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scrappycapydistro.info



Sick Woman Theory

Johanna Hedva

In late 2014, I was sick with a chronic condition that can get bad enough to render me, for anywhere from days to weeks to months at a time, unable to walk, drive, do my job, sometimes speak or understand language, take a bath without assistance, and leave the bed. This particular flare in 2014 coincided with the Black Lives Matter protests, which I would have attended unremittingly, had I been able to. At the time, I lived one block away from MacArthur Park in Los Angeles, a predominantly Latinx neighborhood and one colloquially understood to be the place where many immigrants begin their American lives. The park is not surprisingly one of the most active places of protest in the city.

I listened to the sounds of the marches as they drifted up to my window. Attached to the bed, I raised my sick woman fist, in solidarity.

Solidarity is a slippery thing. It's hard to feel in isolation. In bed, in pain, I started to think about the kind of solidarity in which I could participate as someone stuck at home, alone. I started to think about what modes of protest are afforded to sick and disabled people at all.

I thought of the many others who were not at the protest either, who could not go because it was in some way inaccessible to them, all the other invisible bodies, with their fists up, tucked away, out of sight. It seemed to me that many would be the people for whom Black Lives Matter is especially in service. I thought of how they might not be able to be present for the marches because they had to go to work, or because they lived under the threat of being fired from their job if they marched, or because they were literally incarcerated. They might not be able to go to the march because of the threat of violence and police brutality that exists at any protest. They might not be able to go because their bodies were this peculiar convergence of hyper-visible and invisible, marked and unmarked, which instantiated a dangerous vulnerability around them. They might not be able to go because of their own illness or disability, or because they were caring for someone with an illness or disability. They were many, and we were different from each other in key ways, but what was true for all of us is that we were not there.

If we take Hannah Arendt's definition of the political — which is still one of the most dominant in mainstream discourse — as being any action that is performed in public, we must contend with the implications of what, of whom, that excludes. If being present in public is what is required to be

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6 I used to think that the most anti-capitalist gestures left had to do with love, particularly love poetry: to write a love poem and give it to the one you desired, seemed to me a radical resistance. But now I see I was wrong.

The most anti-capitalist protest is to care for another and to care for yourself. To take on the historically feminized and therefore invisible practice of nursing, nurturing, caring. To take seriously each other's vulnerability and fragility and precarity, and to support it, honor it, empower it. To protect each other, to enact and practice a community of support. A radical kinship, an interdependent sociality, a politics of care.

Because, once we are all ill and confined to the bed, sharing our stories of therapies and comforts, forming support groups, bearing witness to each other's tales of trauma, prioritizing the care and love of our sick, pained, expensive, sensitive, fantastic bodies, and there is no one left to go to work, perhaps then, finally, capitalism will screech to its much needed, long-overdue, and motherfucking glorious halt.

political, then whole swathes of the population can be deemed *a*-political – simply because they are not physically able to get their bodies into the street.

In my graduate program, Arendt was a kind of god, and so I was trained to think that her definition of the political was radically liberating. Of course, I can see that it was, in its own way, in its time (the late 1950s): in one fell swoop she got rid of a political defined by the need for infrastructures of law, voting, elections, and the reliance on individuals who've accumulated the power to affect policy – she got rid of the need for policy at all. Until then, all of these had been required for an action to be considered political and visible as such. No, Arendt said, just get your body into the street, and bam: political.

There are two failures here, though. The first is her reliance on a “public – which requires a private, a binary between visible and invisible space. This meant that whatever takes place in private is not political. So, you can beat your spouse in private and it doesn't matter, for instance. You can send private emails containing racial slurs, but since they weren't “meant for the public,” you are somehow not racist. Arendt was worried that if everything can be considered political, then nothing will be, which is why she divided the space into one that is political and one that is not. But for the sake of this anxiety, she chose to sacrifice whole groups of people, to continue to banish them to invisibility and political irrelevance. She chose to keep them out of the political sphere. I'm not the first to take Arendt to task for this. The failure of Arendt's notion of the political was exposed in the civil rights activism and feminism of the 1960s and '70s. The slogan of the time, “the personal is political,” can also be read as saying “the private is political.” Because, of course, everything you do in private is political: how long your showers are, if you have access to hot water for a shower at all, if you clean the shower afterward or if you pay someone else to clean it, and so on.

