

## **Captions for “Final Video Essay: Problematic Approaches in Communication Towards People With Disabilities”**

“I’m so sorry! You’re so young to have your body be falling apart.”

(I asked a few of my friends with chronic illnesses and disabilities to say phrases that people have said to them in relation to their illness/disability.)

“You need to give up that seat, that seat is actually for disabled people.”

“You should only say your disabled when you have your cane with you, otherwise it just looks like you’re faking it.”

“You’re so lucky! You could have had it so much worse.”

“If you could just take care of yourself better, we wouldn’t be having this problem.”

“You are exaggerating your illnesses so I will feel guilty for you.”

“Maybe if you were in better shape and conditioned more, you wouldn’t have as many asthma attacks.”

“You should be more grateful, at least it’s not a terminal illness.”

(Just because you can’t see the illness, doesn’t mean it isn’t real and doesn’t give you the right to comment on it.)

If you didn’t know me, you would think I was just an average 20-year-old college student. You’d pass me on the street and not automatically think I am disabled because outwardly, you’d be right, I do look like an average 20-year-old. But I’m not. I am a Type 1 diabetic and have been for the past 18 years of my life. But unless you asked, you’d never know this about me because I have what we call in the disabled community, an invisible disability. Despite my disability, I am able to do what any other person my age does. I like to hike, go to the beach, and hang out with my friends. I love dogs and would watch a sunset with you any day. But because I am able to do all these things, many times people assume that I am exaggerating when I say I am having a bad diabetes day or when I need to take a break or sit out because my blood sugars are too low. This is a problem that not only I face, but many of those within the invisible disability community.

By educating yourself and drawing attention to the problematic approaches in communication towards people with disabilities, but specifically invisible disabilities, you are creating an environment that doesn’t negatively impact or burden those suffering with said illnesses or disabilities. Today I am going to be talking about the harmful effects of using war metaphors

when talking about chronic illnesses, why inspiration porn is problematic, and how COVID has impacted the rhetoric when talking about disabilities and chronic illnesses.

(Everyone featured in this video essay has some kind of chronic illness or invisible disability. I did this to try and change the perception of what being “disabled” means.)

(We might not use wheelchairs or canes, but it doesn’t make our disability any less real or valid.)

(I also wanted to showcase that having a disability is not a roadblock and just because we are disabled doesn’t mean we can’t do anything an able-bodied person can do.)

The words we choose to use to describe illnesses are powerful and have a huge impact on the ones with the illness. These words carry weight. For a long time, it has been normalized to use war metaphors when talking about illnesses. Examples of war metaphors: "Fight for a cure", "Battle the disease", "You're a fighter", "Never give up".

But the problem with using these metaphors on people with chronic conditions is that "winning the battle" isn't an option. Chronic illnesses are lifelong which means you are telling them to fight a part of their bodies that is a part of who they are. Life with a chronic illness is a marathon, not a sprint, with lots of turns and dead ends along the way. There is no set beginning and end that their disease is limited to and it won't go away if they "fight" hard enough. According to a study done by Cancer Nursing, it was shown that patients who view their disease as an “enemy” tend to have higher levels of depression and anxiety, and poorer quality of life than those who ascribe a more positive meaning. By describing an illness as a "battle" you are setting the outcomes as either victory or defeat, there is no in-between. You are placing a burden on the patient that they *have* to fight. And what if the person isn't strong enough to "fight", does that mean they aren't deserving of a cure?

War metaphors are just one of the many problematic approaches in communication towards those with chronic illnesses and disabilities. I'm now going to transition into telling you about inspiration porn and why you should stop doing it.

In 2014, comedian, journalist, and disability rights activist, Stella Young, gave a TED Talk where she shared a nine-minute talk titled *I'm not your inspiration, thank you very much*. In her talk, she coined the phrase that many people use in the disabled community called, "inspiration porn". Here's what she had to say about it. Young defines inspiration porn as "objectifying disabled people for the benefit of nondisabled people. The purpose of these images is to inspire you, to motivate you, so that we can look at them and think, “Well, however bad my life is, it could be worse. I could be that person.” But what if you are that person?"

Disabled people are constantly existing in a society that was not built to include them. You have the privilege of being "inspired" by their lives. According to Leah Cameron in her thesis titled

"Inspiring or Perpetuating Stereotypes?: The Complicated Case of Disability as Inspiration, she states: "[Inspiration porn] is problematic because it suggests that disability can be “overcome” with the “right attitude”. This locates the disability within the individual and ignores the social conditions and dimensions of disability.” Inspiration porn belittles the lives of those with the chronic illness or disability and makes everything they do a symptom of their impairments, not a genuine achievement. You can be proud of them and what they have overcome to achieve something specific, but a trip to the grocery store or doing any other basic task doesn't mean they're brave.

Inspiration porn is something that those with chronic illnesses and disabilities face almost every single day and has been around for years. I now want to shift focus to something that has only come to light in the past few months: COVID-19 and how it has changed the rhetoric and communication when talking to and about those with chronic illnesses and disabilities.

COVID-19 has exposed the underbelly of America and the ways people view and talk about and too those who are chronically ill. Not only are those with weakened immune systems due to our chronic illnesses and disabilities at a higher risk of getting severely sick from COVID-19, but we are also having to watch the people around us send us harmful messages, verbal and non-verbally. We are having to watch people across the world, and sometimes that includes our friends and family members, not wear masks which sends us the non-verbal message, they view our lives as expendable. Because of COVID-19, those with invisible disabilities and chronic illnesses could no longer just blend into the crowd. we were forced to take precautions that prevented us from doing what our friends were doing. forced to stay home and isolate. forced to watch our peers living the lives we were supposed to be living. having to watch the world forget about us and return to their normal lives. We don't have the privilege of having the “if I get it, I'll be fine mentality” or “survival of the fittest”. for us, it's more of a “if I get it, how long before I'll have to be hospitalized” if i get it, will I even survive?” We are more than just a statistic that you tell yourself to feel better about ignoring CDC guidelines. We are real people who are suffering because of the harmful messages you are sending us by going out and partying. To us, it is the same as you telling us that you don't care if we live or die.

So, you may be asking yourself, what can I do, personally, to help improve the rhetoric and communication between myself and my disabled and chronically ill friends, family members and peers?

If you have a friend or family member who is chronically ill or disabled, educate yourself on that illness or disability so you know exactly how to best support them if they ever ask for it.

Please, for the love of everything, wear a mask. The simple task of doing that sends a powerful message to those who are still in isolation because of majority of the country's inability to wear a mask. It shows you care about our health and want us to be able to return to our lives. Check your privilege and don't assume anything about anyone who is chronically ill and disabled.

Don't be afraid to ask questions if you don't understand something. I know this isn't the case for everyone, but majority of us would be more than happy to have a conversation with you and talk to you about our chronic illness or disability.

Before you comment on something that someone who is chronically ill or disabled is doing, make sure to think, "would I say this to someone who isn't disabled?" and "Am I only saying this because they are disabled?" We are not here to inspire you; we are just trying to live our lives like everyone else.

And finally, check in on your friends who are chronically ill and disabled. Right now, more than ever, we are feeling lonely and isolated and feeling major FOMO so a simple text asking how we are, means the world!

The topics I talked about today only touch the surface of all the problematic ways those with chronic illnesses and disabilities are talked to and about, but I hope that even the small introduction has you thinking about ways that you can help bridge the gap and work towards more positive approaches when talking to your chronically ill and disabled friends.

(Thanks for watching ☺)