

# Wounds Need Air

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“A wound gives off its own light  
surgeons say.  
If all the lamps in the house were turned out  
you could dress this wound  
by what shines from it.”<sup>1</sup>

Anne Carson  
*The Beauty of the Husband*

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## Abstract

A personal essay in the first-person voice describes the artist's lived experience navigating the American medical industrial complex with multiple misdiagnosed chronic pain disorders. The artist's personal story spans thirty years and is contextualized by illness, gender, race, age, ability, class, and is grounded in the artistic expression of self. Descriptions of mental illness, physical disability, and access to proper healthcare are weaved into an examination of embodied knowledge.

## Introduction

The night was getting lighter, and the sun was about to rise from the horizon. I was startled awake, yet unable to move, unable to breathe. My body was so heavy I thought I would sink through the mattress. The next thing I remember, I'm in my parents' room on my Mom's side of the bed, the left side, the side furthest away from the door. I lay my hand on her shoulder and gently shook. When her eye's opened, I said, "Mom? I'm in so much pain. My chest hurts so bad." Not to wake my Dad, she walked me back to the hallway and said, "show me where it hurts."

I was fifteen when the pain came silently in the night, but now that we've gotten to know one another, it was here long before. It wasn't just one accident or disease but a series of disorders that went undiagnosed and untreated. I appear as a tall, white, thin, able-bodied, cis-gendered, straight woman with light hair and light eyes, the epitome of the Western ideals of health and femininity. I have grown up in a privileged upper-middle-class family with access to private health insurance and a plethora of doctors in the health mecca of Boston, Massachusetts. Often I am dismissed with "*You're too young and too pretty to be so sick*" and "*you need to take a mental health day.*"

I have always marked the start of my medical journey by that night when the pain first came, but now I am not sure why. As a child, I was always sick. By the time I was in 4th grade, I was diagnosed with separate cases of Lyme disease and pneumonia. Once I had graduated high school, I was diagnosed with another case of Lyme disease, severe mononucleosis, clinical depression, a panic disorder, chronic fatigue syndrome (ME/CFS), insomnia, attention deficit hyperactivity disorder (ADHD), and an undiagnosed chronic pain disorder. This, of course, does not include my "normal" menstrual cycle, which causes me to have migraine attacks, cystic acne, heavy bleeding, severe cramps, lower back pain, pelvic pain, and fainting episodes.

Test after test, scan after scan, specialist after specialist, prescription after prescription, everything "unremarkable," "normal," or "negative." The number of times doctors told me that the pain was all in my head is more than I care to remember. However, it worked. I started to believe them. I was doing this to myself, lying to myself, purposely causing myself pain to seek attention. My body was betraying me. Or was it my mind? This started the vicious cycle of trying to determine the truth. I folded into silence. This is where I suffered. This is where I existed. The grueling

self-doubt returned at many stages over the next fifteen years. Everytime I share my pain, friends back away and abandon me as if my suffering is contagious.

My disabled body is not a fixed state but a fluid condition of being. My felt experience and traumas are the result of abuse and neglect from within the medical industrial-complex. Today, doctor's bedside rhetoric is filled with modern terms for hysteria to gaslight and inflict gendered medical abuse. This form of medical trauma is endemic amongst millions of women globally. Our suffering's disbelief is drowned out by the Western ideals of whiteness, beauty, femininity, ability, and health. Corporations monetize chronically ill and disabled bodies while forgetting we are people first and patients second. We continue to suffer as wealth and data accrues off of our *different* bodies and the system continues to fail those who need it most.

When the medical system failed to name my diseases, I fell into photography. My artistic practice developed alongside the pain. While words failed to communicate my suffering, I trusted the visual language to build an image of my pain and its many facets. Photography propelled me forward and urged an empathic honesty with my vulnerabilities. It allowed me the space to slow down, assess my energies, desires, and willingness to achieve.

This turn to photography, in fact, began at a young age when I saw an underwater photography exhibition and became fascinated by what could be illuminated at such great depths. In this instance I saw the potential to provide an alternate perspective beyond surface level perception. The fluidness of the photographic medium helped me bring light while digging for diagnoses. It is only through the expression of my isolation using photography that I have been able to make connections within myself. My self-revelatory<sup>2</sup> practice is always on the emotional edge, a form of therapy, a form of art, and a profound journey inward. By taking off my mask and no longer acting *healthy* I bring to light my authentic self in an alternate performance.

*Wounds Need Air* is a testimony of my lived experience of being silenced and disregarded as a woman in pain. Undertaking the documentation of this inquiry as performance required the articulation of various qualities of attention across text and image. As I push the boundaries of what a photograph can be I also explore the limits of language. Still-images, video, sculptures, and installations work alongside moments of memoir, medical data, as well as the work of historical and contemporary artists whose practices address embodied knowledge. These different forms create multiple access points of deciphering and discernment crafted from digital, analog, and antique photographic processes as a gesture of reclamation of my voice and lost time.<sup>3</sup>

## Someone Once Told Me You Can See Yourself Clearest in the Dark

It didn't take long for the depression to settle in. Depression, a diagnosis upon which western medicine saw quickly and moved swiftly. I thank them for that, but more so I thank my mother for recognizing my descent into self-destruction and my therapists for listening. I have been on antidepressants since I was sixteen. The same medication, Cymbalta, my dose has since doubled to the maximum dosage. Withdrawals now come within hours of missing my medication to bring brain zaps, a sensation of falling and spinning to then be zapped awake, with unwavering nausea and headaches. The chemical imbalance in my brain creates a full-body reaction fracturing my identity. The light begins to rupture and turns into a shadow. Depression and anxiety cast a large shadow over my other symptoms. The only diagnoses in my medical file and I'm written off before I even open my mouth. The full-body reactions of mental illness are comparable to that of physical illness. After all your brain is an organ inside your body. Chemical imbalances in the brain cause mental illness--maybe when the doctor says "it's all in your head" they aren't entirely wrong but it is the centuries of racism and sexism that oozes over their oppressive disbelieving catchphrase.