There is yet another problem with Arendt's formulation, which persists in today's discourse about public space. As Judith Butler put it in their 2015 lecture, “Vulnerability and Resistance,” Arendt failed to account for who is allowed into public space, which means she failed to account for who's in charge of public space. Public space is never free from infrastructures of power, control, and surveillance; in fact, it is built by them. As Butler says,

there is always one thing true about a public demonstration: the police are already there, or they are coming. This resonates with frightening force when considering the context of Black Lives Matter. The inevitability of violence inflicted on Black lives at a demonstration — particularly a demonstration that ignited around insisting that Black lives should not be subjected to such violence — ensures that a lot of people won't, because they can't, show up. Couple this with the multiple forms of inaccessibility of public space, then couple that with people's physical and mental illnesses and disabilities that require more rather than less access and support, and we must contend with the fact that many whom these protests are for, are not able to participate in them, which means they are not able to be visible as political subjects.

There was a Tumblr post that came across my dash during those weeks in 2014 of protest, that said something to the effect of: "Shout out to all the disabled people, sick people, people with PTSD, anxiety, etc., who can't protest in the streets with us tonight. Your voices are heard and valued, and with us." Heart. Reblog.

Since I wrote that last paragraph about the 2014 protests, many uprisings have arisen around the world. The week that I am writing this, in 2022, Russia invaded Ukraine. While watching videos recorded with shaky phones from the street, I realize that, like a lot of others, I have participated in the uprisings of the twenty-first century primarily through social media. Liking, sharing, retweeting; donating to mutual aid, GoFundMe's, charities. I share links and doomscroll, then need to log off, fatigued and weeping as the images of war, oppression, and genocide proliferate on my screen. I think of the surveillance embedded in the internet, a force we know is there but can't see, and how digital space has both expanded public space and narrowed it, making this distinction between private and public even more occluded and confusing. I think of how COVID-19 put our lives, but not our bodies, into digital space in an unprecedented way. I think of how bodies are real, that they have gravity and needs, and are fucking expensive — that this fact motors the world, as much a problem as a poetic.

When I think of this, I feel heavy with my own body and what it looks like, how it carries its Korean-Americanness in skin and bone that pass as white, and what this means about where I can and can't take it, about how visible it is and is not. I am heavy with the violence that's been inflicted

The Sick Woman has been in therapy for years with a therapist who tunnels into her every childhood trauma but has not once brought up capitalism as a cause of her suffering.

The Sick Woman is a Black man killed in police custody, and officially said to have severed his own spine. His name is Freddie Gray.

The Sick Woman is a veteran suffering from PTSD on the months-long waiting list to see a doctor at the VA.

The Sick Woman is a single mother, emigrated without papers to the "land of the free," shuffling between three jobs in order to feed her family, and finding it harder and harder to breathe.

The Sick Woman is the refugee.

The Sick Woman is the abused child.

The Sick Woman is the neuroatypical person whom the world is trying to "cure."

The Sick Woman is the starving.

The Sick Woman is the dying.

And, crucially: The Sick Woman is who capitalism needs to perpetuate itself.

Why?

Because to stay alive, capitalism cannot be responsible for our care — its logic of exploitation requires that some of us die.

"Sickness" as we speak of it today is a capitalist construct, as is its perceived binary opposite, "wellness." Under capitalism, the "well" person is the person well enough to go to work. The "sick" person is the one who is not well enough to work.

What is so destructive about this conception of wellness as the default, as the standard mode of existence, is that it invents illness as temporary. When being sick is an abhorrence to the norm, it allows us to conceive of care and support in the same way.

