

Cystic Fibrosis

After watching the documentary of Claire and seeing what she went through was heart wrenching. Throughout her life, she stayed positive and always thought there's more to do in life than just suffer and be sick. She wanted to find ways on how to help others and not just think oh she's the girl who is sick and will eventually die soon. She wanted to make an impact and change the world for people who had cystic fibrosis. Claire was a person who strived to do the best that she could do while being sick. She inspired people all over the world and change their perspective on life in ways that no one else could. I could honestly say that she changed my perspective on life, and I should be more grateful for what I have. You never know what someone else may be experiencing so treat them with respect and dignity.

Claire was diagnosed with cystic fibrosis at birth. She spent a quarter of her life in the hospital even while her parents were at work. Family and friends would go visit since mom and dad were at work. They didn't want her to feel alone during her stays at the hospital. Cystic fibrosis is an autosomal recessive genetic disorder that is caused by mutation in the gene for the protein's cystic fibrosis transmembrane conductance regulator. It affects the reproductive system, respiratory, gastrointestinal, and the skin. In cystic fibrosis the exocrine glands produce thick and sticky mucus. There is no cure for cystic fibrosis. Some of the symptoms that I noticed that Claire had were shortness of breath, a cough, and she had oxygen on majority of the time. She had a bunch of medications and respiratory treatments that she did throughout the day. Also, she had to consume a lot of calories in her diet to remain active. Throughout the day she took naps and breaks. She had a routine of taking her medications, using her nebulizer, exercising, and knowing the number of calories she had to consume. This was her life, and she was going to make the best of it. Her signs and symptoms were progressing as she was aging. She mentioned that her lungs were at 35% and would eventually give out completely. During her video, she mentioned that if people would donate to help her receive a lung transplant. The

amount of love and support she received was large. Claire ended up reaching her goal of 50,000 and several were still donating to her account.

As a nurse, I would assist with medication administration and help the patient with the nebulizer treatments. I would also assist and comfort the patient and treat her like any other person. I wouldn't hammer the term terminal and constantly say terminal disease when the patient already knows their condition. I would also take the time to talk to the patient and ask how they are feeling. In this instance, with Claire parents being gone from time to time to work. I would sit down and bond with Claire. Then from here, I would assist her with positioning her upright to help with the breathing. Providing the opportunity for exercise and physical therapy can help the patient. Exercising supports the go of airway clearance by loosening the mucus and facilitating affective coughing. This would help the patient feel some relief. We could have the respiratory therapist come in and help the patient with some exercises. Even case management to have some help at home from time to time. Cystic fibrosis requires a lot of attention and managing the symptoms can be difficult.

Towards the end of the video when Claire was getting her lung transplant. The doctor mentioned that everything came out great, but later on had a complication from the surgery. She had a stroke but never felt pain due to not waking up from the original surgery. This part of the documentary was hard seeing. Claire was excited about her new lung and no one was really expecting her to pass away during her surgery. Her parents believed she would pull through, but she didn't and passed away that day. Claire had so much life in her and watching that part just hurts that she wasn't able to say goodbye to everyone. She made a video prior to her surgery mentioning that she wanted the lung because she wanted to do more for others. Claire wanted to keep fighting and making a difference.

Cystic fibrosis is a terminal disease that Claire had and handled it the best way that she could. This documentary was an eye-opener for me and made me realize I should be more grateful. She was a role model for many people and saw the best in life. Claire wanted to be

something big in life and she accomplished more than that. She reached people from all over the world and was able to make a difference. We should always strive to be better and do better no matter our condition.