Swiss psychologist, philosopher, and founder of analytical psychology, Carl Jung (1875-1961) gave a generous interview in a 1959, black and white episode of, *Face to Face*. Jung had an intimate conversation with BBC journalist and show host, John Freeman, and halfway through the interview, Jung reflects on the time when he published his book *Psychology of the Unconscious*, in 1912. It coincided with his clinical work with schizophrenic patients. He had a theory of a collective unconscious, historical conditions with which all humans are born. Jung, a white man, goes on to reflect on a particular patient, a Black patient he treated at a clinic in Washington state:

"He was quiet but completely dissociated, schizophrenic...  
One day I came in and he pulled me to the window and says;  
*'ok now, now you will see,*  
*now look at it look up at the sun and see how it moves*  
*you move your heads like this (swaying from left to right)*  
*and then you will see the funnels of the sun*  
*and you know that's right*  
*the origin of the wind,*

*and you see how the sun moves  
as you move your head from one side to the other..”*

His disbelief of a schizophrenic Black man is evident. He goes on to say: “well, there you are, he’s just crazy.” An individual labeled as crazy generates distrust that those who are mentally ill cannot accurately account for their embodied knowledge. The encounter stayed with Jung, and four years he came across a book by the German philologist, Albrecht Dieterich, a 1903 text which translates the Great Magical Papyrus of Paris, an ancient text, which reads;

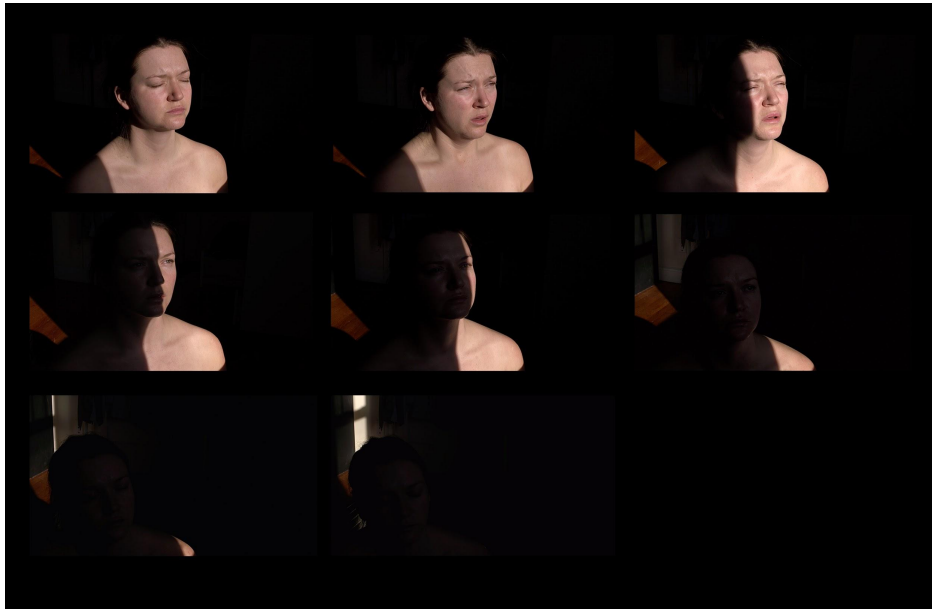
‘Thou will see how the disc of the sun unfolds,  
and hanging down from this the moving down of the wind,  
and when you move your face to the east it will follow you,  
and to the west it will follow you.’<sup>4</sup>

An ancient Egyptian text corroborated a Black man’s perceivably unreliable testimony. A text important enough to be translated, interpreted, and published by a white linguist was enough to convince Jung to publish his theory; the only real danger is the human self. We are pitifully unaware of it. We are the origin of all evil.

There is a light and dark side to each of us, with the light being the most visible. Light exposes our outward persona, our mask, our ego. Which represents our conscious mind, the thoughts, emotions, and memories we are aware of. The ego is responsible for our identity. A person’s physical appearance is the most apparent. The color of our hair, the clothes we choose to wear, our race, our apparent sex<sup>5</sup>. Just like the shadow moving across my face in *Show Me Where It Hurts*, there is another side of the self--a side that often gets pushed deeper and deeper into the darkness. Jung theorized about the shadow or the shadow self early on in his extensive career. He believed that the unacknowledged parts of ourselves are hidden and live in the shadow of the self.<sup>6</sup> The shadow represents the unconscious and the subconscious mind where we contain repressed memories and impulses the conscious mind is not aware of. Fear, grief, disgust, remorse, anger, guilt, and shame thrive in the dark. Jung states the importance of facing your own shadow as an essential part of therapy as it is the root of all our problems. Becoming familiar with your shadow allows you to become more embodied, more in touch with your needs, become more whole and encourage closeness and true intimacy. The externalization of the shadow is through a projection of self onto another. Essentially, critiquing and dissecting the phenomenon that what we dislike most about other people represents something that we dislike within yourselves (Freeman).



These connections corroborated my inclination to orient my sight in a performance of crossing the threshold into my shadow self. Understanding the force of my dark side and digging at the roots of my depression. As a photographer and visual artist, my eyes and light are my greatest assets. The camera is designed to emulate the eye—the aperture like the pupil and the shutter, like a blink. The cones and rods are the film, and our brains are the final print. The route of the word photograph breaks down into two parts; *photo* meaning light and *graphein* meaning to draw. Every decision we make as photographers is based on the source of light and life: the sun. There are many things that doctors advise against when it comes to human interaction with the sun. Sunburn, wrinkles, and cancer are among the top. To protect my eyes, doctors have told me to never stare directly into the sun, but they have never advised against sitting and meditating. The sun also has incredible healing powers. The heat can warm a cold body. Its light brings growth. I set out to sit and gamble with my greatest assets. I would stare into the sun for however long it took until my body was consumed by shadow and document the process through moving image.



*Show Me Where It Hurts*, 2020, stills from single-channel HD video performance (projected), 52 minutes.

The pain of the harsh sunlight was immediate but knowable. There have been plenty of mornings where the sun has been glaring off the snow and ice in front of me, mornings when I've woken from a deep slumber to the kiss of light. The tears came, but they were far from helpful. The water refracted the light and created seven suns. I had only intended on one.

During the performance, I could feel a shadow line on my skin. I could feel the difference between the heat of the light and the cool relief of the shadow. I didn't know how long I would be sitting there or how much time had already passed. Once the shadow passed over my right eye, the searing pain through my retinas dissipated and gave fire to my body. My back muscles began to cramp, my legs were tingling, and my butt was numb. I tried to adjust my posture, make sure I was sitting upright and balanced. My body was collapsing under the earth's gravitational pressure. My spine could no longer support me. I slowly slumped and recoiled away from the light. Yoko, my service dog, barks as I lose feeling in my legs. She's alerting me my blood pressure is low, and I'm close to fainting. It works, and I'm startled with adrenaline. This is where I waited. This was the longest part of the performance--the waiting, the enduring, the maintaining. I wish that the searing pain of the sun would come back. At least I'd be warm. I would open my eyes and search for the sun, but all I could find was my breath. I settled into a rhythm of shallow breathing, waiting for the darkness to welcome me home.