Care and support, in this configuration, are only required sometimes. When sickness is temporary, care and support are not normal.

Here's an exercise: go to the mirror, look yourself in the face, and say out loud: "To take care of you is not normal. I can only do it temporarily."

Saying this to yourself will merely be an echo of what the world repeats all the time.

What would happen if we decided to say the opposite?

danger,” “badly behaved,” “crazy,” “incurable,” “traumatized,” “disordered,” “diseased,” “chronic,” “uninsurable,” “wretched,” “undesirable” and altogether “dysfunctional” bodies belonging to women, Black and Indigenous people and people of color, poor, ill, neuro-atypical, disabled, queer, trans, and genderfluid people, who have been historically pathologized, hospitalized, institutionalized, brutalized, rendered “unmanageable,” and therefore made culturally illegitimate and politically invisible.

The Sick Woman is the elderly or already-sick person that society fed to COVID first.

The Sick Woman is a Black trans woman having panic attacks while using a public restroom, in fear of the violence awaiting her.

The Sick Woman is the child of parents whose indigenous histories have been erased, who carries in their body the trauma of generations of colonization and violence.

The Sick Woman is a homeless person, especially one with any kind of disease and no access to treatment, and whose only access to mental-health care is a seventy-two-hour hold in the county hospital.

The Sick Woman is a mentally ill Black woman whose family called the police for help because she was suffering an episode, and who was murdered in police custody, and whose story was denied by everyone operating under white supremacy. Her name is Tanesha Anderson.

The Sick Woman is a fifty-year-old gay man who was raped as a teenager and has remained silent and shamed, believing that men can't be raped.

The Sick Woman is a disabled person who couldn't go to the lecture on disability rights because it was held in a venue without accessibility.

The Sick Woman is a white woman with chronic illness rooted in sexual trauma who must take painkillers in order to get out of bed.

The Sick Woman is a straight man with depression who's been medicated (managed) since early adolescence and now struggles to work the sixty hours per week that his job demands.

The Sick Woman is someone diagnosed with a chronic illness, whose family and friends continually tell them they should exercise more.

The Sick Woman is a queer woman of color whose activism, intellect, rage, and depression are seen by white society as unlikeable attributes of her personality.

on it and on those who look similar. Then it feels heavier when I think of those who don't look like me, what violences come to them and why. The weight increases when I consider what my and other sick and disabled bodies would need to attend these protests, what kinds of support, and how such supports are not there. I think of all the nuances of violence, the many ways it is oriented toward specific groups and why, but then I think of the totality of it, and this feels heaviest of all.

So, as I have participated in protests over the years while unable to march, hold up a sign, shout a slogan that would be heard, or be visible in any traditional capacity as a political being, the central question of Sick Woman Theory has been formed and honed: How do you throw a brick through the window of a bank if you can't get out of bed?

2 I have chronic illness. For those who don't know what chronic illness means: the word “chronic” comes from the Greek “chronos,” χρόνος, which means “time” (think of “chronology”). In certain contexts, it can mean “a lifetime.” So, a chronic illness is an illness that lasts a lifetime. In other words, it does not get better. There is no cure.

And there is the weight of time: yes, that means you feel it every day. On very rare occasions, I get caught in a moment, as if something's plucked me out of the world, where I realize that I haven't thought about my illnesses for a few minutes, maybe a few precious hours. These moments of oblivion are the closest thing to a miracle that I know. When you have chronic illness, life is reduced to a relentless rationing of energy. It costs you to do anything: to get out of bed, to cook for yourself, to get dressed, to answer an email. For those without chronic illness, you can spend and spend without consequence: the cost is not a problem. For those of us with limited funds, we have to ration, we have a limited supply, we often run out before lunch.

Sometimes a question shoots through me: Are there people who don't have to think about their bodies?

It makes me wonder what conditions, what supports, have conspired in the world to make this true for them. Why is it not true for someone like me?

