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Notes from a body

i. proof

In her short story *Tributaries*, Ramona Ausubel describes a world where falling in love is tangible, evidenced by the growth of a new arm. Teenagers inspect the soft sides of their torsos obsessively, yearning for the first nubby blossom of love to sprout, while one proud man wears a false arm every day, uncomfortably attached to his chest. To possess only two arms announces to the world that you have never loved; more than two or three extra limbs suggests infirmity of some kind. We all want to be capable of love, but to love too easily is excessive, perverted, feeble-minded. Too many arms is abject, a body ruined by its own expression.

As much as *Tributaries* is a crude metaphor for the way love disfigures us, it is also a story about the Janus-face of proof. The wife of the false-armed man must live the proof of their relationship every day in his lack of a limb. She tends to his fake arm, yet she uses only her born-on arms to wash it carefully, her own real love-arm uninvolved in the process. Another character, a teacher named Claribel, cannot hide the fleshy truth of her gaping heart. Her entire upper body is covered in hands that clench and wave, some whose origin she doesn't even know, clawing, wriggling proof of a body given over to evanescent love.

For more than half my life, I have sought proof in the form of a diagnosis. When my limbs turned leaden, when I couldn't rise from the groggy half-light between wakefulness and slumber, I wanted to know: why did I feel like this, where had this come from, how could I be cured and restored to my former feeling of being a body? I was a teenager then, only 14, wide-eyed and trusting that this was possible. But as time wore on and my symptoms fluctuated rather than faded, I learned to crave a diagnosis for other reasons. Because it would language my experience, transform my feelings into facts. Because if I could name it, then maybe I would be believed. Because no one could see what I felt, could touch it or hold a cup to my body and hear the echoes of experience. Without a diagnosis, illness was a feeling alongside guilt and shame. Without a diagnosis, the only proof I had was my body.

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome —the condition I had, although I didn't know it for a while —is determined via a diagnosis of exclusion. This means that, lacking an overly specific or sensitive test for the illness itself, ME/CFS is only diagnosed when other possibilities that *do* have specific tests are ruled out. As with other chronic illnesses, the path to 'proof'

can be long and arduous, and it is common for ME/CFS patients to see four or more doctors before a diagnosis is received.¹ Statistics like this still (always) evoke a blush of shame for me, who continues to find diagnoses elusive, because what if the reason I can't be diagnosed is that there's nothing wrong with me? What if it is all in my head? Sometimes even the proof of my own body, my own *ill feelings*, are not enough for me to wholeheartedly believe myself.

In their book *Ill Feelings*, Alice Hatrick traces a history of ME/CFS, describing the way (primarily female) patients were routinely dismissed as merely 'neurotic' or 'hysterical' when doctors failed to find a root cause for their plethora of mostly invisible symptoms, which ranged from malaise, fatigue, headaches, sore throats, dizziness and nausea to partial paralysis, impaired memory and cognition, pain and muscle spasms in their abdomens, legs, backs, and so on. Hatrick goes on to cite Dr Mervin Ramsay, the consulting physician in the Infectious Diseases Department at Royal Free Hospital in London during the 1955 outbreak of ME. In the years that followed, Ramsay went on to become the authority on the condition and was committed to dispelling misconceptions of a psychological origin. In 1986, he wrote an account of the outbreak which included the reflection that "the basic essential in treatment is correct diagnosis. This is a truism which might be said to apply to all human ailments but I have never seen it so vividly illustrated as in victims of ME."²

No diagnosis is purgatory, but a diagnosis that is incorrect, inadequate or punitive might be worse. The same GP who made my mum and I aware of CFS (but refused to diagnose it) suggested the condition, my condition, was likely psychosomatic, located in the mind rather than the body, as though the mind exists in the cloud or the ether rather than being within and of the body. Even now, with full awareness of how erroneous and damaging this suggestion was (the GP in question has since been struck off), I hold this hard little kernel of doubt in my heart that perhaps none of my pain is or has ever been real. And this makes me question whether I want to be diagnosed at all, because at least when my pain has no name it is mine to know and believe. Hatrick understands this when they write, "When my mother and I enter the doctor's surgery, our symptoms are still opaque and illegible, real and unreal, they are still ours alone to record and, often, self-medicate."³ And later in their book, "Diagnosis is a naming exercise. It groups you together with others 'like you,' turning your singular experience into one of many. But it is also a condemnation."⁴ A diagnosis may offer information, community, proof. But proof, as *Tributaries* teaches, has two faces. How good, to be able to wave your new arm as proof that you love. But how to hide too many arms, how to maintain a false arm day

¹ Alice Hatrick, *Ill Feelings*. Melbourne: Scribe Publications, 2021, 37.

² Dr Mervin Ramsay cited in Hatrick, *ibid*.

³ Hatrick, 11.

