

LaShunda Evans

Reflection: Claire's Documentary

Before April 12, 2023 the name Claire Wineland had no great significance. After watching the documentary Claire Wineland's story is forever etched in my memory as well as on my heart. Her story is inspiring, educational, heartwarming and hopeful. Claire's upbeat spirit and smile pulls you in her account of her life experiences. Although, she completely captivates you with her story her struggle with cystic fibrosis is ever present. You can observe clinical manifestations of cystic fibrosis throughout the documentary, such as her frequent cough, shortness of breath, fatigue and oxygen dependency.

Claire's journey with cystic fibrosis is similar to other with this inherent life-threatening disease. Cystic Fibrosis is a condition where the secretions in the body such as sweat, mucous, and digestive juice become thick and sticky. The secretions then become plugs especially in the lungs and gastrointestinal system, which leads to difficulty breathing, absorbing, and digestion nutrients which explains Claire's cough, dyspnea, fatigue and oxygen use.

Claire's nursing care needs were not specifically addressed in the documentary but would include education in relation to disease process and dietary needs such as high protein, high fiber, high caloric, and vitamin rich food intake due to malabsorption. Instruction should have also been provided regarding use of supplemental oxygen, nebulizer, oscillating vest, and medications (bronchodilator, mucolytics, digestive enzymes, vitamins, and antibiotics). A team of health care providers would also be needed for optimal symptom management and improved quality of life. The team should include an age-appropriate Primary Care Provider, Pulmonologist, Gastrologist, Physical Therapist, Social Worker, and other providers as symptoms arise.

As Claire describes her struggles with cystic fibrosis it is important to remember her parents who also endured the effects of cystic fibrosis through watching Claire struggle with symptoms

and frequent hospitalizations. The parent's financial responsibilities did not cease because of Claire's illness but likely complicated the situation due to the need to continue to work to maintain a home life as well as manage the added cost related to Claire's care. Financial obligation for the family mostly likely meant not always being present with Claire during hospitalizations and knowing in the back of their minds knowing she had a limited life expectancy.

It was amazing to watch Claire's journey. I gained insight into the plight of a person who lives with a life-threatening disease from birth. The statement that most stays with me is when Claire says, "when you pity people who are sick you take away their power". I want to be a nurse that nurtures and empowers my patient's. Because of Claire I will be intentional and assess my demeanor towards patients as to not pity but empower those I have the responsibility of caring for. I always say nursing is a calling, Claire's video has reminded me that I'm not doing all I can every day to fulfill that calling, which makes me want to strive to do the most good for the most people while I can. Although Claire is not physically here with us her words and actions will continue to change many lives.