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Johanna Hedva
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2014

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*amendment: In this talk, I used a term to describe a person that came from a place of ignorance. I used the term 'illegal,' which no one should ever be called. My ignorance was pointed out to me after this evening, and I would like to make an apology and a correction here. No one is 'illegal,' and I'm sorry for using that word. In this imperialist world, someone can be 'undocumented,' the ramifications of which are violent, oppressive, and dehumanizing. I hope that I can continue to be educated around this topic, and I thank the people who brought my mistake to my attention, and I apologize to those who I offended and who were hurt by my ignorance.**

Introduction: Welcome, everybody. We'll just go ahead and get started. Welcome. When Johanna approached us about this event, we did not expect this to be the turnout, but we're so excited to have everyone here, and thank you so much to John in Human Resources for opening this up and letting us do it here so we can have everyone who wanted to come attend.

We welcome you to "My Body Is a Prison of Pain so I Want to Leave It Like a Mystic But I Also Love It & Want it to Matter Politically." We're really excited to have Johanna here. I also want to say thank you to Eva, who's recording it and making it possible that we'll be able to share this with a lot more people who seem very excited to see it otherwise. And thank you so much to Myrrh as well, for helping manage this event.

Welcome, Johanna.

Johanna Hedva: This bench is the bench of support for me. This is my sister. She's going to sit with me while I read my text, because there are moments in it where I seem to not be able to get through them without crying, and so my code word is, "I need a hug from my sister now," and then she will hug me.

I have a few opening remarks that I just want to say before we begin. My original plan for this evening was for a much more intimate affair. I had imagined that maybe five or six of my fellow Sick Women friends and I would sit around on big pillows and dip our feet in Epsom salt tubs, sharing stories about how much our male doctors invalidate us. So please know that my intention was not to deliver a lecture where I'm an expert imparting special information upon you. I wanted this more to feel like a forum where we can all share, and feel heard and seen. It will feel hard with this many people, but let's try to imagine that you're all in my living room.

The format is I'm going to speak for maybe an hour, and then the rest of the time will be for discussion and questions. And I want to say that you can absolutely ask me questions, if you like. But since there are many people here tonight who probably have better answers than me, please consider posing your thoughts and questions to the group.

There are so many incredible and heartening thinkers and writers who've been paving this path for decades, and many who are doing so now. I want to acknowledge that most of them are women of color and/or survivors of trauma, and I want to urge you all to read their work.

I'd also like to make a request, for those of you joining us on livestream, if you have something you want to share or a question or a thought, please please please reach out to me via email. As those of you with chronic illness know, you spend a lot of time in the bed at home, and pen pals are just about the best thing there is. They can literally make life worth living sometimes, so please do reach out to me, if you would like.

Like I said, I'd imagined a much smaller and informal affair where we could all spout and rant as the spirit moved us. But with so many of you here, I fell compelled to be more cogent (or as cogent as I can), so I'm going to be boring and read from a paper. Like I said, though, I hope that the second half of the evening is filled more with your voices and not mine.

So now I think we can start.

In late 2014, I was sick with a chronic condition that recurs about 18 months and renders me, for about five months each time, unable to walk, drive, do my job, sometimes speak, and leave the bed. This particular flare coincided with the Black Lives Matter protests, which I would have attended unremittingly, had I been able to. I live one block away from MacArthur Park in a neighborhood that has historically been inhabited by Latino immigrants and is colloquially understood to be the place for illegal immigrants to begin their American lives. So the park, then, 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 rose up my sick woman fist in solidarity. I started to think about what modes of protest are afforded to sick people. It seemed to me that many for whom Black Lives Matter is especially in service might not be able to be present for the marches because they were imprisoned by a job, the threat of being *fired* from their job if they marched, or literal incarceration. And the threat of violence and police brutality, but also because of illness or disability, or because they were caring for someone with an illness or disability.

I thought of all the other invisible bodies with their fists up, tucked away and out of sight.If we take Hannah Arendt's definition of the political, which is still one of the most dominant in mainstream discourse, that any action that is performed in public is political, then we must contend with the implications of who that excludes. If being present in public is what is required to be 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 tried to get rid of the need for infrastructures of law, the democratic process of voting, the reliance on individuals who've accumulated the power to affect policy. 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 *in*visible space. This meant that whatever takes place in private is *not* political. So, you can beat your wife 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. But for the sake of this anxiety, she chose to sacrifice whole groups of people, to continue to banish them to invisibility and political irrel-

So, thank you so much, everybody, for coming. I hope you have a good night. Drive safe home. And please do email me if you want to talk more.

mensely strong community bonds, and I just thought… So I don't know. I was just glad for you to mention that. That's all.

Hedva: Have you read Audrey Lorde's *The Cancer Journals*? [Audience 11 nods] Okay. Good. She talks about that caring for yourself is often seen as an act of self-indulgence. But it should really be read as an act of warfare. Okay, last one.

Audience 12: I wanted to speak to what you said because I related so much. In April, I was diagnosed with cancer, and I find myself every day straddling the two worlds of having an amazing support system that are there for me in ways I never expected, and also feeling so isolated. I remember going to a party and I was freezing and I was hungry. And I remember thinking "how come no one's asking me if I'm okay? This could be the night that I have pneumonia and I die." And I remember going home and not answering any phone calls or text messages, and I isolated myself. *Which was bad.*

And I found that the thing that helped, and has helped now, is that the more vulnerable I am and the more compassionate I am to my friends, the more that I get back. And I had one friend tell me, "I don't know how to deal with you with cancer, either. We're both going through this together, so you have to tell me what you need." And that has been so freeing. And I know, going back to feeling like, "God I'm such a bummer," because I'm that cancer friend, but I find that it actually is the opposite. People are like, "Thank you for telling me what you need." Tatiana actually gave me an amazing piece of advice the week I was diagnosed, which was don't get caught up in the drama. Which is something that I think had I not heard that I would totally have just fallen apart. And I think it's easy to fall into the drama of any illness and want to feel bad and shitty and isolated and marginalized, but if you don't fall into that, you can really open up the world to your healing, I think.