Installed within a white room, the only light source comes from a projector pointed at a white sheet hanging in the middle of the room, hovering just above the floor. There are chairs and seats and pillows on both sides of the six-foot projected image. Over two speakers, you can hear my breath, sometimes deep and forceful, sometimes a shallow whisper. The performance is a meditation on pain, on suffering. I ask the audience to sit in front of my large bust, look away as my whiteness blinds you, and sigh with relief when a cloud shades me. The almost hour-long durational video recording creates a space for pain to be seen, to be shared, monumentalizing my pain. The audience may question my masochistic treatment of self, and sometimes I suspect it too. The validation of external sources seeing and acknowledging my pain pleases me. I did consciously put myself in a position of suffering to show my image of despair. To put my suffering on a stage, perform my pain, in direct opposition to my daily life of acting healthy. My illnesses are seemingly invisible because most of them happen in private, in my home, or hidden behind my fake smile. People will see the beautiful woman hiking with her dog one day, but you won't see the next day or the day after that, where I can barely walk, and I'm confined to my bed. Much of a chronically ill person's life is waiting, waiting to see the next specialist, waiting for tests, waiting for results, waiting in waiting rooms, waiting for prescriptions, waiting to come back in three months. At first, it was my experience as a chronically ill person but now I identify as a chronically ill and disabled person inspired the making of this piece. Waiting through the

pain. It is the waiting that requires endurance. Time spent waiting can drastically change the perception of seconds passed, minutes can feel like hours, hours can feel like days, days feel like weeks but then there are weeks that disappear and years that only feel like fleeting moments. Time is wide, and it is long. Moments can be suspended in the vast subconscious. Sometimes, I think, if I could just float, all my pain would wash away. Many days I carry a weight that is anchored in the dense darkness of the Earth beneath me. I know my diseases will not kill me, they have become my life. Jung says, “To shrink away from death is to evade life.”



From the onset of symptoms, it took me four years to be diagnosed with Crohn’s Disease,<sup>7</sup> ten years to be diagnosed with fibromyalgia,<sup>8</sup> fourteen years to be diagnosed with endometriosis,<sup>9</sup> and fifteen years to be diagnosed with Ehlers-Danlos syndrome.<sup>10</sup> There is no cure for these diseases. At nearly thirty years of age, half of my life has been spent in pain. I entered high school as a two season varsity athlete but as we all eventually come to know, a lot can change in a year. My life became dark, isolated, and secretive. I fell in and out of a toxic relationship and if I wasn’t sacrificing my own pride or cycling through self destructive tendencies, I felt alone. In a desperate attempt to feel desired, I followed my ex to Amherst, Massachusetts. He was teaching an after-school program at a middle school during our winter break. I hoped this two week stay would mend our relationship but what is fixed will always be broken. Like so many times before, I was left to fill my time, just me and my shadow.

January in Western Massachusetts is gray, wet, and raw. I followed a dirt road, parked my silver Toyota 4runner at the trailhead named after Emily Dickinson. I look back now on Google Maps, the trail is less than a mile long, following the run of the Fort River. Time took on a different form, it began to stretch, when I was with Emily on her trail. A walk that normally would have taken me ten minutes became hours of inspection and listening.

With an upbringing in Massachusetts, Dickinson’s poems had made their way into my education but in my self-obsessed teenage state-of-mind I could only recall a modern-feminist poet and a person who lived in solitude. Only ten poems were published during her lifetime, all anonymous. She was focused more on her craft rather than having her poems be read. The little that is known about her work, there is an emphasis on her decisions to relate her work to her body. From 1858 until roughly 1864, Emily Dickinson gathered her poems into forty homemade books, known as “fascicles”,<sup>11</sup> individually self-published installments of a larger book of her written work. An

alternate definition of *fascicle* as a noun is a small or slender bundle of nerve fibers. If you continue to scroll on the Merriam-Webster website, the dictionary has a *Did You Know?* Section and as I read the following I can't help but ask, *Did Emily know?*

In book publishing, "fascicle" and its variants "fascicule" and "fasciculus" can all be used for one of the installments of a voluminous work; "fasciculus" can also be used for a bundle of anatomical fibers. "Fasciitis" is an inflammation of a "fascia," which is a sheet of tissue connecting muscles. You can also have a case of "fasciculation," or muscular twitching.<sup>12</sup>

Her fascicles were pieces of paper, folded in half, and hastily bound with red and white thread. A life that remained much of a mystery until her sister Lavinia published many of her poems after her death in 1866. "...Hundreds more poems in various states of composition, plus intriguingly, the "scraps," a cache of lines that Dickinson wrote on scavenged paper: the flap of a manila envelope, the backs of letters, chocolate wrappers, bits of newspaper" (Chiasson). Dickinson couldn't contain her ideas, her thoughts, or her words. I understand the urgency in which she worked the more I learn about her confrontations with illness. As biographer, Lyndall Gordon argues that from a brief glance, her life did seem almost invisible but "...there's a forceful, even overwhelming character belied by her still surface. She called it a "still – Volcano – Life", and that volcano rumbles beneath the domestic surface of her poetry and a thousand letters".<sup>13</sup> Dickinson spoke through her work, always consciously but ever so subtly, like leaving little bread crumbs in her poems to hint that sickness was always there. A process of prolonged decay-the structures of the body decomposing-and it eventually becomes a pattern of the body falling and the violence of sickness. Gordon paints together a potential diagnosis of epilepsy, grand mal seizures:

Since the falling sickness, as epilepsy used to be known, had shaming associations with "hysteria", masturbation, syphilis and impairment of the intellect leading to "epileptic insanity", it was unnameable, particularly when it struck a woman. In the case of men secrecy was less strict, and fame in a few – Caesar, Muhammad, Dostoevsky – overrode the stigma, but a woman had to bury herself in a lifelong silence. If this guess is right, it's remarkable that Dickinson developed a voice from within that silence, one with a volcanic power to bide its time. (Gordon)

Her seizures may have been seen or observed by a physician and Gordon goes on to talk about other family members suffering from a similar condition. This diagnosis is only speculative from a biographer studying Dickinson's life but it is not so far-fetched to think that even in 2010 when

Gordon published her article for *The Guardian*, she would be able to look through a broad lens and notice patterns and traces that Emily left behind, and make an informed guess. I knew most of my diagnoses even before it had been confirmed by a doctor due to the immediacy of information on the internet. To reframe Dickinson's work within the context of chronic illness brings an opportunity for new interpretations. Born into the most prominent family in Amherst, Emily Dickinson was given a privileged life with what appeared to be the gift of time and solitude. Her life turned insular and private when her illness was uncontrollable. Silenced, or so they thought.

We grow accustomed to the Dark -  
When Light is put away -  
As when the Neighbor hold the Lamp  
To witness her Good bye -

A Moment - We Uncertain step  
For newness of the night -  
Then - fit our Vision to the Dark -  
And meet the Road - erect -

And so of larger - Darkness -  
Those Evenings of the Brain -  
When not a Moon disclose a sign -  
Or Star - come out - within-

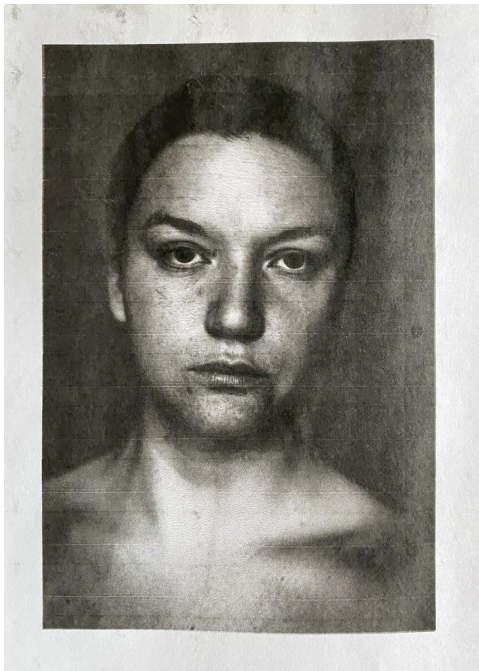
The Bravest - grope a little -  
And sometimes hit a Tree  
Directly in the Forehead -  
But as they learn to see -

