

Kayleigh and Cassidy: Self-Advocacy withing Standard Care

Cassidy: So it's a very risky thing happens when you're in a coma and you get chemo. All of these rapidly, replicating cells, like, they open up and they spill all their contents into the blood. The spike in potassium and internal contents of the cells can kill you like that. I can't remember the exact name of it, but it's essentially a shock to the body. So, I had to actually educate the ICU team on that being a thing, because I was constantly reading about the risks of ICU based, Como- based chemotherapy. Surprisingly only one of the five people watching her had heard of this. And so they were going to do their regular four- hour checks on her blood and all of her vitals and everything.

And they upped it to every two hours and luckily caught that as it was happening and were able to treat it in a way that it didn't kill her. But this was just one of several examples where being on the ball when you have limited standard care resources is life or death, literally life or death. So I didn't leave her side for that whole time. They kept trying to send me home and I kept just sitting there researching. So before we got the diagnosis of a T-cell lymphoma anaplastic, large cell, T-cell lymphoma, which is a very rare type of lymphoma. I had come to the conclusion based on her symptoms and odds and I thought we were dealing with some sort of like diffuse large B-cell lymphoma and the doctors kept saying, "well we don't even know if it's cancer".

So if someone who's not in the medical field can get close enough on a diagnosis like that, it made me really realize, so we gotta be on the ball and we gotta advocate like crazy to get the right treatment here because they're watching X number of patients at any given time. They're not able to give the level of care that an advocate or a family member can do. So I was very fortunate that at least some of the advice I was able to give; I've literally printed out research papers using the ICU printers and giving them to the staff and saying, " look it's not just my opinion, here's the European medical journal article on this. Please read this and pay attention", And very luckily she pulled through and woke up a day and a half after chemotherapy.