Hedva: Yes. I want to end with that and say that you're not the cancer friend. You're the superhero of the group, of your friends.

evance. She chose to keep them out of the public sphere. I'm not the first to take Arendt to task for this, obviously. The failure of Arendt's political was immediately exposed in the feminism of the 1960s and 70s, and the civil rights movement. "The personal is political" can also be read as saying "the private is political." Because of course, *everything* you do in private is political. Who you have sex with, how long your showers are, if you have access to clean water for a shower at all.

There is another problem, too. As Judith Butler put it in her 2015 lecture at the REDCAT, Arendt failed to account for who is allowed *in* to the public space, of who's in charge of the public. Or, more specifically, who's in charge of *who* gets in. Butler says that 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 at a demonstration, especially a demonstration that emerged to demand and insist upon the importance of bodies who've been violently *un*-cared for, and ensures that a certain amount of people *won't*, because they cannot, show up. Couple this with physical and mental illnesses, and disabilities that keep people in bed and at home, 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 activists.

There was a Tumblr post that came across my dash during these weeks 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.

So as I lay there unable to move, 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 formed: How do you throw a brick through the window of a bank if you can't get out of bed?

Okay, this is the hard part. [drinks from bottle of water] It's not strong enough.

I am a spoonie, which means I have chronic illness. For those who don't know what chronic illness means, let me help. The word "chronic" comes from the Latin chronos, which means "of time." So think of chronology. And it specifically means 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 think about the weight of time. Yes, that means you feel it every day. The term "spoonie" comes from a text online called "The Spoon Theory" by Christine Miserandino. She came up with it as a way to explain what chronic illness feels like to people who don't have it. She proposed the analogy of the spoon as a way to mark a unit of energy. Each task you do every day costs you a spoon. To get out of bed, to cook for yourself, to get dressed, to answer an email, all of these cost a spoon. For those without chronic illness, you feel as though you have a near-infinite supply. You can spend spoon after spoon, without consequence. For spoonies, we have to ration our spoons. We have a *limited* supply. We often run out of them before lunch.

Let me explain chronic illness another way. I quote Ann Cvetkovich, who 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" there to be all chronic illnesses. And note that Sick Woman Theory takes this premise to be true.

Before getting into the implications of *that*, I want to take a moment now to recognize that the spoonies who came here tonight had to save up their spoons all day for this, perhaps even all week. They did not do certain tasks, they postponed errands, they stocked up on anti-inflammatories and other medications, supplements, vi-

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ily. The person who was asking about how to cope with family or friends just really not getting it or just saying rude things to you, I think that it's… In my experience, I understand it as a way of perpetual dismissal that we get as like, every chronic pain group I've ever been in they're like, "What are *you* doing here. You're too young." The orthopedist that I just saw was like, "You don't…you couldn't possibly…" And yet.

So I feel like the people; in our lives also just have that thrown at them, that thing like, "Young people don't get sick," and it's fine, and then when they find out that we *do* get sick it's terrifying. And so they want to fight back and resist it and just repeat those things like, "Have you tried yoga? Do you drink enough water? Go on a hike." Those things as a way to ease their own being totally frightened at what's going on with their loved one. It's completely frightening to exist in a body that is sick. It's horrible. But also, it's frightening but it's real, and I just have to own it and be like, "Well, I *do* have an illness. And yeah, I actually can't go to that thing. And I haven't actually left my bed for two days, until I took some pills and got myself here." Which I'm really really happy to have done. But yeah, I think that it's just…we're always being told that we're not what we know we are, and that just standing with that and loving yourself through your sickness will only perpetuate and gather people who have similar experiences and will just grow the love.

And then I thought it was really interesting you talking about not being able to participate in Black Lives Matter stuff. I was in Oakland during Occupy, and dozens of friends were arrested and I was just in my bed, watching the helicopters. Because I couldn't get out of bed, and it was just this whole thing of like, you're a slacktivist, you're not really doing the work. But I felt like by talking to the people in my immediate community about why I couldn't be doing the work that people thought was the "good stuff" like, the radical thing to do, was even more radical. It just seemed like if I can take care of myself and if I can take care of a few people, or offer help, or accept help from a few people, that is building im-

And so I guess I was wondering if that's something you've ever thought about. Because whenever I think about my personhood in relation to utility, I always sort of come up short, but it makes me uncomfortable in a way that takes me to an interesting conceptual space where I feel like I learn more from being in it than from resisting it. And I also feel like whenever I resist it, I feel like I'm giving into what the world wants of me. But also, if I *don't* resist it, I *also* feel like I'm giving into what the world wants from me. It just feels more like politically radical, even though I don't like the word "radical," to live in it, or be in it, and just deal with it. Because it forces other people to deal with it. I don't know if that makes sense.

Hedva: Yeah, I think it makes sense. Does anybody have any thoughts on the word "victim," victimhood?

Audience 10: That resonated with me so deeply because I've been thinking about suffering and the value of suffering, and in thinking about mysticism. The notion that, like we were talking about the annihilation or the crushing of the body can open up a space for love. And then reflect on maybe kind of a paradoxical experience that I have being in a partnership with someone who maybe doesn't subscribe to Sick Woman Theory, maybe subscribes to more conventional and patriarchal notions of wellness. And that to be in that relationship causes suffering, it causes emotional suffering. And I wonder what the value is there, or what I derive from that, by making the intention to put myself in that situation that doesn't have comfort. So that it's not just the suffering of the chronic conditions of the musculature or of the psyche, but of that particular dynamic. And then I also have communities of care that offer this other source of meaning. But there is something about the victimhood or the suffering that seems related to that practice of going so far inside of yourself that you can almost leave yourself and have access to something transcendent, maybe.

