said, "I don't think they'll have anything to offer you guys. We're already doing everything we possibly can here for you."

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Since I had been hearing that for the past three weeks from every doctor we talked to, obviously I thought, I am sure they're doing everything they can help us, but it's not enough. They're doing everything they can in their power with the tools they have and the tools that they have are spread thin. Their time is spread thin. It's not going to hurt to get more than one opinion at least lined up. So if what they're going to give her doesn't work, we don't have to mess around and try to figure out what to do next. We got a Plan B, ready to go, and that was my main motivation for spending the money on a private service, to come up with more treatment options for Kayleigh. So our introduction was traumatic, as you can tell. And it's probably a big reason why we got this drive to go above and beyond the standard care because we didn't know what time we had to work with.

We didn't know a lot of things in the picture and we had a lot less trust than we used to in the the care system-- in the standard care, which is not your typical introduction to cancer treatment, because most people come in with a background of every time I've had to go to the doctor, they seem pretty confident. They know what to do. You know here's what we do going forward. That doesn't work. No biggie, we'll have another round of approach. Their doctors are very confident that Canadians shouldn't have to pay anything out of pocket, if they don't need to. So they want to make sure that their patients are getting access to healthcare without additional fees, which is great, but they never tell you what those limitations are.

Nobody knows that until it's too late or they're in a situation where they've learned, " Oh I had other options? Man. I wish I had actually explored them." But when you have that gradual introduction and you're trusting the path laid out for you over a longer treatment plan for cancer, it's not until that treatment fails that you're typically looking at alternatives. I think that's why our case is a little bit unique as we didn't think we had the luxury of that option, based on how severe her introduction was and how long the diagnosis took.