

Reflections on Intergenerational Pain, Disabled Maintenance and Radical Vulnerability.

Recently my body has begun to let me down, in much larger and more inconvenient ways than it has before. Before, its unreliability could be forgiven as a quirky yet irritating foible, but it has got to a point where I'm having to reconsider our relationship. Sometimes I wish I could just cut it out of my life like a bad friend, but, unfortunately, I need it to keep me alive, even if it's not doing a particularly good job of it. When my mother was in her 30s, her body did a similar thing to her. The same thing happened to two of her sisters and a female cousin when they passed 30. I remember the Great Maternal Depression - the laying in bed for days, the crying, long stretches off work, the back spasms when she carried the shopping inside. With my nerves and brain still functioning the way they ought to, I couldn't understand why, but I realised then that my mother was, in fact, a real person, not just a mother, and that she was in pain.

Fibromyalgia is most common in women, and because it is a disease of female pain, it is easily dismissed. We have become a secret society, and we speak the secret language of chronic pain, irritable bowel, fatigue you can't shake like concrete shoes. You don't want to be in the club, trust me.

I read Alice Walker's essay 'In Search of Our Mothers' Gardens', in which she describes the inheritance of female pain. Walker's pain is not my pain, nor the pain of my relatives, but her words made me consider how struggle and creativity have been bequeathed to me through my elder women. She speaks about the unrecognised creative genius of Black women in the past who were exploited, ridiculed and undervalued, how their signatures mark the works of their daughters today. In a similar way, my survival as a disabled woman celebrates the survival of the women in pain who survived long enough to birth me;

"guided by my heritage of a love of beauty and a respect for strength - in search of my mother's garden, I found my own."¹

The question I face is what this survival must consist of, now that the pain has made itself present. A few months ago, I planned a performance in which I would daily chip away at a block of wax, the same weight as my body, until nothing was left but shards and dust, then re-melt the debris back into a block. That was how I saw my existence, the exhausting violence of attempting high functioning life in a low functioning vehicle, work which culminated to nothing. The silently gathering up, starting again without ceremony when I had spent all my fuel. Nobody would know or care about this. I wrote a list where I promised to do the work. I wasn't sure to whom this promise was, but I wrote 'I will, I will, I will' and pinned it to the wall for everyone to see.

People asked me why I had to do it, the chipping. I didn't know, I just had to. The work wouldn't be valid without it. What would it mean to choose not to do it? It was a terrifying idea.

¹ Walker, Alice, *In Search of Our Mothers' Gardens*, published in Mitchell, Angelyn, ed. *Within the Circle: An Anthology of African American Literary Criticism from the Harlem Renaissance to the Present*. Durham: Duke University Press, 1994. 409

In disability theory there are two models of disability, social and medical. The medical model posits that disability is brought about by the impairment of the person, while the social model believes that it is brought about by the way that society is organised - in such a way that the non-normative body or brain struggles to function within it. Along with the social model comes the unseen labour expected of the disabled individual so that they can survive in such a hostile environment. This comes in the form of bureaucracy - form filling, emails, assessments, phone calls - as well as emotional labour - fielding invasive questions, brushing off micro-aggressions, performing as able bodied emotionally and physically.

For me, the energy I expend on this concealed labour often matches or even outweighs the energy spent on the things I am trying to access with it. Mierle Laderman Ukeles explains in her Maintenance Art Manifesto what she calls the life and death instincts. "The Death Instinct: separation; individuality; Avant-Garde par excellence; to follow one's own path to death—do your own thing; dynamic change. The Life Instinct: unification; the eternal return; the perpetuation and MAINTENANCE of the species; survival systems and operations; equilibrium."² In everyday practice, the CEO uses the death instinct while the cleaner uses the life instinct. Death = macro, Life = micro.

The disabled person's limited energies are largely used on the maintenance of their life: showering, eating, cleaning etc. There is little left for development, development is a luxury. What Ukeles believes, and what I am coming to terms with, is that this life maintenance is still valuable, it is still art, or as she aptly phrases it: "MY WORKING WILL BE THE WORK." I may be producing nothing but my survival is infinitely impressive. With this in mind, having made only one piece of what I considered 'work' in the first term, I printed out the swathes of emails, applications and appointment forms which I had worked through in order to officiate my disabled existence. I stacked them in a large pile and said, 'this is the work.'

Johanna Hedva's Sick Woman Theory has also deeply influenced my thinking around the validity and value of my everyday survival. Firstly, in terms of the domestic; my art invokes it because I am frequently housebound, either by my brain or my body or a combination of the two. Hedva challenges Hannah Arendt's definition of the political as anything that is done in public. If this is true then a vast amount of disabled people can be "deemed a-political simply because they are not physically able to get their bodies into the street."³ [They] argue that the Sick Woman, by very nature of continuing to exist in a world where 'we were never meant to survive' is making a political statement.

Hedva goes on to reference Judith Butler's work on precarity and resistance:

"Because the premise insists that a body is defined by its vulnerability, not temporarily affected by it, the implication is that it is continuously reliant on infrastructures of support in order to endure, and so we need to re-shape the world around this fact."

² Laderman Ukeles Mierle, MANIFESTO FOR MAINTENANCE ART, 1969! Proposal for an exhibition: "CARE" (1969)

³Hedva, Johanna, 'Sick Woman Theory – Mask Magazine'. <http://www.maskmagazine.com/not-again/struggle/sick-woman-theory>. (Jan 2016)

Every person is, to some degree, reliant on other people or systems in order to survive, and yet late capitalism idealises self-sufficiency (e.g meritocracy, the self-made success, pulling oneself up by the bootstraps.) In these terms, the disabled person has failed. We need help to take care of ourselves, and we do not have the excess energy to be constantly producing. In our society, wellness is the default state, sickness is framed as only temporary, and so the chronically ill outstay their welcome in the already unwanted realm of care. The notion that we are a burden to society is repeatedly drilled into us, and so the intense shame of needing assistance continues. We strive to become the mythical 'good disabled person', the paragon of inspiration who achieved so much despite their struggle, and kept a smile on their face the whole time. This is the only image of disability that the able bodied are truly comfortable with: one that they can mould into their own narrative without having to face the rough-edged, inconvenient reality.

Yet what Hedva advocates is a radical acceptance of vulnerability. That in caring for each other and for ourselves, without motive of monetary compensation, we challenge capitalism in an infinitely powerful way. If every person is defined by our ability to be vulnerable, then by crushing this vulnerability we suppress the thing that ties us together. To be disabled is to be thrown into the deep end of vulnerability; it is intensely frightening and yet radically freeing. To be forced out of the comfort of self-reliance in this way forces one to place their trust in other people, to embrace limitations and to radically love a body which is (for want of a better word) failing, which can only lead to a deeper understanding of others. To move past the inhumane conditions of capitalism, a counter-culture of care must be fostered, and so this is the research I am undertaking by surviving as a sick woman: how can we care more deeply for ourselves and for each other?