Audience 11: So many things have come up in my mind that I want to say in response to everybody. But two things primar-

tamins, and they will probably pay the price for sitting here by being in pain for days after. Also, as to have enough energy to drive here, park, walk in, sit down, listen, pay attention, then walk back to their car and drive home. I want to recognize that as I am speaking, their bodies are uncomfortable, in pain, and struggling, simply because they are here. I want to thank them for their resilience, and recognize the worth of their presence.

I'm not interested, though, in making a contest out of suffering or constructing a hierarchy of who has it better or worse. So to this end, I'd like to try to locate us in our bodies for tonight. I'm going to try something in the hopes that we can all find a common ground of somatic sensation, a shared physical experience.

Some friends and helpers are now going to pass around some small rocks. I ask those of you who do *not* suffer from chronic illness, pain, injury, disability, or past trauma to take a rock and put it in your shoe. Please keep it there for the duration of the talk. I'm also going to ask you to take a rock if you do not come from a colonized, displaced, or oppressed people, from a history of political, cultural, and racial trauma. If you do not come from this, take a rock. If you are livestreaming and this applied to you, you can find something nearby that will work as a substitute for the rock.

I think it's important for me now, as I'm asking you to do this, to say that I am white-passing, and I intend to use the privilege to critique white supremacy to the white people here. Studies have shown that white people will listen to other white people talking about race more than to people of color. So look at me and listen up, white people.

Also let me say you do not need approval from me or a doctor or anyone else to know if you have pain, trauma, or chronic illness. You know your body better than anyone else. You know if you already carry the weight of the rock.

This rock ritual is a gesture toward creating a commonality in our bodies. I ask those of you with rocks in your shoes to notice the discomfort that they cause. Notice how it doesn't go away. Notice how you can be distracted away from it *sometimes* but that it comes back, and it will take up your attention. Notice your body shifting around it, trying to adjust to it. And let's acknowledge that this room and this world is filled with people whose bodies feel this way always, without literal rocks. So does everybody have their rock? Your physical or figurative rock?

A dear friend and mentor once told me that the more specifically personal you can make something, the more universal resonance it will have. Another mentor suggested that for tonight's talk I should go as deep into the vulnerability of my "I" as I can. No small task. So with them as my guides I'll just plunge in and speak frankly about my situation, so you know where I'm coming from.

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 has been useful, first I'd like to suggest some other ways of understanding my experience.

Perhaps it can all be explained by the fact that my moon is in Cancer in the Eight House. Or that my father's mother escaped from North Korea in her childhood and hid this fact from our family until a few years ago when she accidentally let it slip out, and then violently denied it. Or that my mother suffers from mental illness that was actively denied by her family, and was then exacerbated by a forty year long drug addiction, and to this day remains undiagnosed as she makes her way in and out of jails, squats, and homelessness. Or that I was physically and emotionally terrorized as a child, raised in an environment of poverty, addiction, abuse, and violence, and have been estranged from my parents for thirteen years. Perhaps it can all be encapsulated in the word "trauma." Or perhaps I am simply more permeable than is acceptable. More sensitive than is considered "functional." Perhaps I've just got a thin skin and have had some bad luck.

where people would dismiss me, and I don't know really how to be in this space where I want to be heard, yet the people that are in those spaces who are privileged, white, able-bodied, make me feel very marginalized already. And I don't know how to feel safe in activist spaces.

Hedva: I think that's a fantastic point that you brought up. I don't know if I have an answer for you, but I will say to the white people here, it's the epitome of white privilege to expect a person of color to calmly and rationally explain their situation and their story. So, if you are in a space where a person of color is emotional, just shut the fuck up and listen to them. And maybe a person of color can better speak to you and offer you some tools for navigating those spaces.

Audience 8: Please don't stop. That's what I would ask.

Audience 9: Hi. Thank you for the thoughtful lecture. I guess…I haven't really full formed this question, so I don't know if it'll come out like a question or a statement. But, throughout your lecture I sort of noticed that, for obvious reasons too, you sort of have a resistance against the language of victimhood or hysteria and things like that. And it's definitely something that I've personally dealt with myself. And I guess something that I wonder, especially about language as it's talked about with illness, if I were to interpret your definition of illness as being something that's like a form of bodily discomfort, that could be any type of identity marker, whether it's your skin color or whatever.

I always feel like when I'm dealing with it, I'm usually dealing with other people's sort of guilt and shame, because they don't know how to deal with that space. And a part of me almost wants to immerse myself in victimhood and in illness in whatever capacity in order to overcome it. Because when I do that I could animate that victimhood for a type of political ends, or for a type of productive outcome, even if it doesn't look productive in a conventional way.

the spoons that folks of color, trans folks, queer folks, etc. Radical folks, people who are choosing to step in as allies… Where can we all see maybe the spoons, or some metaphor, as the currency that we're all expending, that can be private, but we all know the energy that it takes to get up and walk out the door, if you are radical or marginalized in one way or another. So I think kind of aligning those feels really important, and it makes me think about the radical kinship which you talked about, which I think is really beautiful and is what we need in our times.

So yeah, I think just that it's real important that you brought that idea of the private, and I wanted to throw that idea there of the spoons kind of being a larger idea of whether you're just having to get through the day with, what was the metaphor, of what's come to you, the visitors that've come to you. Or also, what it means to walk out the door and be trans or a person of color, with a mental illness or whatever it is. So yeah, thank you.

