

Hope in the Hallway

We can help Jude...

These were the first words Dr. Franz said after he'd greeted us in the exam room. I admit I was skeptical. It felt like every emotion and positive thought were exposed like raw nerve endings. I was spent. Jordana was spent. Jude was spent. I wanted to believe someone could stop this nightmare, but in that moment, I just let his words bounce off of me like a pebble on metal armor.

Author Anne Lamott says that "Hope begins in the dark." I think she's probably right, but what I didn't anticipate was just how long the darkness can last. If we're not careful, it can outlast whatever hope we summon and leave us stranded.

Over the next minutes and hours, we met all kinds of pediatric neurology team members. I don't even remember who everyone was, or what sorts of conversations we had. I was sort of waiting for the punchline, like that key moment in a show or movie, when the hero finally delivers. We'd be told Jude could be helped before, only to be devastatingly disappointed, so I was halfway wondering if in the end, they might run some sort of test and say, "Oh, we didn't realize it was going to be like this...unfortunately, we won't be able to help."

Fortunately, that's not how the story unfolded, at least not on that particular day. For the first time since Jude's health crisis began, we felt as though we finally had allies – a team of people who were with us, here to help us navigate this expansive new world of illness and care and treatment and survival.

At that particular point in the journey, nothing felt within my grip. But, somehow, the precious advice from our favorite PBS neighbor, Mr. Rogers, was discernible above the noise of all the hardship: "Look for the helpers."

I still remember walking out of the exam room with Jordana and Jude in the stroller. As we stepped into the hallway, a horde of helpers in scrubs and lab coats were there, smiling, speaking hope. Despite the reality that Jude didn't have a cure, that the medicine and treatment could help him, but not answer every question or remove every challenge...hope.

Whether you're in the place Jordana and I were with Jude more than ten years ago, or miles along in your caregiving or self-advocacy journey, here's three pieces of advice I try to remember. The more I practice these, the better I care for myself and for Jude:

- Look for the helpers. But, they can't help unless you ask...every bit of research, every question, every visit helps improve the quality of life for you or the person in your care.
- Don't hide your struggle if everything is terrible, let them know. Tell them you need help and support to figure it out. Never sugar coat, just tell the truth. Truth saves lives. Reality is, if you don't, who will?
- Remember why you're a caregiver or self-advocate, because a diagnosis has completely changed life's trajectory. It's easy to get caught up in the painful daily grind and forget who you are and what care is all about.

Tolkien leaves us with these words: "The world is indeed full of peril, and in it there are many dark places; but still there is much that is fair, and though in all lands love is now mingled with grief, it grows perhaps the greater."

Caregiving is indeed a journey of constant love and constant grief. Let's not pretend, let's keep unearthing hope - in the hallway, in the park, in the passenger seat, in the elevator, in the bathroom. Seek it. Find it. Share it.

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