⁴ *Ibid*, 39.

after day, year in and year out. Where next, when you are given the proof you longed for, only to discover it changes nothing.⁵

ii. spoiled identity

“So-and-so was young, healthy, a runner... and now he’s a piece of SHIT.”⁶

This is the shorthand used by Artie Vierkant, co-host of the podcast *Death Panel* and co-author of the book *Health Communism*, to describe a dominant media trope in the reporting around long COVID. In an episode dedicated to unpacking the media narratives surrounding this (ongoing) mass disabling event, Vierkant and his co-hosts Beatrice Adler and Abby Cartus point out that this trope isn’t new, is in fact an extremely predictable response, merely a continuation of the already extant, dominant belief that disabled people are the diametric opposite to “productive members of society” i.e., workers, and are therefore deemed surplus, unable to work and thus an abject drain on society.⁷ Furthermore, these media narratives also serve a fear-mongering function, laying bare how long COVID can come for *anyone*, levelling becoming chronically ill as a population-level threat. As Adler Bolton puts it, “at any moment you too... could become disabled and experience this poverty, this rejection, this unemployment, this lack of access to care. This is used to frame disability as unequivocally bad and a doomed destiny.”⁸ Such narratives reveal just how deeply ingrained and socially normalised our understanding that becoming chronically ill or disabled is a fate worse than death, the end of your life and your joy, the spoliation of your identity.

The idea of the ‘spoiled identity’ was popularised by sociologist Erving Goffman, who uses the term to define ‘stigma’ – the topic and title of his 1963 book. Stigma, Goffman writes, “is a process by which the reaction of others spoils normal identity.”⁹ It is a context-sensitive judgement, as one group’s ‘normal’ is another’s stigma. But as Adler, Cartus and Vierkant posit, when the spoiled identity narrative of illness and disability is reproduced continuously in the media, it creates *the* understanding of what it means to be sick and disabled,

⁵ As Hatrick explains – and as I heard during my own experiences – some consider CFS the ‘trash can’ of diagnoses, partly because so little is known about it, but mostly because this means there is little that can be done for you “except what you could do for yourself.” Ibid, 40.

⁶ Beatrice Adler Bolton, Abby Cartus and Artie Vierkant, hosts, “Long Covid Media Narratives (11/17/22)” *Death Panel* (podcast), November 17, 2022. Accessed June 1, 2023.
<https://soundcloud.com/deathpanel/long-covid-media-narratives-111722>

⁷ Although as Adler Bolton and Vierkant make clear in their book *Health Communism*, capitalism still deems the surplus population ripe for value extraction. “...the surplus population has become an *essential* component of capitalist society, with many industries built on the maintenance, supervision, surveillance, policing, data extraction, confinement, study, cure, measurement, treatment, extermination, housing, transportation, and care of the surplus. In this way, those discarded as non-valuable life are maintained as a source of extraction and profit for capitalism.”

Beatrice Adler Bolton and Artie Vierkant, *Health Communism*. London: Verso, 2022, 5.

⁸ Adler Bolton, Cartus and Vierkant, “Long Covid Media Narratives (11/17/22)”

⁹ Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster, 1963, 3.

and therefore informs sick and disabled folks’ —especially those newly coming to terms with becoming disabled or chronically ill—sense of self. To become disabled or chronically ill in this landscape is to be told over and over again that your illness is bad, and your illness is your identity, and therefore you are bad, worthless, surplus.

In this discussion, the Death Panel hosts seem to gesture towards what Foucault terms “technologies of the self,” which are concerned not with “how power operates through force” but with the more insidious processes by which “knowledge is taken up by the self and used to produce truth about the self.”¹⁰ To listen to people with long Covid describing themselves in these media interviews is often to hear them perform ableism against themselves, turning themselves into spoiled identities, often taking on the legitimised language of medicine to describe themselves, equating their own value with their ability to be ‘productive.’

In my own diary of my teenage illness I recount a story of correcting a class mate who described me as “always sick,” telling them that was what I wanted them to think when really, I was wagging. Far better to be seen as a truant than chronically ill, or pretending to be chronically ill. Reading it now, I can remember that moment vividly, not the where and how, but the feelings of frustration and obstinacy: how dare they call me sick, they don’t know me, they don’t know what sick means. I wanted to overturn their assumptions, to imagine for myself a new identity beyond illness because yeah, I was sick, but I was pretty sure that if I wasn’t sick, I would wag.

In *Tributaries*, the proud man’s fake arm ends with a stump, sewn up to make it appear as though the hand has been amputated. He knows that fake hands look fake, and so he has fabricated a story about how he lost his hand in a fire from which he saved his wife and daughter. “He is sure that if he *did* have a love arm, and if he *had* lost the hand to it, he would have wanted a replacement. It’s the kind of man he is —everything in its place. So, attached to the very real-looking stump with big, obvious screws, is a wooden hand. It is the fakest he could find, an art class model. Against this, the arm looks especially life-like.”¹¹ His teenage daughter knows his arm is fake, but she doesn’t tell his secret. She loves the lie, loves “that he built himself what did not come on its own. He said yes, and though his physical form stayed silent, he created a voice for it. Made it sing the notes of his song.”¹²

Revolution could look like telling a lie, spoiling your identity for yourself.