Hedva: I'll just say to you that the Spoon Theory, you could just Google it. It's a blog post by a woman named Christine Miserandino. Just Google "The Spoon Theory" and you'll find many lovely Tumblrs devoted to it.

And just keeping in mind the spoons that are dwindling and the pain that we're all starting to feel, let's just maybe have like two more questions.

Audience 7: It's actually more of how can…you were talking earlier about women of color in activist spaces who are thought of like problematic, and I do a lot of work with the trans community and queer community in San Diego, and at one point some people actually thought of me as being very radical and made jokes about me petrol bombing police cars and stuff. Eventually I had to leave this base, and for me, I don't really know how to get past that idea of, I'm trying to rage about getting a better world out there without alienating some of the white allies that I have. Because there were a lot of moments where people were racist, made racist comments, and I would call out their privilege. And then I got into a cycle

I think it is important that share the Western medical terminology with you, in that hopes that it can provide a common vocabulary, so we can better understand each other. But let me preface this with the fact that in the Native American Cree language, the possessive noun and verb of a sentence are structured differently than in English. So in Cree, one does not say, "I am sick." Instead, one says, "The sickness has come to me." I love that. 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 can cause chronic pain, and epic, monstrous bleeding, and means that I've had a miscarriage can't have children. When I explained the disease to a friend of mine who didn't know about it, she exclaimed, "So your whole body is a uterus!" That's one way of looking at it, yes. And you can imagine what the Ancient Greek male physicians would've had to say about that. 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.

Bipolar disorder type I, panic disorder, and depersonalization disorder have also come to me. This means only that I live between this world and another one, one created by my own brain after it's ceased to be contained by a discrete concept of self. Because of them, I have access to incredible extremes of emotions and dreamscapes, to the feeling that my identity has been obliterated into stars, to the sensation that I have become nothingness, as well as to intense ecstasies, raptures, sorrows, and nightmarish hallucinations. 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 medication I was prescribed cost $800 a month. I only took it because my doctor slipped me free samples.

Nervous breakdowns, or whatever you want to call them, have come to me three times in my life, and I'm certain they will come again. Attempts at suicide have come to me more than a dozen times, the first one when I was nine years old.

Finally, an immune system disease that still baffles all the doctors I've seen has come to me, but refuses still to be named. My doctor wants me tested for fibromyalgia, to see a specialist, etc., but my insurance won't cover it. Autoimmune diseases bring unimaginable fatigue, susceptibility to illnesses, pain all over, etc. But the worst symptom that *mine* brings is chronic shingles. For ten years I've gotten shingles in the same place on my back, so that I now have nerve damage there which results in a ceaseless, searing pain on the skin and a dull, burning ache in the bones. If I don't take daily medication, I get shingles once a month which take me out for about three weeks at a time. My acupuncturist described it as "a little demon steaming black smoke and frothing around, nestling into my bones."

So with all of these visitors, I started writing Sick Woman Theory as a way to survive. Sick Woman Theory is for those who are faced with their vulnerability and unbearable fragility every day. For those who, in Audrey Lorde's words, were never meant to survive. Because this world was built *against* their survival. This is for my fellow spoonies. 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. You don't need to be fixed, my queens. It's the world that needs to be fixed.

So, Sick Woman Theory is for you brave, fierce, unsurrendering spoonies, in recognition, in solidarity. And though I'm a pacifist, I offer this as a call to arms. I hope that my thoughts can provide articulation and resonance, as well as tools of survival and resilience. And for those of you who are not chronically ill or disabled or carrying trauma, Sick Woman Theory asks only for you to stretch your

I think I really loved the talk and feel so inspired by this. And I think there's a common vulnerability there, and this point of vulnerability and love has to go both ways. There has to be more radical communication in those relationships. And I think the loved ones are called to that radical vulnerability, and it is really…I don't know, I think going to be pretty messy in terms of living with uncertainty of death for all of us, but especially in your continued openness to the uncertainty of what's going on with your loved one or whatever, that's sick. I don't know if that answers your question, but I feel that pretty deeply, and have tried to live that in my life pretty deeply. And it's been hard. And I don't know, I think trauma just…the definition and the net of it is really wide. And the definition and net of okay is really wide, and something that we all should be more comfortable with being *wider*. So I really appreciate you talking about that.

Hedva: Thank you.

Audience 6: First of all, thank you so much for your criticality and your vulnerability together in one. I was thinking a lot about the wellness discourse that you were talking about, and thinking about the "get better," the linear imperative, and how that ties into the neoliberal complex of the individual, and how that goes directly into the politics around the "pull yourself up by your bootstraps," which is the core of the empire in America in a lot of ways.

So I was thinking the idea of the spoons, which I think is a helpful physical or metaphorical way of thinking about the energy that it takes. And having dealt with trauma and also an illness that I thought was chronic that I've come out of, I very much understand what you're talking about. And I think that that idea of spoons, having some idea of a currency, is helpful in terms of thinking about the parallels that I think you were trying to create, or you were creating between folks who are dealing with chronic illness or trauma and the private behind-the-scenes reality that you're in. So then the spoons, how many spoons do you have to get through the day, and I think it's really important to then maybe think about anxieties and fears coming out of them and maybe coming out in a wrong way, of misunderstanding or ignorance, which falls on the back of the chronically in pain person or sick person, which is really unfortunate because a lot of that misunderstanding or expectations comes from loved ones and people who are there to support us.

