Self-Assertion with a Body Out of Control: Chronic Pain, Transition, and Body Modification

By Lee Cicuta

I have been in nonstop pain for the last five years of my life. While pain and frequent illness have been features of my lived experience for as long as I can remember, chronic pain introduced itself first through a TMJ disorder and over the years since has made itself at home in most parts of my body. I have spent these years repeatedly throwing my body into the machine of the medical industrial complex in an attempt to find answers or simply relief, thus far finding very little of either. Chronic pain, how it is felt both as an internal force and how it is responded to by social systems, is a beast that serves as a regular reminder of how many of the conditions of my own embodiment are outside of my control. The resulting feeling of helplessness often manages to inspire more terror and dread than the pain itself.

Pain, like pleasure, is a means by which the body communicates. Something is wrong! The animal of us cries out to run as fast as possible from the source of the pain, to soothe it quietly in a safe place, or, if all else fails, to rip at it with our own teeth. When pain is chronic or constant, it is a blaring alarm that, instead of heeded, must generally be ignored as much as is possible. The feeling of urgency—panic—never leaves, but one becomes aware soon enough of how little can be done at any given moment: helplessness to endless physical suffering becomes a mundane fact of life.

These feelings of helplessness don't only spring from the physical realities of chronic pain, but from the social ones as well. I am unable to soothe the source of my pain. I need help! In the grips of the worst of my flare ups it is the concurrent feeling of social abandonment that drags me further into anxiety and despair. I am overwhelmed by the messages of urgency my body is constantly sending, but very few of those around me see and reflect that urgency. In fact, I must fight for years and years against a "healthcare" system that has established a monopoly on healthcare resources and has communicated in no uncertain terms that my life and wellbeing is not of primary concern. Searching out small political subcultures that at least posture at supporting disabled people does little, in an ongoing but generally ignored pandemic, when in practice the people in those subcultures display almost as much apathy towards supporting and protecting disabled people as our physicians do.

Indeed, while many in radical scenes may gesture at a politics of solidarity with disabled people, the reality is that very few have done the work to deconstruct their ableist and healthist beliefs, even when the political conditions of the *ongoing* COVID-19 pandemic gave them ample opportunity to do so. They cling to a individualistic and logic-devoid idea of public health, in which the individual choices and personal preferences of those least (for now) impacted by ableism determine the material conditions and terrain of risk for everyone else. In practice it looks a lot like just individual choicing disabled people out of public and political life entirely.

All of these factors and more make me feel alienated from my own body, and finding ways to connect with it that do not remind me of or otherwise compound these realities is arduous. So much of my embodiment is something I unwillingly experience, rather than something I intentionally direct and bring about myself. The system inflicts itself upon me by disabling my body, by keeping necessary resources for its care out of my reach, and by making social spaces in which I could be seen and valued (and have my grievances heard) inaccessible to me. On an individual level there is very little I can do to respond to or change that system. My sense of my own entrapment and my helplessness in the face of that entrapment is immense. My pain will not be soothed. My cries for help fall on apathetic ears. My comrades see taking steps to protect my life and wellbeing as intrinsically incompatible with what they think makes a life well lived. Where, then, do I find a sense of personal empowerment and agency? How do I feel connection to this body that I experience primarily through pain and alienation?

The Alienated Body

I doubt I will ever stop wishing or hoping for an end to pain. After all, it is that desire (to be free of pain) that the body utilizes when it communicates pain so that we will (if possible) see to resolving the source of the pain. Pain demands attention, but chronic pain must also be lived with and a body in chronic pain must be lived in. I cannot speak for all people who struggle with chronic pain, but I need to see my own agency expressed through and on my body itself. I have lived and struggled to live with my body being acted on, shaped, and constrained by external forces, and so I have a powerful desire to put my hands on every tool that will allow me to express my own will through my body. I may indeed have little recourse but to live my life in a condemned and crumbling building, but they can't stop me from tagging it from top to bottom.

I'm talking about body modification, and in this essay I'm talking about body modification in a way that explicitly includes body modifications we typically refer to as forms of gender transition (hormone replacement therapy, gender affirming surgeries, etc.) This is undoubtedly influenced by my own personal feelings and unique relationship to transition as a trans masculine butch woman. While I do use "transition" and "trans masculine" as more easily understood shorthand and approximations to describe the path I'm taking with my own body and the resources I require to get there, I relate to the actual process in a similar way that I do with other body modifications like tattoos and piercings. They are each and every one an affirmation that *this body is me*.

This body is me. A seemingly matter of fact and perhaps rather obvious statement, is less obvious, and far from a matter of fact, when your body exists in the margins, both as a disabled body and a gender marginalized one. You are surrounded by messages that you and your body are separate entities and that the disembodied You is individually and uniquely responsible to care for and shape your body into a proper tool of production. Not simply capitalist production, but all forms of production, the social as well as the material. Further, if you fail to maintain your body to industry standards, the general ableist consensus is that you are not responsible enough to keep it, or at least not keep it to yourself. Indeed, it is *everyone's* first experience of extreme marginalization—youth—that teaches many that ownership over one's body is something that must be *earned* through achieving "adulthood" (a class designation that is only partially awarded to many disabled adults, and outright denied to many others.) Up until that point you, and thus your body, is considered the private property of adults, to be shaped, coerced, and objectified by their whims. While generally adults have more control over their bodily autonomy than children are ever allowed, this ownership is only partial for many, and one's ownership (such as it is) can be revoked. The body is a product and a commodity. It is meant to be utilized and consumed. What else are the reactionaries targeting trans and reproductive healthcare hoping to achieve but to dispossess us of the ability to consider our bodies our own?

