

Emily Goolsby

1/13/2021

End-of-Life Reflection

I can relate to Claire's journey not so much on the same level as her dying, but living with chronic illnesses. I myself am living with Type 1 Diabetes, Hypothyroidism, and Addison's Disease. I relate to Claire in that instead of feeling sorry for myself, you have to go out and make the most of your journey in this life. The people you leave behind won't remember all of the days you were sick, they will remember the impact you had on their life and the legacy you left behind.

While watching the video, I felt inspired by Claire's will to do something with her life meanwhile also taking care of herself. She didn't want to be remembered as the sick kid, that was just a part of her, she wanted to leave a lasting impression on this world with what time she had left. Claire was living with Cystic Fibrosis which is a genetic disorder in which her lungs produced an excessive amount of thick, sticky mucous. This disease lead to the difficulty breathing and her not being able to oxygenate well without the help of supplemental oxygen. Cystic Fibrosis also lead to other issues like coughing, diabetes and the need for an extremely calorie dense diet.

If I was Claire's nurse I would want to assist in self-empowerment, and by this I mean I would want to enable Claire to take control of her treatments and exercise. I would want to assist in maintaining a positive environment and letting her talk about how she feels about her condition. I wouldn't want to make her feel like I pitied her for being sick. In order to maintain a helpful environment, I would involve physical therapy to help with exercises that she can do, and I would also involve dietary to help her figure out how to incorporate the large amount of calories that she needs per day.

The financial struggle for Claire's family was that she was in the hospital quite often to get the treatments she needed to get better and that is very expensive. Instead of getting to spend time with her while she was sick in the hospital her parents had to work so they could continue to provide for her. Along with all of the hospital stays, she required a lot of medications in order to stay healthy. I'm sure that total added up quickly as well.

From Claire's story I have learned that not all sick kids feel sorry for themselves. They feel as though their sickness is just a part of their story and that allows them to create purpose for their life. They have so many things they still want to do with their time on this earth and we should help them accomplish these things. I will apply this to my future clinical practice by not making the child feel like I am feeling sorry for them and not trying to avoid the more difficult questions with them. I will rather enable these children to fulfill their dreams and goals.

I think knowing that Claire wasn't afraid of dying and how she said she "had a relationship with death" made the sudden loss of her after her transplant surgery a little easier on the family. It also made it easier on the family that Claire had lived her life the way she wanted to. She didn't let the disease stop her from fulfilling her dreams and she lived everyday like it would be the last. I also think getting to be with Claire as they said their goodbyes and being with her as she passed away made it easier on the parents as well.

Claire's story is inspiring to me because she didn't let her disease run her life. She was able to take control of what she could control and made an impact on so many kids life's. She turned her life into something to be proud of and help others with. This applies to me because as a young child with Type 1 Diabetes a lot of people assumed I couldn't do a lot of things like sports or activities that others could. I of course proved these people wrong and excelled in sports just to show them that I wasn't going to let Diabetes or anything stop me from living a full life. You can do anything you set your mind to.