Ann Cvetkovich writes: “What if depression, in the Americas, at least,

could be traced to histories of colonialism, genocide, slavery, legal exclusion, and everyday segregation and isolation that haunt all of our lives, rather than to be biochemical imbalances?” I’d like to change the word “depression” here to be all mental illnesses. Cvetkovich continues: “Most medical literature tends to presume a white and middle-class subject for whom feeling bad is frequently a mystery because it doesn’t fit a life in which privilege and comfort make things seem fine on the surface.” In other words, “wellness” as it is talked about, and sold, in America today, is a white and wealthy idea.

Let me quote Starhawk, in the preface to the new edition of her 1982 book *Dreaming the Dark*: “Psychologists have constructed a myth — that somewhere there exists some state of health which is the norm, meaning that most people presumably are in that state, and those who are anxious, depressed, neurotic, distressed, or generally unhappy are deviant.” I’d here supplant the word “psychologists” with “white supremacy,” “doctors,” “your boss,” “neoliberalism,” “heteronormativity,” and “America.”

There has been a slew of writing in recent years about how “female” pain is treated — or rather, not treated as seriously as men’s pain in emergency rooms and clinics, by doctors, specialists, insurance companies, families, husbands, friends, the culture at large. In a 2015 article in *The Atlantic*, called “How Doctors Take Women’s Pain Less Seriously,” a husband writes about the experience of his wife Rachel’s long wait in the ER before receiving the medical attention her condition warranted (which was an ovarian torsion, where an ovarian cyst grows so large it falls, twisting the fallopian tube). “Nationwide, men wait an average of forty-nine minutes before receiving an analgesic for acute abdominal pain. Women wait an average of sixty-five minutes for the same thing. Rachel waited somewhere between ninety minutes and two hours,” he writes. At the end of the ordeal, Rachel had waited nearly fifteen hours before going into the surgery she should have received upon arrival. The article concludes with her physical scars healing, but that “she’s still grappling with the psychic toll — what she calls ‘the trauma of not being seen.’”

What the article does not mention is race — which leads me to believe that the writer and his wife are white. Whiteness is what allows for such oblivious neutrality: it is the premise of blankness, the presumption of the universal. (Studies have shown that white people will listen to other white

neoliberal, white-supremacist, imperial-capitalist, cis-hetero-patriarchy. Sick Woman Theory argues that all of our bodies and minds carry the historical trauma of oppression, and that, although they manifest in each of us differently, these differences ought not to be erased or flattened into any totalizing condition. Sick Woman Theory claims that it is the world itself that is making and keeping us sick.

To take the term “woman” as the subject-position of this work is a strategic, all-encompassing embrace and dedication to the particular, rather than the universal. Though the identity of “woman” has erased and excluded many (especially women of color and trans/nonbinary/genderfluid people), I choose to use it because it still represents the un-cared-for, the secondary, the oppressed, the non-, the un-, the less-than. The problematics of this term will always require critique, and I hope that Sick Woman Theory can help undo those problematics in its own way. But more than anything, I’m inspired to use the word “woman” because I saw this year how it can still be radical to be a woman in the twenty-first century. I use it to honor a dear friend of mine who came out as genderfluid in her mid-thirties. For her, what mattered the most was to be able to call herself a “woman,” to use the pronouns “she/her.” She didn’t want surgery or hormones; she loved her body and her big dick and didn’t want to change any of it — she only wanted the word. That the word itself can be an empowerment is the spirit in which Sick Woman Theory is named.

The Sick Woman is an identity and body that can belong to anyone denied the privileged existence — or the cruelly optimistic promise of such an existence — of the white, straight, healthy, neurotypical, upper and middle-class, cis- and able-bodied man who makes his home in a wealthy country, has never not had health insurance, and whose importance to society is everywhere recognized and made explicit by that society; whose importance and care dominates that society, at the expense of everyone else.

The Sick Woman is anyone who does not have this guarantee of care.