There are no such separate entities as The Body and The Mind, and one certainly cannot establish ownership over the other. The brain is meat and juices just as the rest of the body is mostly meat and juices. The body-mind is one, and its internal processes and machinations are far, far more out of the control of our inner will than many like to think. I know this to be true, but when I am in pain (always) this is a hard thing to feel. It is much easier to feel my body as a separate being, an adversary. My body is screaming "DO SOMETHING DAMN IT" and I often experience myself as that separate entity, begging the body to understand, to stop *inflicting itself* on me. I feel at war. I feel that I am being pulled in two. I am made up of warring factions. Or at least so it feels. The influence of the popular cultural conceptualization of body-as-object is difficult to disentangle oneself from, even more so when under the pressure of pain inescapable.

Body Modification and Transition

Coming, finally, to a mode of resistance. My chosen tools for self-affirmation: body modification and transition. At the beginning of this year I received top surgery, I have been on HRT for over a year, and I have also collected a number of piercings and tattoos over the years. I have, to the eyes of others at least, heavily modified my body. Many of these modifications are held up as scary "irreversible changes," and while I don't find them scary I will certainly agree that returning to a "before" state is not a possibility. Though this isn't something especially unique to body modification. After all I cannot return to any single "before" state with my body, even in the aspects (like pain) that I would jump at the chance to do so. What I, and many other trans people, don't accept is that this is an argument against body modification rather than an argument *for* it.

Systems of violence try to claim monopoly over the right to put lasting marks on our body-minds: irreversible reproductive damage from police tear gas, climate crisis, workplace injury, forced pregnancy, forced COVID-19 infection, forced imprisonment and institutionalized torture, domestic violence, and the list goes on and on and on. But to put marks on one's own body, to lay claim to one's embodiment through taking control over our endocrine system, through changing our anatomy with surgery, through having needles pierce our flesh to adorn ourselves with art, is to lay claim to the self, to communicate the self through embodiment, to deny that the body is but and only a tool of reproduction. In transition it is to not only deny the myth of biological and binary sex, it is to demonstrate our denial with our very bodies, in many cases—whether we wish to or not—to be *the embodiment* of that denial in social space. For me, it is also a project (however tenuously or haltingly) of self unification, of affirming my body as me. I have so little control over its internal processes and a roughly equivalent amount of control over the external forces that further marginalize and disable it, but there are things about it that I *can* change, and exploring the breadth of what is possible to change or to just fool around with in regards to embodiment is what makes this body feel like me, even in the midst of pain. I am here. There are more marks on this body made by me, or at the least initiated by me, than there are marks made by systems of violence overriding my will. Here and there are records of who I was, who I am, and who I am becoming. I can't change the realities of my gender marginalization, but I can take and distort the gendered symbols and rites and practices held so dear and natural and irrevocable by patriarchy and make of my body, and thus myself, a visible and *intentional* blaspheme against it.

It is not lost on me either that a majority of the body modification I adore requires some payment of pain to acquire it. While I have never been among the body modifiers who hold the pain as an important rite of passage (I have enough pain in my life and I don't find its endurance a particularly or intrinsically meaningful endeavor) I do think there is something rebellious, too, in willingly and intentionally choosing to endure pain for a purpose, an aesthetic outcome, a self-affirmation. In body modification the pain can be minor to extreme, but—if all things go well— it is a pain that can generally be expected to be bound in time. There is a timeline along which tattoos, piercings, or double mastectomies generally heal. I know pain is coming; I scheduled it! And I can hold onto a reasonable hope that the pain will fade with healing over time. I even get a little care sheet that tells me how long it will take and exactly what to do to help it along. What is often so destabilizing to me about chronic pain is how unbound it is. It is not for two weeks or four months or two years. It is always. There is no end in sight. No horizon to look for. Because of this there is always a lingering ambiguity, that things *might* be different, one day. One day when I have enough money. One day when I find the right doctors. One day when I find the right medication. One day when I finally have some answers. But to give oneself up to hope in that one day is, in another way, to condemn oneself to a life of waiting, of putting off living until that one day finally comes around and I can have my life as I once knew it back. Taking on pain that is (when things go as can generally be expected) bound in time sometimes helps give me a very needed reminder that not *all* pain in life will become chronic. Some pain goes on. Some pain changes. But some pain does indeed end. The practice of opting into risk, into pain—especially when I intimately know how it can linger if things *don't* go right—feels like a kind of rebellion against chronic pain. If I must carry this, if this is a part of my embodiment, then so to will art be, will gender transgression be. I am made, but so too do I make myself.

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