Either the Darkness alters -  
Or something in the sight  
Adjusts itself to Midnight -  
And Life steps almost straight.<sup>14</sup>

Emily Dickinson  
*We grow accustomed to the Dark*

*We* are the beginning of the poem, a collective *we*, a *we* that is understood as a basis for universal comparison. It is commonly understood that growth does not happen in the dark, and that life comes

from light. In the first line Dickinson quickly tells us that “the Dark” is a place of significance, a singular site that is devoid of light. The light being held by the Neighbor contains a warmth of friendship and companionship, but as soon as *we* set off on our own journey into Darkness, we are paradoxically alone. At first, the contrasting cool Darkness is total oblivion, darker than expected, the unknown of a new environment creates a natural fight or flight response. But the body adapts. The pupils dilate and what was once obscured by darkness *we* can see “the Road”, a common symbol for life itself. The third stanza, “And so of larger - Darkness -” shifts us to a less literal and more symbolic understanding of Darkness to a psychological site of mental illness. There is no guiding light in the depths of this disorienting Darkness. In the hard or difficult times in life, Dickinson suggests leaning into the Darkness blindly. The “Bravest” will be met with hasty and clumsy setbacks, but human courage and resilience will persevere and prove that facing our pain and trauma will aid in our ability to see clearly in the unknown. By leaning into the Darkness eventually something concedes whether it is our body, my body, or Emily Dickinson’s body, something or someone adapts and we can see in the metaphorical midnight, typically the darkest time of the night. In the end it is only the individual that can navigate the Darkness.



*Diagnosis (self-portrait), 2020, grayscale print, 4”x 6”*



*Emily Dickinson by William C. North (1846 or 1847)*

For many temporarily able bodied people, the Covid-19 pandemic, quarantine, and the country/world shut down was their first altercation with illness dictating the course of their life longer than 3-5

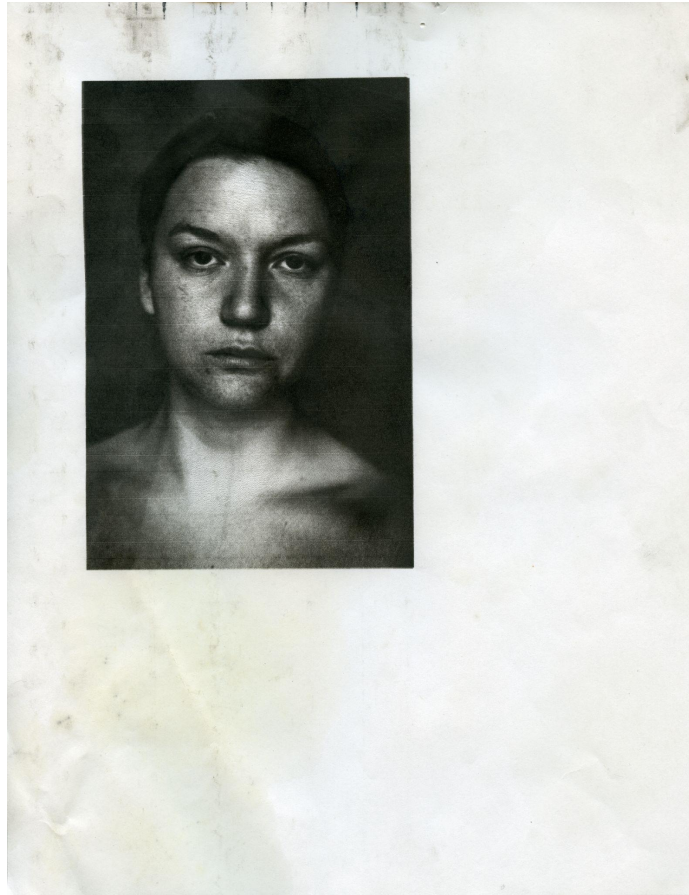
days. For a moment I felt like I had more in common with the general population than ever before. The orders to stay home turned my practice into a resourceful ‘use what you have and make it work’ mentality. My digital camera, although heavy and cumbersome to me now, had witnessed, documented, and recorded much of the last six years. Self-portraiture is a form of expression I continue to return to, a desire to see myself, a desire to share myself. In *Seeing Ourselves: Women’s Self-Portraits*, Frances Borzello states that women’s self-portraits are not reflections of what I look like but rather what I believe in.<sup>15</sup> As an oppressed demographic, women are scrutinized so that a self-portrait by a male artist isn’t. An artist who identifies as anything other than a cisgender, white male has to think considerably harder about their self-presentation. To produce self-portraits forced a reconciliation between what society expects of women and what is expected of artists (Borzello, 35).

So why did so many women artists present themselves in a subdued manner? Perhaps it is holding a pose for the medium or the male-dominated field of art that selectively filtered out their unwanted representations of women’s authentic self. Emily’s portrait made by William North was made in the early conception of photography. Remaining still was essential to getting a clear photograph. Exposure times ranged from seconds to full minutes and holding a smile would cause strain and movement of the subject. Women of privileged families had to maintain poise and grace. Stillness, as witnessed in *Diagnosis (self-portrait)* and Emily’s portrait above can be interpreted as a form of control. The ill body is full of moments of uncertainty, fear and anxiety. Preserving energy and managing stress creates a lifestyle of alterness. The only thing certain when managing chronic illnesses is unpredictability and all you crave is control.

In front of my bedroom window I stared down the lens of my camera, relaxed my gaze and saw past the immediate. I felt my eyes unfocus and through the blur, I reached out to the shutter, my arm stretched out twenty-seven inches, the red light flashed and the auto-focus was locked. The shutter created a rhythm and I was lulled by its mechanical function. Everything was increasingly more digital and what was once the cornerstone of my practice was too immediate. I desired to touch and embrace objects. The closest thing I had to a photo printer was my Canon PIXMA iP2600 that had an almost empty black ink cartridge left. I had regular old computer paper and straight from my preview application I pressed `cmd+p`, print. Like Emily Dickinson, I felt the immediacy to express myself and I grabbed whatever piece of paper was closest to scribble down my ideas.

In the first print, I appeared as a ghost. My skin was literally paper white. I decided to feed it through again, and then again, and again, and again, printing myself on top of myself copy after copy. After the fifth print, the catchlights that once illuminated my eyes had disappeared and fallen into the darkness of the back ink. My patient files at the offices and hospitals don’t show me. My

name and my birthdate have been typed, printed, confirmed in my medical file more than any image of me. Years of images and data have accrued as evidence, yet the inner workings of my body rarely show my pain and resist to show my face.



