

A black and white photograph of medical tubing and connectors on a dark, textured surface. The tubing is clear and flexible, with several black plastic connectors. One connector is on the left, another is in the center, and a third is on the right. The tubing is coiled and loops across the frame. The background is a dark, textured fabric or surface.

On Shame and Dying

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drive

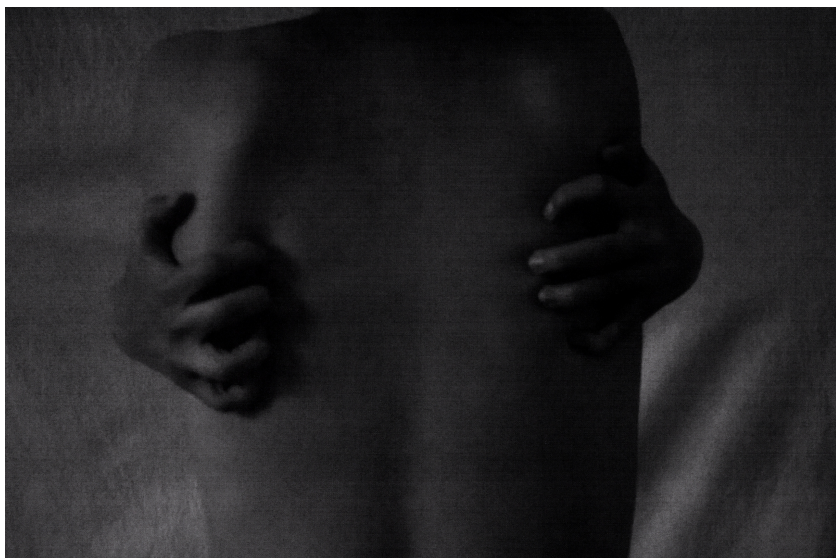
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My Ugly, Shameful, Sometimes Beautiful Crippled Place in the World

When I first saw *Untitled Action Sculpture* (Wade Guyton, 2003) in a fleeting moment as I navigated the Whitney Museum, moving from one exhibit to the next, I was quick to think ‘I don’t understand modern art.’ Upon first glance, you may think that this visceral object isn’t art, nor should it belong in a museum. Yet, something drew me back through the gallery to look at it a second time— the same way that seeing your reflection might draw you back again when something looks off-kilter.

The sharp bends and curves, the way it takes up space— this altered steel chair and I are intertwined. Like some warped piece of metal, I too feel as if my own framework is ugly and uncomfortable. As my disability continues to progress, I am more and more displaced from my own body. This detestable chair and my ill-functioning body are so closely related to one another.





What is it about this chair that makes one so quick to judge? The way it is sprawled out on the floor asks you to step over or around it simply by just existing as it is. Are disabled people not regarded in the same sense? The distorted shape claimed by steel is such a familiar state of being to me. I can no longer take a deep breath and am so hyper-aware of what I am lacking in each waking moment—each wheeze of my lungs, every time on I put on the mask to my CPAP machine before bed, each tangled mess of oxygen tubing, breathing treatments and inhaler puffs that make me cough until I'm red in the face. Each and every curve, bend, twist, and break echoing a distant memory of the previous form. My heart beats strangely, even in my sleep. I am perpetually existing in an uncomfortable space. Is this what my body is made for? Is this all that I will amount to? Akin to this ghost of a chair, I am so far removed from normalcy. Instead, I take on a new form; something so strange and twisted that I become almost unapproachable. I, too, take up space- reaching out and up, as people around me are pushed away by someone diseased and dying. Don't you think I also want to exist as something else?

My very existence is molded by the configuration of a damaged body and some semblance of shame for living and dying in the way that I am. The ignominy and indignity that follows alongside the progression of lung disease, or any disability for that matter, is something that I've come to find to be even more nauseating than terminal illness itself. This shame is not innate; it is learned over and over again in the tireless day-in and day-out of existing as different. What is it about being disabled that makes people so uncomfortable? I'd argue that their unease about my sickness is even stronger than my own.