And I just have a question for anyone about…I guess personally I feel like I'm in this really interesting shedding period where now more of my loved ones after like three years now they're like, "Oh, you're still in pain. Oh, it's not going to go away." But they react to that differently. And sometimes that makes me feel really sad, and people say things that yeah, come from a place of anxiety and ignorance, and it's really hard when your best friend says something kind of mean or ignorant. Because those are the people that maybe in the past have come over and given you painkillers or cooked you a meal. So that is a really scary feeling, when your loved ones maybe feel alienated *from* them, which personally makes me shut down more, and then I alienate *myself*, which makes the line of communication [or] understanding even more severed.

And as anyone knows, being chronically in pain and ill is very isolating and lonely. I'm at a point now where I'm really excited to be in this room. I've never been around so many chronically in pain people. I mean, on the the street I bet you we *are* surrounded by them all the time. But people who are like, "Yeah, I am right now," I just want to know, because I want to feel like my friends are still my friends, and my loved ones are still my loved ones, but how do people cope with feeling like it's sort of like they don't know you anymore because you have this thing, and then you don't know them anymore. It's really scary.

Hedva: Anyone's thoughts on loved ones or friends issues?

Audience 5: I'm so nervous to say anything at all, but I kind of wanted to say something, though, *as* a loved one and a friend, I guess, of a parent who had mental disability and addiction, and of a sister who's bipolar, and a mother-in-law sort of, that is, too.

empathy this way. To face us, to listen. We're not invisible, and we're not dead yet, and by God I'm not even warmed up.

So here's what it is.

Sick Woman Theory is a mode of political protest that is internalized, lived, embodied, and no doubt suffering. It is an existence that endures in the face of certain and inevitable obliteration, but also *redefines* existence itself as something that is primarily and always vulnerable. It insists that a body is defined by its vulnerability, not temporarily affected by it. And so we need to reshape the world around this fact. Sick Woman Theory insists that the body and mind are sensitive and reactive to regimes of oppression, particularly our current regime of neoliberal, white supremacist, imperial-capitalist, cisheteropatriarchy. It is that of our bodies and minds carry the historical trauma of this. 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. Though the identity of "woman" has erased and excluded many, especially women of color and trans and genderfluid people, I choose to use it because it still represents the uncared for, the secondary, the oppressed, the non-, the un-, the less-than, the not yet, the particular rather than the universal. The problematics of this term will always require critique, and I hope that Sick Woman Theory can help undo those 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 21st century. I use it to honor a dear friend of mine who came out as genderfluid last year. For her, what mattered the most was to be able to call herself a woman She loved her body and didn't want to change it. She didn't want surgery or hormones. She only wanted the word. That the word itself can be an empowerment is the spirit in which Sick Woman Theory is named.

So 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 and silence of everyone else.

The Sick Woman is anyone who does *not* have this guarantee of care. The Sick Woman is told that to this society, her care, even her survival, does not matter.

The Sick Women are all of the dysfunctional, dangerous and in danger, badly behaved, crazy, incurable, traumatized, disordered, diseased, chronic, uninsurable, wretched, undesirable and altogether dysfunctional bodies belonging to women, people of color, poor, ill, neuroatypical, differently-abled, 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 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 suffers from the trauma of generations of colonization and violence. The Sick Woman is a homeless person with any kind of disease and no access to treatment, whose only access to mental health care is a 72-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 50-year-old gay man who was raped as a teenager and has remained silent and shamed, believing that men can't be raped.

fighters during the Spanish Civil War and was so disillusioned with that kind of political action. And so maybe it's about a different kind of definition for what counts as politics, which probably goes back to what you were saying about Arendt. But, yeah. I don't know. I was just…I would love to hear more. Thanks.

Hedva: I think that's a fantastic point. Does anybody have any thoughts?

Audience 1: I just have thoughts about politics as expectation. The only thing that has ever made me suffer, aside from my physical body, which I can deal with, is any expectation placed on me. Expectation of how I should parent, expectation on what sex looks like for me. Any thing that I have to twist to meet somehow, or that there's a normal way of doing something is so enraging to somebody who is so self-denying. And so for me, overcoming and defining everything in my own way, and trying to be open and inclusive to everybody else's way as well, but my own way—it's very time-consuming. It's been a life journey or whatever.

But literally, parenting was something that I never in a million years thought would cause me so much suffering, and it had nothing to do with the relationship between me and my child. I have a fifteen year-old daughter and she's wonderful, and *we* are wonderful. But the expectations on what parenting looks like in this country and what you're supposed to do as a mother and what you're supposed to be able to do as a mother…

I mean, when you have limited mobility and you live in chronic pain or whatever your sickness or your particulars are, there *is* not norm in anything. There *is* no norm. So for me, *that* is politics, *that* is patriarchy. Any norm at all. What my daily life should look like, what vacation, what recreation, what pleasure. *Any* of it does not apply to me. Nobody can tell me what anything is supposed to look like, because it just doesn't work like that.

Audience 4: Thank you so much for this talk. I'm so moved and inspired. Thank you so much. I guess speaking to the idea of expectation or even what another person said about other people's

So I think important to acknowledge it, to talk about it, to complain. All of that stuff needs to be allowed in this space, in this world. Because by doing that, it can possibly heal. Not that we will be better. If we have a chronic illness, there's no cure, but there's a lot of ways to make it more liveable. And one of those things that I find for me that's really difficult is the healthy trying to fix me. Because if I could be fixed, *I would.* It's not like you choose this.

And that idea that our culture blames us. There's already, inside of us all, that feeling that we've done something horribly wrong, to have a chronic illness. We walk around with it daily. So I think it's important to talk about, and I really appreciate that.

And in terms of the drug thing, also struggle with that a lot because there's such a culture around drug addiction, and I wouldn't be here right now without painkillers. And also right now there's this whole, "Well, if you smoke pot then that'll be better…" but sometimes you have to do what you have to do to survive, or to be able to get up and have a quality of life. And those choices are for each person individually. But yeah, I have to go back and forth with that, and we struggle with that on a day to day. And only the person who's sick can ultimately make that decision.