*Diagnosis (self-portrait)*, 2020, printed 2021, grayscale inkjet print, 11"x8.5"

A six-inch by four-inch image is positioned in the top left corner of a standard sheet of printer paper. The original grayscale print is non-archival because the paper is too acidic. Meaning, over time the image will change depending on environmental conditions. Re-scanned a year later you can see what I mean. My hair is barely distinguishable from the background. My skin appears to show years of sun damage. The once white printer paper, shows ink stains from the rollers next to yellow oil stains from my careless organization system. This print has sat in a stack on a desk and filed away with other experiments. When I realized the significance of what this image meant to me, I pinned it up on my studio wall with just one clear thumbtack slightly off center. I was forced to reconcile with



my own gaze watching me. When I made the first print, by feeding the paper and the printer would layer ink, I printed the image five times on top of itself. At the time it felt like an accurate representation of the exhaustive measures gone to create an image of pain in search for a diagnosis. A year later, and even though the print has changed, it continues to feel like an accurate representation of my odyssey. As I shed more light on my experiences past and present the print continues to darken over time. My embrace of the darker aspects of my life, both physical and psychological are apparent in my confrontational gaze.

## A Letter to Elaine Scarry, Author of *The Body in Pain*

Dear Elaine,

I have been reading your book *The Body in Pain*, and while much of your argument is applied to the macro view of the world, I have been applying it to an individual, personal, and micro experience in comparison.

When I tell people about my chronic pain syndromes, they immediately distance themselves, as if my pain is contagious. They move away as I am trying to get closer; who wants to exist inside another person's suffering? They apologize for my life experience as if they had caused the pain but they have only further denied my accessibility through normalcy. I often reply with "oh, it's ok." But you know what? It's not ok.

We all experience pain, which is what makes it appear to be a universal experience. Our lived experiences, past interactions, and unique biology make pain an individual and subjective experience. Your introduction articulates this so well by comparing the body in pain to the body not in pain. How can the body, not in pain, know, understand, comprehend, confirm, believe, or recognize a thing that cannot be seen? It is not only ignored but also not recognized.

Words have failed me in communicating my pain. The lack of language around pain prolonged the process of naming my diseases. How do you explain the ineffable? Lack of language around pain leaves room for doubt, for other's to determine, control, and manipulate. You state: "Physical pain does not simply resist language but actively destroys it..."<sup>16</sup> If pain is too powerful for words, across many languages, the body in pain must be proved. According to your introduction essay, physical pain accesses a state of consciousness unlike any other because pain resists objectification. It just simply is. That is why there are no other words for pain (Scarry 7-8). There are only descriptors--attempts at translation--which are just objects that inflict pain.

Physical pain not only makes the physical world inaccessible but also makes language inexpressible. If a doctor cannot diagnose the cause of a person's pain, the pain does not have a name. I wished for so long to call it something else but the only word that was accessible to me was pain. I turned to my artistic practice of photography to convey a visual experience. However, it wasn't until recently that I concluded that the most advanced diagnostic imaging has also failed me.

Photography has failed me. Images are unable to see the microscopic tissues, lesions, inflammation, and misfiring nerve synapses that cause my agony.

In a study published by the *Journal of General Internal Medicine*, on average, doctors only listen to their patients for eleven seconds before interrupting, not to be an empathetic listener but to be searching for the definitive account, something tangible in an abstract concept.<sup>17</sup> To bring it to back to a macro level of pain, torture is used wildly among our government for access to information. Intelligence gathered from a person being subjected to intentional persecution is unreliable. If language cannot define pain and if images cannot show pain, how does a patient communicate their experience to a doctor that already isn't listening and doesn't believe their personal truth, to put their faith in a medical industry that is doing nothing else but torturing individuals who are seeking relief?

Sincerely,  
Camilla

## I Tried So Hard To Keep It All Together

I am a patient patient. I have waited in different iterations of the same room with the same wholesale factory rug, the upholstered chairs with the wooden, pine-stained armrests, covered in at least 10 coats of glossy polyurethane. To then be brought to another different but the same exam room, to wait cold and sterile.

“Your name?” the nurse asks.

They don’t even have to phrase it in the form of a question.  
They know, I know the routine. They know this isn't my first rodeo.

“Camilla Jerome” I replied.

“Date of birth?” she asks.

“11/15/91”.

The next question they always regret asking:  
“What brings you here to see Dr. \_\_\_\_\_ today?”

My answer varies in different forms of:

“I have multiple chronic pain conditions and so I’m never quite sure if a new pain is *normal* or if it is some cause for concern. So, I’ve had this \*insert one or more pain descriptors\* pain in my \*insert body part\* for \*insert estimated amount of time\*. I am sure it's nothing but it's better to be safe than sorry.” The answer is always along the lines of being in pain, a new or different pain, a pain that moved, a pain that changed. They feel bad for me and we make small talk. I default into making them feel better about my suffering, and not about the lack of providing me with proper care, nor helping me find answers.

The nurse takes my vitals; pulse, temperature, blood pressure, respiration rate. All normal if not vitals of an athlete. They are surprised when I tell them I don’t work out because of the pain. I think to myself, *shouldn't this be concerning? But, maybe my daily life is enough exercise, maybe my panic attacks, not eating during the day, and then binge eating at night are actually good for me. I roll my eyes at myself. Don't be stupid, Camil-*

The nurse interrupts my negative self talk and asks me my favorite question; “On a scale of one to ten, ten being the worst pain you’ve ever experienced, emergency room level of pain, and one being no pain, how much pain are you in today?”

An average day is somewhere between a six and an eight. I always round up in hopes they take me more seriously.

The nurse prepares the instruments for the doctor. Depending what office I am visiting there will be big swabs, little swabs, tweezers, forceps, speculum, injections, ultrasound. I am handed the same but different hospital gown and tell me to undress, remove my bra and underwear, and keep the opening in the back. Sometimes I am alone, but not always. It depends on whether I'm getting news or instructions. I sit naked in a thin cotton gown, a gown that has been worn by those before me, for so many people this gown has been the only barrier and the only protection between them and their abuser. How many bodies has this gown shielded? How is a gown designed for access supposed to make me feel safe? I twist and tuck the gown under and between my legs, hoping my butt is covered. I feel like the collar is choking me. I'm in a cold sweat, I'm always sweating and now the thin sanitary paper is sticking to my butt and it rips and it's shredded and now there's nothing between my skin and the plastic exam table. How many people have sat..... A knock. The door creaks open. I perk up and prepare my elevator pitch.