A woman a bit older than me stopped me in the street today to ask about the heart monitor on my chest. It was too hot to bother with covering it up and I'd been acutely aware of eyes drifting down to the sterile appendage for the past few hours. She told me that she was surprised to see someone wearing "something like that so openly" and was dumbfounded that I would still be out living my life; that it wasn't "slowing me down." Her line of questioning seemed so innocent to me; a woman my senior with a childlike curiosity wondering how I was able to go to Trader Joe's and if I was feeling okay. To believe that disability in and of itself would hinder someone from living out their life in the same way as any other person is a foreign concept to me. But the disabled body will always be destabilizing to people as long as we collectively continue to feed it shame and hide it away.



The brutally honest tone of “Inside All of Us Is a Gross Girl” by Ione Gamble offers further insight into the deplorable nature of the disabled person and the intricacies of a repulsive identity; “Being outwardly gross also signals a complete rejection of social norms, of our societal stereotypes, and of the patriarchal order of the world. Being gross isn’t just about being open about the disgusting things that happen to us on the inside, but also being entirely unafraid of who we are on the outside” (Gamble, 116). The belief that disability equates ugliness is so ingrained in us that even as a disabled person, I still cannot shake it. I feel as if disabled people are often failed by the people around them, their communities, and society at large. Yet, even simpler than that, disabled people are almost never taken into consideration in general. In this day and age, we are surrounded by a culture of celebrating and recognizing diversity, however, I don’t always feel seen in those conversations. My disability is integral to understanding both myself and my place in the world, but I struggle to see that place when others are swept under the rug and disregarded entirely. Through no fault of their own, most of us are spoon-fed the idea that being chronically ill is inherently tragic and something to pity. This belief continues to be perpetuated through the stark lack of representation within the media. This loss of visibility shoves disabled people into a corner and leaves them without a voice.



Really the only visibility disabled people have is from the inspiration porn you find plastered on social media as a way to make able-bodied people feel better about their lives and to think of disabled people as a ‘charity case’. It’s not difficult to find videos of disabled people, often kids with special needs or cancer patients, doing something such as walking after being in a wheelchair, going to prom, receiving a Make-A-Wish, or even something as ridiculously stupid as having able-bodied friends. The majority of these events are so minute and day-to-day occurrences; they don’t necessarily need to be shared online and praised simply because the person happens to have a disability. If you were to take a video of me with my heart monitor going to Trader Joe’s and post it to Facebook, it wouldn’t be unreasonable to assume that at least one able-bodied person on that platform would feel inspired by something so objectively ‘lame’. The captions that accompany this type of content are often along the lines of ‘this should make you realize your blessings in life’ or ‘be grateful for what you have’. At what point can disabled people openly exist just as they are without becoming ‘inspirational’? When this media is consumed and promoted it only goes to further objectify disabled people and remove them from any respectable conversation. How can we ask people to understand, or at least empathize with, the disabled experience when they have no relatable concept of this kind of existence?

My illness is not always visible, which means that I have the privilege, or lack thereof, of watching how people treat me differently when it does become apparent. I've been infantilized, pitied, ignored, and patronized by people who may think that they mean well, but more often than not are falling victim to the concept that disabled people are not capable, nor do we have any intrinsic value to offer culture in a broader sense. "In the case of my disability," writes Gamble, "my body may behave in ways that make me feel hopeless, but through this comes an immense power: the power to confuse a world that only accepts an empowered woman when she acts within the parameters of usefulness to society." (122)