So anyway, it's great to have this forum, a place where all of these people here who maybe are sitting around and have this invisible thing that no one sees, that can actually feel safe. Like, "Oh, look, all these other people might be suffering, too." And it's not crazy. So, thank you.

Hedva: Thanks.

Audience 3: Your talk was so beautiful. Thank you so much. I feel like I'm really learning a lot from being here. I was so moved by this idea of vulnerability being the default, and the connection you were making to mysticism, this idea of willfully entering the default. That sense of self-explosion. And I have questions about how this constitutes a politics. I'm thinking about Simone Weil in particular, as a person who…she tried to be with the resistance

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 since early adolescence and now struggles to work the sixty hours a week 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.

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, illegally emigrated, shuffling between three jobs in order to feed her family, and finding it harder and harder to breathe.

Et cetera, et cetera.

In Sick Woman Theory, the binary to be abolished is "sick" and "well." Sickness as we know it in today's discourse is defined by the capitalist maxim of being unable to work. A sick body is one that can't work. If you can't function in society in terms of labor, money, value, and product, then you're sick. Your body doesn't "work right."

Crip theory explains how this works for the term "disability," which is a body without the ability to be sold for its labor. So inversely, to be well, or to get better, is to be able to go to work. To get *back* to work. Under the conditions of capitalism, we are taught that to be sick is a rare occurrence. Think of Susan Sontag's famous declaration which opens *Illness as Metaphor*, that,

"Illness it night side of life. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."

That other place…the night side of life…at least for a spell, Sontag said.

Tell that to those of us who are differently abled, or who suffer from chronic or terminal illnesses, conditions that will never heal, get better, or be cured. What does one do with the news that it will never go away? In some, that it will only get worse. Indeed, many of us have been told that our diseases will one day kill us before something else will. That our bodies will turn against us.

When your own fragility, your own vulnerability to obliteration, your own death, are all around and inside of you, constantly, somatically, and then reinforced by the world *outside* you that tells you not only is there no cure but also that this world will *perpetuate* your suffering, I'd like to know then what the fuck does getting better mean?

When I first started talking about my illnesses among friends, I noticed a trend. First a lot of people told me they hoped I'd get better soon. Some even *commanded* me to. They'd sign their emails with "be well." I've always read this as a militant threat. You'd better be well, or else. Or else what? Poverty, stigmatization, pathologization, victimhood, irrelevance, extinction.

Also, "be well" implies that I have a choice in the matter, that I am the one who decides upon my wellness, and maybe that I just simply forgot to be it. I knew there was something I meant to do today. Oh, that's right. *Be well.* I of course can't fault those well-meaning friends who hoped I'd get better soon. They were simply repeating the wellness discourse of racial capitalism. They failed

and my heart-mind connection, and my politics. And I'm really glad to be here tonight. I actually feel pretty good today, so I'm here. All of your thinking, I was with you the whole time, and I would love to… Well, you're going to film it, so I'll be watching it again and share it with the people that love me, because I have found that even though I come from the opposite family of origin, like a very entitled and arrogant and privileged and unable to see me and share my awareness—I wasn't even diagnosed until I took myself to the doctor at 22. That through me, being viscerally raw, and not a victim, like very strong in my vulnerability, I've been able to literally, beat to beat, share my experience and receive love back from the very people who shamed me and made me feel like a freak, and called me clumsy or walk like a duck— All of the people who were really ultimately my perpetrators growing up love me now and see me for who I am. And that's been very… I mean, it doesn't really matter because I was me with or without them, but it has been on some level, like I said, to cultivate a culture and to cultivate compassion is the solution that I've been able to find. And it's worth it to me.

Hedva: Thank you for sharing.

Audience 2: I wanted to thank you for talking about kind of taking back the issues of being okay with your illness. Because I feel like one of the issues, at least that comes up for me a lot, is the guilt around our society's issues with illness. Things like if you just exercise, or if you just drink some more water, or whatever. Or stop complaining, your whole life will change. That kind of stuff. And I think it's an important thing to acknowledge, for people to be able to hold that thing that is already hard enough, and for those that are healthy to also hold it. Because I think the reason, where that comes from, for people, is their own fear, their own realization that our bodies are fragile and they too, at any moment could wake up and have what we have. And there's that fear, and that fear isn't something they want. And so they push it away, by nature. We all want to do that.

to do with love and desire, particularly love poetry. I had this idea that to write a love poem and give it to the one you desired was the most radical resistance. But now I see I was wrong. The most anticapitalist protest is to care for an other. To take on 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. A radical kinship.

Because once we are all ill and confined to the bed, sharing our stories of therapies and comforts, forming support groups, listening to each other's tales of trauma, prioritizing the care and love of our ill, pained, expensive, sensitive, fantastic bodies, and there is no one left to go to work, perhaps then finally, capitalism will screech to a halt. I say let's give it a try.

And to close, I want to take as my protest slogan the great line of the queen of our time, "I woke up like this. I woke up like this. We flawless, ladies tell 'em."

Thank you.

—-DISCUSSION—-

Hedva: Let me hold my crystals of courage and strength. So now I hope that we can maybe have a discussion, and I hope that I'm not the voice dominating the room. If you have questions, thoughts, stories to share, please do. Thank you so much for coming. I really appreciate it.

Audience 1: First of all, thank you very much because your story resonated very strongly with me, and inspired me greatly. I've spent probably 70% of my life in bed, with a genetic mutation and a muscle disease. So I heard you and I could feel you. And I guess the solution that has been borne of me is I guess I believe deeply that I can somehow cultivate a culture of compassion by sharing my story, by all of the things that you said. By just the authenticity and the vulnerability, the surrender, the courage.