The Sick Woman is the person upon which care that is in fact a tool of eugenics — care that masks control, surveillance, and domination — is inflicted.

The Sick Woman is told that, to this society, her survival does not matter.

The Sick Woman is all of the “dysfunctional,” “dangerous” and “in

on erotics is as formative to this text as her writing on cancer. What so impresses me about Lorde is how she lets herself fall open, with questions as much as in pain and despair, but never abandons her body. Rather, she insists on its capaciousness, what it needs and wants, how it hurts and how it pleasures. I love her most for how she insisted on survival for herself and those who were never meant to survive.

With these instigators and godmothers, Sick Woman Theory was born as a manifesto for those who were never meant to survive, for those who must live in a reality that is unbearable but which nevertheless must be borne. It is for those who are faced with an untenable amount of vulnerability and fragility every day, who have to fight for their experiences to be not only politically valued, but first made visible as such. It's for my fellow sick and cripp crew. You know who you are, even if you've not been attached to a diagnosis: one of the aims of Sick Woman Theory is to resist the notion that one needs to be legitimated by an institution, so that they can try to fix you according to their terms. You don't need to be fixed, my queens — it's the world that needs the fixing.

I offer this as a call to arms and a testimony of recognition. I hope that my thoughts can provide articulation and resonance, as well as tools of survival and resilience.

For those of you who are not chronically ill or disabled, Sick Woman Theory asks you to stretch your empathy this way. To face us, to listen, to see. I will ask you not to turn away from the guarantee that you, inevitably, will join us.

5 Sick Woman Theory is an insistence that most modes of political protest are internalized, lived, embodied, suffering, and therefore invisible. Sick Woman Theory redefines existence in a body as something that is primarily and always vulnerable, following from Judith Butler's work on precarity and resistance. Because Butler's 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. Sick Woman Theory maintains that the body and mind are sensitive and reactive to regimes of oppression — particularly our current regime of

people when talking about race, far more openly than they will to a person of color. As someone who is white-passing, let me address white people directly: look at my white-looking face and listen up.)

The trauma of not being seen. Again — who is allowed into the public sphere? Who is allowed to be visible? I don't mean to diminish Rachel's horrible experience — I myself once had to wait ten hours in an ER to be diagnosed with a burst ovarian cyst, so I get it — I only wish to point out the presumptions upon which her horror relies: that vulnerability should be seen and supported, and that we should all receive care, quickly and in a way that “respects the autonomy of the patient,” as the Four Principles of Biomedical Ethics puts it. Of course, these presumptions are what any person with a body should have. But we must ask the question of which bodies are allowed to enjoy such assumptions. In whom does society substantiate such beliefs? And in whom does society enforce the opposite?

Compare Rachel's experience at the hands of the medical establishment with that of Kam Brock's. In September 2014, Brock, a thirty-two-year-old Black woman, born in Jamaica and living in New York City, was driving her BMW when she was pulled over by the police. They accused her of driving under the influence of marijuana, and though her behavior and their search of her car yielded nothing to support this, they nevertheless impounded her car. According to a lawsuit brought against the City of New York and Harlem Hospital by Brock, when Brock appeared the next day to retrieve her car, she was arrested by the police for behaving in a way that she calls “emotional,” and involuntarily hospitalized in the Harlem Hospital psych ward. (As someone who has also been involuntarily hospitalized for behaving “too” emotionally, this story feels like a rip of recognition through my brain.) The doctors thought she was “delusional” and suffering from bipolar disorder, because she claimed that Obama followed her on Twitter — which was true, but the medical staff failed to confirm it. She was then held for eight days, forcibly injected with sedatives, made to ingest psychiatric medication, attend group therapy, and stripped. The medical records of the hospital — obtained by her lawyers — bear this out: the “master treatment plan” for Brock's stay reads, “Objective: Patient will verbalize the importance of education for employment and will state that Obama is not following her on Twitter.” It notes her “inability to test reality.” Upon her release, she was given a bill for \$13,637.10.