I once heard that those who identify as male rate their pain score at an average of eleven whereas women would choose between a six and an eight for the same type of pain. I have been unable to corroborate this claim and I have stated that I believe pain is an entirely subjective experience. I have also heard medical school educational texts use him/his pronouns are used when describing physical ailments whereas she/her pronouns are used for discussing mental illness. I have not been able to confirm this in my research. I do know that over our lifetimes, women experience more pain than men and that perception of pain differs between male and female. However, I have been able to confirm that women are thirty percent more likely to be misdiagnosed, undiagnosed, or dismissed for their chronic pain. Eighteen-percent of women have experienced sexism and misogyny while seeking medical care. Those horrific numbers double and sometimes even triple for Black women and women of color.<sup>18</sup> More than half of medical school students still believe that Black people feel less pain and that dark skin is thicker than that of lighter or white skinned people.

Western structures of knowledge are cemented in the white, cis-gendered male body perspective, making claims and discoveries based on evidence on data. Technology was supposed to revolutionize the medical industry, allowing doctors to noninvasively look inside ‘the body.’ “The

body” is overused and rarely defined. It is a term that needs to be used with specificity and inclusion. Artist and educator, Gordon Hall, argues against the standardized use of the ‘the body’:

The first and what seems to me the most obvious objection to this term is that it generalizes across bodily differences. Insofar as it does not refer to a plurality, it creates one body as a stand-in for all of us. Depending on the specifics of where this term is used, this singular body is usually one that walks, is of a standard vertical adult height, and that sees and hears and senses in “normal” ways. This body is not in a wheelchair, not deaf, not blind, not autistic, not ill, not high, not any of the other endless ways that our bodies and senses deviate from a normalizing standard. In other words, “the body of the viewer” is almost always a non-disabled and typical body, as close as possible to a normative ideal body, in other words, a body that is arguably a non-existent fantasy. The term “the body” disregards the full range of bodily differences in favor of prioritizing typicality, standardization, and predictability. In so doing, it aspires toward an inaccessible world, designed for the typical and disregarding the different.<sup>19</sup>

The normalization of the term ‘the body’ is due to the way in which we are taught to view various bodies and our lack of desire to accommodate an array of bodies on a societal level. Hall states that by minimizing the multitude and unique biological makeup of each of our bodies renders western culture as inaccessible. They advocate for inclusivity as the way we define our own bodies and identities are constantly in flux, rarely static, and completely subjective. The unpredictability of life has been consciously cast aside. Standardizing bodies across gender, sexuality, ability, religion, or race will always hold an individual that identifies the closest to “normal” as the most important and most desirable.



I was in a photographic rut. When holding the camera, I felt like I was making pictures that I had made a thousand times before. This was incredibly stressful during my first year in grad school at the Rhode Island School of Design (RISD). I had gone to see artist Liz Deschenes give a lecture at Brown University. She told a story about a collector who had bought a piece of hers and later wanted to return it because it no longer looked the same as when they had bought it. She was kind and took the piece back and offered them something else of hers in exchange. But she laughed and explained that the collector had missed the point about her work entirely and that change is at the center of all her work. “A conservator’s nightmare” she joked.

Deschenes is a contemporary artist who makes site-specific and minimalist installations with her photograms. Using traditional photographic processes and chemicals she creates cameraless images that become sculptures. During her mid-career survey at the Institute of Contemporary Art (ICA) Boston in 2016, one gallery would demand attention through the purest saturations of color and then the next gallery, you might walk right past her work if you aren't looking closely. Deschenes pushes the limits of the medium, embraces its fluidity and the chance for happy accidents. She gives agency to the viewer allowing them to view the photograph from multiple angles--in front, inbetween, and behind. Each person's movement is a little different just like the spacing between the life-size, cool-toned photograms seen below.



Liz Deschenes, *Installation View*, Institute of Contemporary Art, Boston, 2016.  
Photo by Charles Mayer Photography.

A carefully crafted meditation on the photograph and on photography as a medium, Deschenes, challenges what viewing a photograph means. What makes a photograph a Photograph? I believe that if there is a recording of light or a surface is affected by light there is a process of photography happening. Some of Deschenes work like *Timelines*, was installed in a gallery that looks out over Boston harbor at the ICA.



Liz Deschenes, *Timelines*, Installation view, Institute of Contemporary Art, Boston, 2016, Photo by John Kennard.

Built into the architecture with a backdrop of a grand ocean landscape, Deschenes installed curved, narrow, and vertical photograms. The combination of traditional black and white chemistry mixed with ammonium hydroxide brings out the silver and creates the appearance of a mirror.<sup>20</sup> Often a distorted reflection mimics the viewer but the concave photogram simulates the ripples and currents of the waves behind it, playing with the viewer's perception.





*Sterile*, 2020, inkjet print hand washed in bleach, 30" x 20".

A few months after Liz Deschenes lecture, it was my second semester of grad school when the Covid-19 Pandemic hit. With the quarantine classes were moved online and my first solo exhibition for my series *Anhedonia* was put on hold, indefinitely. I had all my final prints at home with me because they never made it to the framer. I had critique the next day and nothing to show. I was in a frustrated rage at 7am on a Sunday pacing around my one bedroom apartment while my partner slept. Bleach was nowhere to be found online or in stores but we had about half a gallon of bleach left under the sink. Print after print went into the tub and I would pour a quarter of a cup of bleach onto the face of the image. The time soaking in bleach varied because I couldn't see what the bleach had done until I began to wash the ink away with soap and water. The process was freeing and exhilarating. The unknown end result during such a mundane time felt familiar. *Sterile* was the only piece that I deemed successful because like the confinement of quarantine, my lifestyle of isolation negates the appearance of my existence. It's a struggle to be seen and in the final print I am erasing

myself. Maybe a past self that doesn't feel familiar, but I am still there, I am still here no matter how much of myself has changed. Now I have this print, this unique object that lives, the emulsion slowly flakes, the ink slowly fades.



It was June, and I was teaching in Berlin. The sweat rolled down my back and between my breasts, my hair was wet and slicked back, and I was beginning to chafe between my legs as I walked. There were few places you could go to seek relief and be enveloped in air conditioning. Luckily, the museum, Gropius Bau, was just the place to spend my afternoon. Initially there to see installations by Philip Parreno, I was instead lured upstairs. *Covered in Time and History, The Films of Ana Mendieta* spanned six rooms and twenty-six of her earth-body moving-image performances. Born in 1948 in Cuba, Mendieta draws from her experience as a child in her homeland. The themes of displacement and the inseparable human connection to the Earth fueled her work. At twelve years old, she and 14,000 other unaccompanied Cuban children were relocated to the United States. Between 1960 and 1962, a secret program by The United States, Operation Peter Pan, brought school-aged children, whose parents were targeted by Fidel Castro's regime, to refugee camps and later placed into orphanages across the U.S.<sup>21</sup> Mendieta was placed in an orphanage in Iowa where she later received her BA and MA from the University of Iowa.

A key figure in interdisciplinary practices in post-war art, Mendieta produced installations, drawings, performance, photography, and sculpture. The center of her work is the merging of her skills to create, Earth-body art, a unique and authentic expression of self. Oransky describes her work as:

[*Crossing*] many borders including artistic and time-based disciplines, geographical and political boundaries, and the investigations of history, gender, and culture... At the core of her work we find a sustained and unflinching investigation of what it means to be human.<sup>22</sup>



Ana Mendieta, *Creek*, July 1974, San Felipe Creek, Oaxaca, Mexico, Super-8-Film, color, silent, 3min. 11sec.