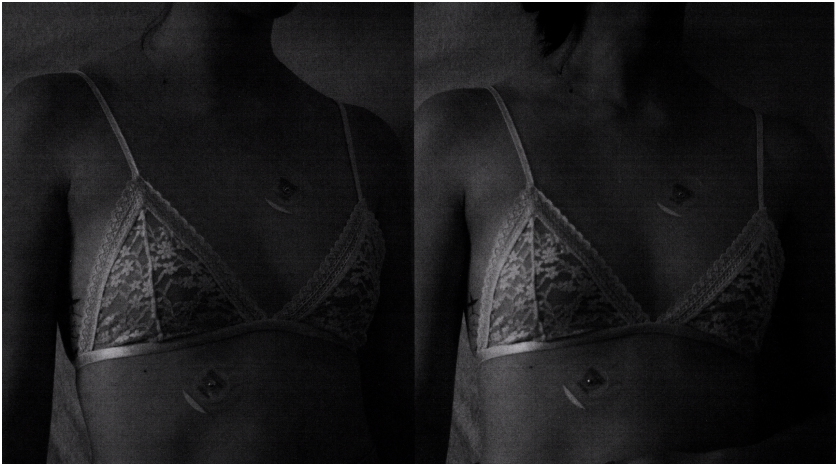
This shame-fueled and confusing existence is true of both the disabled person and of weird and unsettling art such as *Untitled Action Sculpture*. The artist and their work can only be so ugly and unashamed before it becomes too much for others, even for art. The inherent need and subsequent lack of shameless occupancy of space and visibility as a disabled person leads me to envy *Untitled Action Sculpture* and the way in which it can be considered a work of art, as visually upsetting as it is. The perpetration of societal shame will continue to infiltrate our concept of ourselves as long as we continue to consider marginalized identities as inherently lower than the cis-het able-bodied white man.



When you give suffering and difference the room to exist as it is, to look at it without judgment, and abandon the belief that it is somehow a moral failing, you are also making room for you to exist just as you are. In my own practice as an artist, I find myself driven to reconcile with my physical body and the outward appearance of disease. In a photography series titled *Disabled Looks Like Me*, I adorned my body and the space around me with visible representations of sickness— heart monitor stickers plastered across my skin, a wheelchair offering both a place to rest and support to stand, an oxygen cannula, and hands gripping flesh in a futile effort to ease pain and discomfort; to remind myself and to grapple with the fact that this is my existence. The spectacle that is a disabled body is often raw and unpleasant. Yet it is something you cannot turn away from— like a disconcerting creation; the same way in which a twisted chair drew me in closer.

This push-and-pull of invisibility and visibility in the form of physical shape is clear in ceramic artist Michelle Kaun's essay "Clay Body". She writes of her return to the studio after taking time to rest due to illness, stating that "It feels meaningful that I am here now, deliberately committing to the creation of imperfect forms with my two hands. That the uneven bulges I once called ugly are now alluring. [...] Is it because my vessel, too, is no longer whole?" (Kaun, 24). The concept of ugliness and disfigurement is a strong focal point within her creative work of sculpting and molding people who are labeled as 'different.'





While my shame is still ever-present, and on some level always will be, I no longer feel such a strict obligation to hide my body away or to pretend that my disability is not there. In living as openly sick, I feel more at ease with this painful existence and can allow it to take up space; to influence my work and the ways in which I consider my occupancy within the world. Later, Kuan goes on to say:

Sometimes, I find myself wondering which of my chronic illnesses will ultimately best me. Will I go by the slow, painful drowning of my lungs? A malignant lump in my breast? My anxiety follows me. [...] Is it the desire for permanence and legacy that has given me the urgency to write more, draw more, build more? [...] I now feel a profound desire to embrace my markings and material impressions, to leave tangible relics of myself in the world (24, 25).

Public acceptability is out of my hands, as it is with any marginalized person. There is nothing I can do to make society see me as anything more than sick, even though there are so many more layers to my identity outside of illness. Disabled or not, people deserve to have permission to exist as objectively ugly and to create art that reflects the most unnerving spaces within our identities, even if in doing so we jeopardize the comfort of others. As Kuan writes, “Nothing about this vessel is perfect, but it is undeniable proof that I was here” (25).



Works Cited

- Gamble, Ione. "Inside All of Us Is a Gross Girl." *Poor Little Sick Girls: A Love Letter to Unacceptable Women*, Dialogue Books, London, 2023.
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