The question of why the hospital's doctors thought Brock "delusional" because of her Obama-follow claim is easily answered: Because, according to this society, a young Black woman can't possibly be that important — and for her to insist that she is, must mean she's "sick."

How many people are rendered "sick" in this way? How many times has the autonomy of a person been stripped from them in the name of "care"? Why does it happen so differently to a person like Rachel than to Kam Brock? When both are made into sick women, but this determines radically different outcomes, how do we understand the sick woman? Should she exist at all?

3 Before I can speak of the "sick woman" in all of her many guises, I must first speak as an individual, and address you from my particular location.

I am antagonistic to the notion that the Western medical-insurance industrial complex understands me in my entirety, though they seem to think they do. They have attached many words to me over the years, and though some of these have provided articulation that was useful — after all, no matter how much we are working to change the world, we must still find ways of coping with the reality at hand — first I want to suggest some other ways of understanding my "illness."

Perhaps it can all be explained by the fact that my Sun is in the Sixth House of Labor, Work, and Health; and my Moon's in Cancer in the Eighth House, the House of Death; and my Mars, Saturn, and Pluto are in the Twelfth House, the House of Illness, Suffering, Misery, Bane, and Toil. Or, that my father's mother left South Korea during the war, pregnant by an American soldier who left her not long after, and she then spent the next thirty years in America working double shifts as a maid in a hospital, not once taking a day or a weekend off. Or, that my mother spent her life suffering from undiagnosed mental illness and was probably neurodivergent, both of which were actively denied by her family, conditions then exasperated by a forty-year-long drug and alcohol addiction, sexual trauma, and hepatitis from a dirty needle, as she made her way in and out of jails, squats, and homelessness. Or, that I was physically and emotionally abused as a child, raised in an environment of poverty, addiction, and violence, where

Another instigator was my desire to create a response to Audrey Wollen's "Sad Girl Theory," which proposes a way of redefining historically feminized pathologies into modes of political protest for girls. Critical of Sad Girl Theory's centering of whiteness, beauty, heteronormativity, and middle-class resources, I started to think through the question of what happens to the sad girl who is poor, queer, and not white, when — *if* — she grows up. Although I understand the impulse behind pretty girls taking selfies in hospital gowns in their doctors' offices, I can't help but wince at them. I think about how I waited a year to see a specialist and never did because my insurance wouldn't cover it. I think about how lucky these pretty white sad girls are to be able to afford to go to the doctor at all.

While reading Kate Zambreno's *Heroines* at the time, I felt an itch to fuck with the concept of heroism that gets leveraged by white feminism. I loved the premise of Zambreno's book — a reclaiming of the wives and mistresses of twentieth-century art and literature who'd been institution-alized and/or pathologized as crazy and hysterical for what was essentially their talent — but as I made my way through chapter upon chapter of Zambreno writing about white women through the lens of a normatively patriarchal heroism, I felt my excitement be replaced by a familiar bitterness. The cover of Zambreno's book features a collage of people like Simone de Beauvoir, Jane Bowles, Sylvia Plath — and Nina Simone is front and center, the only person who is not white. I kept waiting for the chapter on Nina, and when it didn't come, I closed the book, simmering with rage. I wanted to propose a figure with traditionally anti-heroic qualities — namely illness, idleness, and inaction — as capable of being the symbol of a grand Theory, but I also wanted to recuperate such a heroine from the white supremacy and heteronormative patriarchy that normally attends her. I wanted to dig into the apparatus that differentiates between the "sick woman" of the white upper class, and the "sickening women" of the non-white working class, a notion expressed by Dierdre English and Barbara Ehrenreich's 1973 book *Complaints and Disorders: The Sexual Politics of Sickness*. I wanted to follow how this has accelerated, especially under the logic of eugenics wrought by COVID-19, which saw lives categorized as disposable, based on their class, race, gender, and disability.