The *Siluetas Series* evokes the deep temporalities and elemental energies. Sculpted contours of her body are formed by dirt, rocks, wood, water, and/or fire only to be silently witnessed by a camera and recorded on Super-8 color film. Holes are dug into the sand, twigs are piled up, blood painted on grass. I was drawn to one film in particular, *Creek*, made in July 1974. The camera is positioned above San Felipe Creek in Oaxaca, Mexico looking down at Mendieta, laying on her belly as the water trickles past her. Arms above her head she braces herself to hold her head above the water, away from the camera. The film is silent yet I can hear the water trickle. I can feel my neck begin to tire and my shoulders begin to hurt. This may have been the time where the seed was planted and grew into the idea of my private moving-image performance, *Show Me Where It Hurts*. Both Mendieta and myself create embodied works of art under the conditions of endurance. When we are physically present within our own respective works, we test the limits of ourselves to withstand Earth's elements. Myself, staring into the sun and sitting for too long. Mendieta, laying face down trying to keep her head above water. Two elements that are essential to life and healing, the sun and water.



Ana Mendieta, *Untitled: Silueta Series*, 1976/2001, suite of nine color photographs, framed, 16x20," 20x16"

Materially, Mendieta's work will ultimately disappear. Her Earth-body sculptures made of sand will be blown or washed away, the material will remain on the beach in a new but different form. The use of photography and video create an alternate and permanent representation of her decomposing sculptures.<sup>23</sup>

Mendieta tragically died in 1985 when she fell thirty-four floors from her New York City apartment. Her husband, Carl Andre, who was home at the time she fell, was charged with her death but was later acquitted. The reasonable doubt around her untimely death, was incited by the metaphors of mortality within her work which have been further projected as her death is argued as suicide. Posthumously, Mendieta did not have control in the presentation of her work: "the canonical artist is victimized in absentia, and the compound and mysterious emanations of her work become displaced by a fantasized hindsight premonition."<sup>24</sup> The sensationalism and fetishization around her suspicious death leaves viewers unable to separate it from her work. Gropius Bau may have made a mistake evading and not addressing Mendieta's death but it created a space to witness the artist's transformative use of performance and sculpture and move away from the fetishization around her death to refocus on her life.



I was born in the midwest, in downtown Chicago, mere blocks from Lake Michigan. Fresh water. In the summers, we would drive south, then southeast, east, northeast then north, around the curve of the lake to a small Michigan town called Lakeside. On clear days you could see the city

skyline on the horizon. This is where I learned to swim. This is where I fell in love with water. On hot days I would lay belly down in the shallow water. Watching the fractals of light dance across the sand and illuminate red and gold light off my floating hair. In the winter, waves would be frozen in time like a photograph. I don't think I ever swam in that lake on the Illinois side, only in Michigan. I've come to learn that the Earth does not abide by property lines. I like to think that the water that touched my skin traveled west to the other shore, waiting to wave at me when I returned on my drive by.

On our last day before moving to Massachusetts, my mother and I were the last to leave Lakeside. I was six and spent the day with my brother's friend, Spencer, who was probably about sixteen at the time. I wanted to go for one last swim. It was a warm summer rainstorm, no thunder, no lightning, just rain, and wind. The lake was a misty green; the sand was all churned up by the large crashing waves. And like so many times before, we ran and we dove. We bobbed and we dunked. We floated. I felt the push become a pull. The rise becomes a fall. The coming and now the going.

At many times in my life, I have craved the sweet relief from gravity that only water can bring and the beginning of quarantine was no different. I began making work out of my bathtub. The same tub I rely on to relax and soothe my muscles. In the harsh winter of New England, it is the closest I come to floating. My optimal bath is to infuse the water with a minimum of three cups of Epsom salt, which will seep magnesium into my muscle to help with the pain and cramping. It will draw out impurities to detox the body. I add some bubbles, CBD, eucalyptus, rosemary, and or lavender for added benefits. And then I soak. I wait. At some point, the water will turn cold, I will get fidgety, or I'll just be laying in a half-empty tub clinging onto relief.

My bathwater has become a material for my work during a time when I didn't have access to other bodies of water but was lusting for its comfort. My main goal while soaking in the tub is to achieve partial or temporary relief. The added benefits of an Epsom salt bath are the detoxifying properties by removing heavy metals and dead cells from my body. At the end of the soak, pieces of me float inconspicuously in the water. I dunk a mason jar in and fill it to the brim. I collect the water, I seal it, and write the date and bath ingredients on the lid. It is then stored in a cool and dark location. This water is used to mix the chemicals for cyanotype and film processing.

Water is a major theme throughout all of my artistic interests, as has my fascination with genetics and biological makeup. During my art openings, my father requires the aid of a chair to rest. This chair is a special arrangement often tucked in a corner away from the art. I began to notice the pleasure I once received from going to museums and galleries was waning. Driving to a part of the city, finding a spot to park, paying to park and the longer you stay the more you pay. I hate taking the

subway. So many stairs. Fuck stairs. To then wait, with few to no options for sitting, to stand on a cement platform, to hopefully get a seat but most likely stand inside a moving object. To then have to go walk and stand some more all in search of having an emotional response to art, is too much. My art viewing experiences are replaced with the reminder of fatigue and fighting to keep my body vertical and moving through space.



*Walking Studie on Pavement, 2020, cyanotype, and bathwater on canvas, 72" x 24"*

During a studio visit with Alex Strada, I stated that I needed to sit, she also asked for a chair and met me on my level. I was showing her my first iteration of my walking studies. She brought to my attention my desire to sit, that sitting brought me relief and sitting allowed me to focus. In contrast to the work we were discussing, I immediately thought of my dad, and my heart began to ache. Even though there are fifty years between us we share a similar experience. Neither of us have lost the use of our legs, and despite their persistent effort to demobilize us, we are grateful to be walking. So I walk. I walk so my feet can feel the earth and so that the Earth can feel me. We exchange and share our energy. I think about my weight pressing down into the earth, my body being slightly absorbed with every step. The Earth is blue and green with specks of white, solid but unstable. My disabled body is not a fixed state but a fluid mode of being. I dip my feet into a footbath, filled with cyanotype solution mixed with my bathwater, and walk on a seventy-two inch piece of thick canvas. Canvas too thick to stretch. These walking studies on canvas become a cloud, a river, a wave. It is imagined, it is my weightless body, floating. Can I float? Can I walk on Water? I'm fairly certain I cannot. Instead I walk on pavement, grass, and mud. The solution is initially

yellow, as it fades to green to blue to brown. The rectangle canvas lays in the sun, exposing under the ultraviolet rays. A brief mimicry of the shifting colors of planet Earth.