¹⁰ Michel Foucault referenced in Juaune Clarke and Susan James, “The Radicalized Self: The Impact on the Self of the Contested Nature of the Diagnosis of Chronic Fatigue Syndrome.” *Social Science & Medicine* 57, no. 8 (2003): [https://doi.org/10.1016/S0277-9536\(02\)00515-4](https://doi.org/10.1016/S0277-9536(02)00515-4) , 1388.

¹¹ Ramona Ausubel, “Tributaries” in *A Guide to Being Born*. New York: Riverhead Books, 2013, 228.

¹² *Ibid*, 239.

iii. anamnesis

Through the blue summer of 2021 and into the following winter, I saw my acupuncturist once a week. Under the radiant warmth of a heat lamp, my abdomen was massaged deeply and painfully before being pin-cushioned. While she kneaded my stomach or agitated a needle, we talked about all manner of things, but especially about me, my circumstances and my pain. She would examine my tongue, ask about my period, tell me to eat more bitter foods, more chicken liver, vegemite, to only drink hot water. Sometimes, when I told her about something difficult, she would stroke my hand very gently.

Despite six or so months of regular needling, there was one evening when I just couldn't take it. As the needles went in, I felt a wave of such horror and discomfort that hot tears squeezed from my eyes. It was as though the needle had punctured a deep seam of sorrow and rage, letting it spill forth into my body. My skin crawled, I felt furious and raw, like a child throwing a tantrum, all the world was unfair, poison, pain.

When Proust raised his first taste of tea-soaked madeleine to his lips, his response was immediate. "No sooner had the warm liquid, and the crumbs with it, touched my palate, a shudder ran through my whole body, and I stopped, intent upon the extraordinary changes that were taking place... I had ceased now to feel mediocre, accidental, mortal. Whence could it have come to me, this all-powerful joy?"¹³ Proust's experience of anamnesis, a recollection or remembrance of the past, was as blissful as mine was despairing, and by the end of his written account he has satisfyingly recalled the memory conjured by his madeleine. In medical discourse, *anamnesis* has its own distinct meaning: it is the patient's own account of their medical history, an alternative to the more widely accepted epicrisis, which is written by the doctor. When my medical centre began using an online patient portal, I suddenly had access to (some of) my medical records. I was able to trace my own history and discovered the pain I had been in for "a few years" had actually been going on for a decade.

I have long wondered about the night the needle pricked forth so much. Was it the needle? What did it signify? How could I seize upon and define it? After a few mouthfuls, Proust realises the answers to his questions cannot be found in the tea but are in his own mind, eventually locating his memory. I am sure the answers to my questions are not in the needle but in my body, however, I am not sure there is a satisfying memory to be found there, just the truth of a body sick of itself.

¹³ Marcel Proust, *In Search of Lost Time, Volume I: Swann's Way*, rev. ed, Great Britain: Modern Library, 1992, 60-61.

iiii. paradox

In their essay *Sick Woman Theory*, Joanna Hedva references Judith Butler, whose writing “insists that a body is defined by its vulnerability, not temporarily affected by it.” If this is so, Hedva rallies, “we need to reshape the world around this fact.”¹⁴ Every so-called able body in this world is one viral infection or workplace accident away from becoming disabled and experiencing this vulnerability for themselves. So where is the empathy? In *Health Communism*, Adler Bolton and Vierkant similarly call for “all care for all people... a radical abundance of care that functionally casts off centuries of ideologies of austerity, subjection, and extraction”, the only logical response to the paradox we live in where capitalism requires the health of the worker to function while simultaneously rendering health impossible under the conditions it creates.¹⁵ It is ultimately this same paradox Hedva invokes when they describe a utopia in which everyone has become disabled and, confined to their beds and unable to work. Capitalism, they write, “will screech to its much needed, long overdue, and motherfucking glorious halt.”¹⁶

I want to end this essay with an original idea, or failing that, at least on an optimistic note. But I am led to the same place as those before me: our bodies are all we have, and they are vulnerable. The only thing we can do is care for them and the only way we can ensure that everyone can care for their body is to change the conditions they are subjected to. Bodies don’t need to be put to work, they need care, an abundance of care, an excess of care, so much care it becomes too much, our bodies opening themselves to new ways of being, telling stories about themselves, sprouting new limbs to express our love, our appreciation of being so very, very loved.

¹⁴ Joanna Hedva, *Sick Woman Theory*, 2020, https://www.kunstverein-hildesheim.de/assets/bilder/caring-structures-ausstellung-digital/Johanna-Hedva/cb6ec5c75f/AU_SSTELLUNG_1110_Hedva_SWT_e.pdf, 5.

¹⁵ Beatrice Adler Bolton and Artie Vierkant, *Health Communism*, London: Verso, 2022, xii-xiv.

¹⁶ Hedva, *Sick Woman Theory*, 8.