The only thing that I've ever had access to, because my mobility is limited and because my pain is great, has been my relationships,

to understand what the word chronic means. Remember, it means a lifetime, so there's no "get better soon."

Also, many spoke to me about healing. They had much to say about *my* role in my healing. They described it as a kind of exercise, like I'd enrolled myself in a class. They spoke of what I would learn from it. They'd talk to me about my "journey." They also became future tellers. They knew that healing would happen for me and no doubt soon, because I *deserved* it. That I *deserved* to heal. Does this mean that there are some who don't?

Above all, they stressed the importance of my own proactiveness in my healing, that it was up to *me.* That I could make it happen, I could heal myself if I only decided to. And it of course involved some kind of expensive therapy or product that I had to buy, which I of course couldn't afford. I'm on food stamps, state aid, and Medi-Cal, and I can assure you things such as guru-sponsored, energetically-purified water (something that was suggested to me by someone) are impossibilities to someone of my income, and indeed to many people around the world in countries that say, don't have access to clean drinking water.

To say the least, I'm antagonistic to these suggestions and the discourse they propagate. When we believe that our sickness will soon pass, and that we have a choice in *when* we get better, *and* that it's all up to us and us alone, the exploitation that capitalism requires of its laboring bodies continues. The insistence on the power of the individual to heal themselves is a neoliberal, brainwashing, and a white supremacist idea that stinks of upper- and middle-class privilege. It violently divides you from a community of support. It makes you believe you can and should do this alone, that you *ought* to be able to afford it, and that any infrastructures of care that you'll require are "luxury items" to be "granted" to those who deserve them. It insists that your situation is your own doing. Not the result of an unlivable world, of generations of inequality, brutality, racism, sexism, homophobia, transphobia, ableism, classism, patriarchal trauma, to name only a few.

I again quote Cvetkovich that,

"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 in America today, is a white and wealthy idea. It presumes that its subject can afford such medicines. It presumes that its subject can and should be fixed. And it presumes that its subject lives in a world where they can say, call the police for help and get it, to say the least.

Further, the notion of "getting better" is insidiously conservative. To get better is to return to a perceived normal state of comfort and ease in life. The capitalist medical institution peddles health as a eugenic, corrective way to go back to the way things were or "were supposed to be." The implications of wellness and healing within the medical insurance insurance industrial complex uphold a *tradition* of health, but *whose* tradition, and at *whose* expense?

Everywhere in our discourse on illness, trauma, grieving, and pain, is the notion of moving on and getting over it. Getting back to work is what keeps the capitalist patriarchy going, so silence, denial, and erasure are necessary. At most, we can show each other our scars, and maybe if the space is safe, tell each other the stories behind them. The premise being that once we've healed, we'll all have the scars to show for it, passive evidence of our trauma.

I want to make a case now for the callous as an analogy for trauma, not the scar, and here I not do Chandler McWilliams for suggesting this to me (who's here tonight) among other endless support he's given me as one of my dearest friends and mentors. The scar is a mark on the surface that shows that something happened beneath it but is now passed and is over. A callous is something that builds up to protect the part of the body being used, and then it continues to be used. It's not over, it doesn't end. And what's great about the callous is that it makes the task easier. For anyone who plays an instrument or uses a tool or is a

who was reported to have fled into the forest because she was so disgusted with the people around her, and she survived for three months by drinking her own breast milk.

Now, how does all this answer the question of how we Sick Women can cope and care for each other in 2015? So, what was so heretical to the patriarchs about Porete's text, and most of the writings of women mystics is that the *political* of those mystical states is basically communism, but particularly something called mystical anarchism. If the self is destroyed, the notions of me and you, mine and yours, vanish. No private property, for one thing. No violence against an other. Because that would be a violence against the self, which has been obliterated, so is now in communion with everything. So violence against one is violence against all, *literally*. What binds such a community together is solidarity *against* the patriarchal institutions of church, empire, law, and corrective morals, which is why it's anarchistic. And crucially the community is bounded together by love. Love for God, or whatever you want to call the force that is bigger than you, but specifically the love that has become the force of your own body, mind, and soul. So love as both the self and other, and a politics of love.

As Anne Carson has written in her work about Porete and other mystics, this kind of love is the act of giving what one does not have. Porete's idea of love is, as Simon Critchley put it, "an act of spiritual daring that eviscerates the old self in order that something new can come into being." That something new is a community bound by love, that cares for each other.

Let me end by saying that I would not be alive and here tonight if not for a group of people, many of whom are in this room, who have made caring for me one of their priorities. When I am sick in the bed, the wheelchair, and even up until this very afternoon, they come over, cook me meals, drive me to the doctor, email and text daily to say "You can do it," and show me a kind of care that none of the institutions of supposed wellness in this society have come close to. I used to think that the most anticapitalist gesture left had

I'm coming to the end of my time so I'm only going to focus on this mystic Marguerite Porete, though I will do her a great disservice in providing just a crude summary of her work. Porete was a Frenchwoman of the nomadic and mendicant clan of the Benguines. She was burned at the stake in 1310 for heresy, mostly for a book she wrote and refused to destroy when the church ordered her to. It's called *The Mirror of Simple and Annihilated Souls Who Remain Only in Wanting and Desire of Love.* Isn't that beautiful? I'll say it again. The mirror of simple and annihilated souls who remain only in wanting and desire of love.

Porete's book is a kind of how-to manual of the seven stages toward attaining grace, which for Porete meant a way to God via the annihilation of self. Anne Carson compares this to Simone Weil's idea of decreation, which is the "active undoing the creature in us." Porete's seven stages are lengthy, but I'll share a quote from just one that I think is one of the most extraordinary. She writes that in the third stage,

"one must crush oneself, hacking and hewing away at oneself, so as to make a place wide enough so that love can get in."