Not all the instigations came from things that made me furious. If Sick Woman Theory has a guardian godmother, it is Audre Lorde. Her writing

with my new German doctor on November 9th, 2016, the day after the U.S. election. I arrived as if shell-shocked by the news of Trump winning. I sat in the waiting room and stared at the wall. When she called me in, the first thing she asked was how I was doing with the news. Then she told me, “If you ever need anything, if you start to feel bad when you think of him and you need to talk, you can always come here. No appointment necessary.” I will not say that, since I’ve moved away from America, I am now cured or healed or any other ableist conclusion to this narrative, because none of that is true. I still have chronic illnesses that I need to manage every day, and I still have flares that take me out for months. I will say that living in a society that supports my body and its needs has proven almost inexplicably different from living in one that did the opposite. But the difference is not immeasurable — it is the difference between my being able to live or not.

4 I started writing this text in 2014 as a way to survive a reality that I find unbearable but which nevertheless must be borne. I wrote to bear witness to a self that does not feel like it can possibly be “mine.” I wrote as a way to find my way into a world in which I don’t know how to belong, and yet here I am.

The early instigation for this project of a “Sick Woman Theory,” and how it found its name, arrived from a few sources. I was moved to write mostly because I felt swarmed with ideas, and the language attendant to them, that I disagreed with and wanted more critique around. Like any good instigator, they sparked my fury and made me want to fight. The primary idea was how illness, disability, and vulnerability *feminize* — e.g., render “weaker” and “more fragile” — any person regardless of gender who requires, or is defined by, care. That disability and femininity are co-constructed, and why — what and whom this benefits — got stuck in my throat. It did not intuitively make sense to me to say that the sick are weak because being sick is fucking metal. It has nothing to do with weakness and everything to do with blood, shit, agony, vomit, pus, and death. What narrative does it serve, then, to denigrate the sick to the sphere historically occupied by women? The one kept out of the public sphere? The one not legible as political?

sometimes there wasn’t enough to eat. Perhaps it’s because I’m poor — according to the IRS, in 2014, when I started writing this text, my adjusted gross income was \$5,730 (a result of not being well enough to work full-time) — which meant that for years my health insurance was provided by the state of California, that my “primary care doctor” was a group of physician’s assistants and nurses in a clinic on the second floor of a strip mall, and that I relied on food stamps to eat. Perhaps it’s because I’m queer and gender nonbinary, first coming out to my parents at age fourteen; finally leaving home at age sixteen with the last black eye I was willing to receive from my mother’s hand. Perhaps it can be encapsulated in the word “trauma.” Perhaps I’ve never gotten over anything. Perhaps I’ve had some bad luck.

Or perhaps this is not something that should be scaled down to my own individual experience. Perhaps the more accurate way to account for myself is to say that I am alive on this planet and imbricated into its social, political, economic, and historical systems — that my individuality is determined far more than I might like by institutions of domination and the ideologies that feed them.

It’s important that I also share the Western medical terminology that’s been attached to me — whether I like it or not, it can provide a common vocabulary: “This is the oppressor’s language,” Adrienne Rich wrote in 1971, “yet I need it to talk to you.” Of course, I fucking hate that in order for my testimony to be validated as true, I have to legitimate myself in this way. Yet, I also understand that my specific embodiment is an important thing to attach to my words.

But let me offer another language, too. In the Native American Cree language, the possessive noun and verb of a sentence are structured differently than in English. In Cree, one does not say, “I am sick.” Instead, one says, “The sickness has come to me.” This feels like a more productive understanding of illness because it respects both the self and the illness as separate entities that can interact and encounter each other, rather than one subsuming the other. Based on my own experience, this feels more accurate.