*I Tried So Hard To Keep It All Together*, 2020, cyanotype, and bathwater on canvas, unraveled by hand, 80" x 30"



*I Tried So Hard To Keep It All Together*, 2020, detail, cyanotype, and bathwater on canvas, unraveled by hand, 80" x 30"

I bring the exposed canvas into my bathtub and I bathe the canvas. Flipping her over again and again, she begins to turn blue. In the installation, *I Tried So Hard To Keep It All Together*, the

featured form is the result of a walking study on mud. The beige tone of the canvas is juxtaposed with not just one shade of blue but varying shades and saturations. For thirty hours I cut, and unraveled her six-foot border. Tedious but satisfying work. The viewer is able to move freely around the installation, three hundred and sixty degrees. Ultimately, the canvas is suspended by the threads I pulled out, hanging by pieces of herself, and latching onto a white frame above. Seamlessly floating the frame is a point of reference for defining normalcy. Accessibility is a key to changing this social frame. In, *Disability as a Fluid State*, Mary Jo Deegan theorizes that “feeling normal” emerges when the social constructs allow people with disabilities to be a part of everyday life. Alienation arises in “the colonization of self” when the acceptance of able-bodied normalcy doesn't change. Everyday interactions for people with disabilities can result in repeated failures while attempting to meet the standard. A new frame for defining the experience of disability by giving up the able-bodied standards to develop a new self.<sup>24</sup> Positioned below the canvas is a white wood enclosure which is home to a large thirty-inch by eighty-inch sheet of mirror. Mimicking a reflecting pool the mirror allows the viewer to see the underside of the canvas. The lights bounce off the mirror and onto the walls. Casting shadows and unlikely forms. At times you may catch glimpses of another viewer's gaze and make eye contact through the reflection. Sometimes you see yourself.



One day I found myself scrolling through @disability\_visibility account on Instagram. A project started by disabled activist and media maker, Alice Wong, to create an online community for disabled media and culture. I was led to a virtual event: Shannon Finnegan in Conversation with Alice Wong. Finnegan is a disabled artist based in New York. In 2018 they started a project, *Do you want us here or not*, a series of furniture pieces and cushions designed for accessibility within the museum. In 2020 a stool, a chaise lounge, or a bench were fabricated on site for a large group exhibition at The Museum of Contemporary Art in Denver. The simple and straightforward structures are painted in painter's tape blue, with a natural birch and poplar wood edged trim, showing the layers of plywood glued together. In white all capital letter handwriting the furniture offers respite. “I NEED A BREAK. REST IF YOU AGREE.” the stool reads. A bench says “THIS EXHIBITION HAS ASKED ME TO STAND FOR TOO LONG. SIT IF YOU AGREE.” Shannon's individual desire to feel welcome and comfortable around art and the art institution expanded into the devotion of expanding art accessibility.





Shannon Finnegan, *Do you want us here or not*, 2018 - present. Baltic birch, poplar wood, plastic laminate, 73.5"L x 27"W x 35.5"H

I wonder why blue is the color of accessibility. Accessible parking and automated door openers are painted bright and blue. Like the sky and the ocean appear to be blue. In the spectrum of colors; red, green and blue, blue light travels the slowest and reaches our eyes last compared to red or green. It travels slowly through water and glass which produces the unmistakable sky blue. Due to its slow speed the light gets absorbed into an object or element and reflects that light back. Finnegan uses blue contrasted with white paint and the yellow tones of wood, hinting to the accessible signage that is scattered around public spaces. Like the signs, Finnegan's benches and stools are reproducible and resist an attachment to an original. Photographs can be turned into multiples both physically and digitally, sent via email in a matter of seconds. Recreated and reprinted as acts of protest and documentation. I ask myself how the unique objects I am making are accessible? I create multiple modes of entry in order to understand our work that needs to be expressed across various forms. Objects and sculptures, using photography as a tool from all its limits, black and white film, color film, contact print cyanotypes, printmaking, color digital, moving image. A reference to an individual body, my body that is constantly in a state of flux. I don't want my body to be accessible to medical

control. I want to be accessible to myself and to others. Finnegans benches give access to certain places and my work creates a space for an accessible self.

## Conclusion

Graduate school had been a goal of mine since undergrad. I met female professors that proved they were not only educators but also partners, mothers, business owners, and artists. I saw my future and ran towards it. I knew that my diseases would persist and would continue to raise their ugly heads. It was almost immediate. The pain grew exponentially, the nausea prevented me from eating, and the hunger fueled my tremors. Remote learning turned out to be a blessing. I don't think I would be completing this degree without the option.

By August of 2020, I had lost thirty pounds in six-weeks and I was desperate for relief. Everything I thought I knew about my menstrual cycle wasn't normal. Painful periods are not normal. After three negative COVID-19 tests, a two week quarantine, one MRI, two CT scans, an EKG, and eight tubes of blood later, I was cleared for laparoscopic excision surgery to remove endometriosis; a disease where similar tissue to the uterine lining grows outside of the uterus. Adhesions of scar tissue glued my internal organs together, causing sores, inflammation, and nerve pain. The pain of my insides being torn apart was medically proven to be true.

I was asked by a professor to make a picture with a four-by-five large format view camera, the task seemed impossible. The labor of setting up the camera alone was exhausting. However, photography allows me to respond to my energy. I had been struck with a fear, a self consciousness, that using a digital camera to make my work somehow made me less of a Photographer or Artist. I decided to push myself and try not to care about the tool I was using, and I never fully stopped photographing over the last two years. A combination of cell phone images, a Canon 5D Mark III, a Fujifilm 6x9, and an Instax mini documented much of my life over the last two years. My cell phone and instax often accompany me into doctors offices and hospitals. The canon is used for posed self-portraits, the fuji to guide my attention to the Earth. The ability to switch between cameras and use whatever had available opened and freed my practice. Selected photographs made over the last two years have been compiled into a vertical, six-by-nine book. The midnight blue silk hardcover book is wrapped in a canvas dust jacket with a single footprint that wraps front to back.



*Wounds Need Air*, 2021, book spreads.

The book is another point of entry into the self. In the last nine months I have received my two biggest diagnoses yet. Endometriosis and Ehlers-Danlos syndrome (EDS), both connective tissue disorders that cause abnormal tissue production within the body. Neither disease can be seen through diagnostic imaging. More often than not people with these conditions are mis- or un-diagnosed and only learn the name through meeting diagnostic criteria (i.e. a checklist of related symptoms) and process of elimination. My experience in a game of educated guess and check within the medical system is reflected in my photographic process:

1. Follow my intuition.
2. Experiment.
3. Wait.
4. Document.
5. Share Results.
6. Doubt.
7. Reflect.

It is safe to say that making art is deeply intertwined within my life. I don't just want to make it, I need to. I have the ability to recontextualize my lived experiences and take control of my narrative to reclaim my power. The joy that comes from my artistic practice is a counter balance to the endurance of chronic illness. You cannot heal without answers and maybe healing is the gentle embrace of it all - yourself, your life, and the ground beneath your feet, rising to meet you, as you walk through all of your moments.

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