As someone who dissociates regularly and feels a violent obliteration of my body as though I'm being blasted apart by light and the void, I can tell you that this resonates deeply. Also, on a more mundane note, to get yourself to the place where you can ask for help and accept love, can feel a bit like a part of you has to get destroyed.

A sidenote here is that most *male* mystics, when they imagine a union with God it's like a tranquil, calm, conversation about reason. Whereas for the women mystics, not surprisingly, it is *always* bodily, rapturous, erotic, and unhinged. Margery Kemp is described, for example, as *ceaselessly* weeping. The wailing and animalistic sounds of the ancient Greek women in religious ritual gave birth to the patriarchal idea of hysteria and that women's emotive expression ought to be silenced. Another favorite example of mine is Christina the Astonishing, a Belgian mystic of the 11th century

dancer, you know that once you've built up your callouses, the job will go smoother. And among your colleagues, your callouses are recognized as signs of all your hard work, and you can admire and appreciate each other's callouses.

Also, sometimes callouses can rip off, and then you've got to start from scratch building them back up. There's such poetics in that image to me about how healing works, that it's cyclical, continuous, and it is part of everyday use. I want to propose the callous when thinking about sickness and trauma because it means that instead of rejecting these experiences, moving on, and getting over them, silencing them, and of thinking of them as something that will and *ought* to end, instead we envelop them into our daily, lived, accumulating and embodying experience.

With this in mind, I want to propose that we think of the resistance and resilience in the act of coping. For me, the notion of healing comes wrapped up in implications that it will one day be done. Just gotta get through this healing part, and then the real living can begin. Then I'll be free.

But what if that is never the case? What if this will be with me for my entire life? What if I will always feel this pain? What if I never get over the abuse, the trauma? What if I will always have to take this medication, go to the doctor, use a can, spend portions of my life in the hospital? What if I will never be able to afford the therapies that peddle wellness for X number of dollars? What if I was born in a country devastated by globalization and imperial wars and will live there for my entire life? What if I *always* feel the trauma of my colonized ancestors? What if the violence against my people continues? What if my black friends continue to be shot in the street? [*feb 2, 2016: I'd like to amend this: it's a mistake to say "my black friends," because it presumes that they need to be my friend before I will care. This is not what I meant, and I'd like to change it to say "What if unarmed black civilians continue to be shot in the street?" JH]

What then?

This neoliberal directive to "be well," to heal yourself, has got us all running around alone, thinking if we just did this and that and more importantly, bought X, Y, and Z, then and only then can we finally once and for all be well. I want to suggest that coping instead implies that trauma is embodied, that vulnerability is the default, that the struggle is real, and that all of us require constant care and support forever. Not just sometimes, but for our entire lives. And I want to insist that we cannot do this alone.

So, in the words of my other mentor Fred Moten, what're we gonna do now? How are we going to cope? How are we going to care for each other?

Here's where I've ended up at the mystics, particularly around mystical anarchism. I'm still early in my research, but I want to present it here as one possible solution. And I'll get through this part fast because I hope that many of you have other possible solutions to share.

I first started thinking about mysticism after my second breakdown in 2012. After a manic episode that lasted three months, I dissociated for two weeks. Dissociation, if you don't know, feels like you've been yanked out of your body and blasted into an abyss-like space where nothing holds together. So during this time, I couldn't speak or understand language, control or feel my body, and I obviously couldn't go to work.

In the neoliberal West, where we, especially we white people, have been conditioned to think of ourselves and our bodies as sacred, protected, and invincible, this explosion of the self felt like a violent undoing of everything I'd known. When I returned to this world, that long list of DSM psychiatric words got attached to me, the strangest of which was this "depersonalization disorder." That I was a de-person was, to say the least, terrifying. But also a comfort to know that it's simply caused by trauma, and in a way it's the body's way of protecting itself.

I was sent to a therapist who saved my life. Her name is Linda Hoag. If you ever have the opportunity to talk with her, please do.

She was a practicing Zen Buddhist and a poet, and she just told me simply, "You know, in another culture, another time, you'd just be considered a mystic." She didn't give me books like "Dealing With Mental Illness for Dummies," like I had been given before. (It's true. The woman that gave me that was a Freudian.) Instead, Linda gave me the writings of Sor Juana Inés de la Cruz, Hildegard of Bingen, Julian of Norwich, Margery Kempe, and accounts of enlightenment by Buddhist monks and nuns.

The working definition that I'm using here for mysticism is that it is a state of experience that attenuates or blurs and interweaves and undoes (or in a word, dissociates) the boundary between the self and the other, the world, God, nothingness, grace, love. Depending on the writer, this "other" can change. For Simone Weil it was love, for Marguerite Porete it was grace. Many scholars before me have seen that these women's mysticism was a form of feminist protest against the patriarchy, the church, the law.

Each of these women did something radical: they not only obeyed their own bodies and minds, which they had been taught were evil, but they insisted upon them. They went away from the society that persecuted them, and wrote about their experiences in obtaining oneness with "God." I use quotes here because this force is described in different ways depending on the writer. And all of it has to do with a process of obliterating the self as a container that separates us from the rest of all things.

An interesting sidenote is that medical researchers have recently found that the default mode network of the brain, which can be understood as the physical location of ones ego or narrating "I" (the narrating self), decreases during hallucinogenic experiences in the brains of those practicing meditation, and in the brains of schizophrenic and bipolar-disordered people. So it's interesting to consider that the barrier separating the self from the world can indeed go away, and to positive effects. People who've tripped often describe a connection or union to the world that was not there before, for instance.