

## End of Life Reflection

Throughout the video, I was so inspired by Claire's outlook on life and death. I thought the way that she was brutally honest and shared both her joys and sadnesses with the world gave an amazing, whole perspective of the experience that many with chronic illnesses may have. She was never afraid to admit her fears and her thoughts, and I felt this could be so relatable and uplifting to people with similar experiences. When she was scheduled to get her lung transplant, I felt so much joy for her, you could sense her nervous excitement in the film. It was heartbreaking when the surgery did not have the outcome that was hoped for, especially when seeing how resilient and strong that she was. Even after death, Claire's story is so inspiring and impactful and I feel she continues to make a big difference in the lives of many, both through the foundation and her experiences that were shared with the world.

Claire had cystic fibrosis, which is a chronic disease in which the mucus produced in the body is abnormally thick. This can lead to blockages in ducts, passages such as intestines, and bronchi. The blockages cause an increased risk for infections. The problems that were evident with Claire were the blockages in her lungs and the cough that was often in her recorded videos. She always had a nasal cannula, indicating that she required oxygen supplementation, and there were also some clips in which she was using a nebulizer or chest wall oscillator to help loosen the mucus in her lungs.

The clinical manifestations that I noticed were her chronic cough, fatigue, and inability to gain weight. You could hear the mucus build-up when she coughed and saw that it was physically difficult to clear that airway. In some of the videos, she also looked like she struggled to gain weight and this is due to malabsorption in the GI tract as well as the increased metabolic requirements of the body to breathe and fight infections. In one video, Claire mentioned that she had to eat around 5000 calories a day to meet her body's energy needs, as well as mentioning that at times her life just consisted of treatments, eating, and taking naps because she was tired from the treatments and meals.

Sarah Kearney

Nursing interventions for this patient would include providing frequent, smaller meals to reduce the energy spent while still maintaining caloric needs. It would also be important to have a careful aseptic technique as this patient is prone to severe infection. As she grew older, it was evident that Claire was very active in her care, but for a young child, it will be important to provide treatment on the different treatments and medications as well as proper use of all of the equipment.

Many members of the care team will be important for achieving goals. This will include her pediatrician, GI specialist, nutritionist, pulmonologist, surgeon, nurses, respiratory therapist, and physical therapist. Claire had many interventions related to her care such as different exercises, breathing treatments, dietary needs for increased caloric intake, education for lung transplantation, and general healthcare throughout her life. This chronic disease requires a multi-faceted treatment plan, and the members of the healthcare team need to communicate with each other as well as Claire and her parents to coordinate the best care for her.

Claire's condition required frequent treatments of many different types. They would have had to pay for medications, equipment, and lengthy, frequent hospital stays when Claire was ill. Furthermore, they likely had to travel a lot to see different specialists as her disease progressed. Claire started a GoFundMe in preparation for her lung transplant, and that in itself had many additional treatment costs during and after the surgery. Also, when a child is in the hospital, parents will likely need to travel or take off work to be with their child in the hospital, which can put an additional financial strain on a family. Insurance was not mentioned in the video, but families may not have the many extensive bills from the hospital covered by insurance and the insurance in itself may be very expensive.

Through this experience, I was reminded how important it is to not pity a sick person but to empower them and be a supportive presence to help them reach their goals. Claire was a very headstrong example of the value of life, despite sickness or health. This story was impactful in that it

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showed the ups and downs that patients and their families face with chronic conditions as well as seeing what a person with cystic fibrosis may experience through the progression of their disease. Claire showed that there can still be so much joy in life and she shared that realization with many others in her position.

In my clinical practice, I will apply the concept that Claire mentioned regarding not receiving pity. Often the patients with these chronic conditions are very aware of the reality that they may die soon, so rather than caring for a patient in a manner in which I tip-toe around them, I need to recognize the fullness and potential that the patient can have to enjoy life and seek ways to empower them and enable them to reach their goals, even in the little things. This may be seen in giving them the opportunities to perform their own care rather than trying to do everything for them.

Before actually being in the pediatric module, I thought that this concept was too sad and I would not be able to handle it. However, in the videos and clinical experiences, I have found that it is such an honor and privilege to get to care for children that are actively dying. This provides an opportunity for holistic care and support of the child, parents, and siblings. It still makes me feel very sad to think about caring for a child in this situation, but I would hope that I could be able to bring comfort and peace in my presence as a nurse for the child.

I was so amazed by Claire's joy and ambition to leave her mark on the world. She did not shy away from death and truly embraced that her time was precious. Stories like hers are very inspiring and a big reminder of how blessed I am to have healthy loved ones and the ability to go to nursing school and be a part of the care of people like her.