

[Opinion](#)
[Spirituality](#)



Screenshot from Claire Wineland's Twitter account



by Christian Mocek

[View Author Profile](#)

[Join the Conversation](#)

October 25, 2018

[Share on Facebook](#)[Share on Twitter](#)[Email to a friend](#)[Print](#)

It wasn't her sickness that captivated me, although it was the reason I learned about her. Diagnosed at birth with cystic fibrosis, a genetic condition that overloads the organs with an excess of mucus, Claire Wineland had a unique and charismatic way of turning hardship into blessing.

She was a social media icon, creating videos with titles like, "[Dying 101](#)," "[What It Feels Like to Die](#)," and "[How the Oxygen Tube Works](#)." Her YouTube videos and Instagram posts garnered millions of followers, drawn in by her upbeat persona and humorous yet frank candor about living with a terminal illness.

At the age of 14, she gave a [TED talk](#) in which she said, "People tend to get discouraged when they have problems or a thing to overcome, when really that's the part to cherish in life the most, you know? That's when you get the most out of every second of your life." She then rattled out a cough and joked, "Whoops, hairball!"

She was like that. Deep, inspirational and funny at the same time.

Unfortunately, she died last month at the age of 21 after suffering a massive stroke while recovering from a successful double lung transplant. Her death garnered worldwide media attention, her story picked up by CNN, The Washington Post, BBC, and others. Her story blew through the media like the strong wind she was, leaving those who read about her a little better and a little different.

I was one of those who admired Claire from afar. I never knew her, at least in the way one typically knows someone. She was so vulnerable, forthcoming, and honest in her videos that it felt like I knew her after watching them.

I also knew what she was talking about. My wife was diagnosed shortly after birth with cystic fibrosis, so when I listened to Claire I could relate, not in the way my wife could, but also differently than those who knew nothing of what she had.

This is actually something Claire talked about often — how even though most didn't share her sickness, all of us knew suffering. In a recent [video](#) discussing her lung transplant, she shared, "Very few people can relate to what it feels like to be, like, slowly suffocating all your life and needing new lungs. That's not a normal person issue — thank goodness. ... For me, the point of sharing everything I'm going through isn't to make you all feel as if your lives are not as equally insane as mine is. 'Cause maybe on the surface they're not, but fundamentally we're all in the exact same boat with this."

Advertisement

That's where Claire Wineland spoke most to me. Claire never wanted pity for her suffering or to be set apart as another inspirational sick girl, once saying that her memoir wasn't going to be "another happy sick person book."

Claire wanted us to see that sickness and suffering can be used for great things. Teaching in a [TED talk](#), "Life isn't just about being happy. ... It's not about how you feel second to second," she said. "It's about what you're making of your life and whether you can find a deep pride in who you are and what you've been given."

By all accounts, she was given a tough journey to walk in life, but that wasn't the end of her story nor should it be the end of ours. How often do we find ourselves waiting for the next best thing? Or waiting for the hard times to end? Or find ourselves believing that the grass is greener on the other side — at another job, with another partner, or in purchasing another thing?

The answer to our unsettled hearts is not on the other side of our struggle; it's in the way we embrace our struggle. It's in the way we take what we're given and offer that as a gift to others.

Claire did this beautifully. She was intentionally forthcoming in sharing her suffering, so we would know our own suffering. She shared her joy, so we would know there could be joy in our hardship. She told us that struggle was an invitation to embrace every moment, not a burden to wallow in.

What kind of world would it be if we followed her example? If we sought communion in our suffering, saw giftedness in struggle, and didn't fear the invitation to see opportunity where the world sees burden?

Breathe easy, Claire. Thank you for giving us your whole self and for teaching us all that life is beautiful because of our struggles, not despite them.

[Christian Mocek is the director of annual giving at St. Meinrad, a Benedictine monastery, seminary and school of theology. He lives in New Albany, Indiana, with his wife and one son.]

Editor's note: We can send you a newsletter every time a Young Voices column is posted to NCRonline.org. Go to this page and follow directions: [Newsletter sign-up](#).