So, here is what has come to me:

Endometriosis, which is a disease of the uterus where the uterine lining grows where it shouldn’t — in the pelvic area mostly, but also anywhere,

the legs, abdomen, even the head. It causes chronic pain; gastrointestinal chaos; epic, monstrous bleeding; in some cases, cancer; and means that I have miscarried, can't have children, and have several surgeries to look forward to. It means that every month, those rogue uterine cells that have implanted themselves throughout my body, "obey their nature and bleed," to quote fellow endo warrior Hilary Mantel. This causes cysts, which eventually burst, leaving behind bundles of dead tissue like the debris of little bombs. Yeah, the pain is annihilating. And for someone with a shitload of gender dysphoria, who does not identify as a woman, having a uterus at all, let alone such an abject one, has been a mindfuck. When I explained the disease to a person who didn't know about it, she exclaimed: "So your whole body is a uterus!" That's one way of looking at it, yes. (Imagine what the Ancient Greek doctors — the fathers of the theory of the "wandering womb," in which the uterus was said to roam the body in search of fertilization, supposedly the cause of madness or "hysteria" — would say about that.) But I try to keep close something someone else once said to me when I told them how confusing this disease has been as a person who does not identify as a woman: "Well, you shouldn't identify as a uterus either." (But, can a dysfunctional body part ever not be pathologized, pathologizing?)

Bipolar disorder, complex PTSD, panic disorder, and depersonalization/derealization disorder have also come to me. I know that I inherited some, and that some were caused by the sort of childhood I had, but this has meant little in the way of comfort, because no matter from where or why they came to me, they have come, they are here. This can mean that I live between this world and another one, one created by my own brain that has ceased to be contained by a discrete concept of "self." Because of these "disorders," I have access to empyreal emotions, flights of thought, and dreamscapes, to the feeling that my mind has been obliterated into stars, to the sensation that I have become nothingness, as well as to extraordinary ecstasies, raptures, sorrows, and despair. I have been hospitalized, voluntarily and involuntarily, because of it, and one of the medications I was prescribed once nearly killed me — it produces a rare side effect where one's skin falls off. Another cost \$800 a month; I only took it because my doctor slipped me free samples. If I want to be able to hold a job — which this world has decided I ought to be able to do according to its terms — I must take an anti-psychotic medication daily

that can cause short-term memory loss and drooling, among other sexy side effects. It also steals my consciousness every night for a minimum of ten hours, so I can never wake up before noon, making me even more unemployable — a cruel causality dilemma: the meds I need to be able to work make me unable to work. These visitors have also brought their friends: nervous breakdowns, mental collapses, or whatever you want to call them, several times in my life. I'm certain they will be guests in my house again. They have motivated attempts at suicide (most of them while dissociated) more than a dozen times, the first when I was nine years old. They cloak me with a constant fear about what might happen if I have an episode in public — though, because I pass as white, at least I know I will not be shot by the police.

On the same day in 2016 that this essay was originally published in *Mask Magazine*, a neurologist diagnosed me with "100% fibromyalgia," as a "place to start." More than one year before that, my "primary care" doctor (which I put in quotes to mark the absurdity of this claim) had referred me to see a neurologist, rheumatologist, and immunologist, so I could begin testing for MS and other autoimmune diseases that some of my symptoms pointed to. My insurance never approved these referrals, nor could it find a specialist within 150 miles who was covered by my plan; the neurologist who diagnosed my fibro agreed to see me out-of-network, cash-only, as a favor to my psychiatrist who was his friend. Sometimes I fit into the symptoms of fibromyalgia and sometimes I don't. This is true for all of the conditions I have listed above. But as I said, I need them to define and categorize me — submitting to them affords me access to treatment and medication at the same time that it yokes me to the medical-industrial complex — and this is the conundrum all sick and disabled people live with. To be pathologized is to be allowed to survive.

In June 2016, I moved to Berlin with my partner, who is a German citizen, basically so I could have better healthcare. My life changed — now we have affordable rent, pensions, and I can just go to the doctor when I need to. My German health insurance has no deductible, no co-pay, and it comes to me from a state program made specifically for freelance artists. Sometimes I need a prescription that is not covered by my insurance, and it costs a whopping €15. When I come back to L.A., my friends marvel at how healthy I seem, how strong. I remember that I had an appointment