

Survivor Stories: Kayleigh and Cassidy's Lessons

The Importance of Self Advocacy and Science Based Research

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 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, I thought she-- we were dealing with some sort of like diffuse large B-cell lymphoma. 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. I mean, it made me really realize, okay, so we gotta be on the ball and we gotta advocate like crazy to get the right treatment here. They're watching X number of patients at any given time and 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 with some-- I literally was printing out research papers using the ICU printers and giving them to staff and saying, "Look, like, it's not just my opinion. Here's the European medical journal article on this. Please read this and pay attention." Very luckily she pulled through and woke up a day and a half after chemotherapy.