UNUSUAL VELVET (BACK STORY)

by

GENEVIEVE KARLIE GUZMÁN

(Under the Direction of Reginald McKnight)

ABSTRACT

This creative dissertation, a collection of disability poems, opens with an auto-ethnography that theorizes why it took me sixteen years of disabling mystery illness to embrace disability studies. As a patient of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), I felt sick in the first place, disabled in the second, and studied the medical humanities for insight into living with chronic illness. On diagnosis with a genetic disorder of the connective tissue, I learned I had been disabled the whole time by faulty collagen, and I pivoted to disability studies to understand the disabled experience in turn. A former waltzer forced into early retirement by debility, I survey contemporary disability literature for modes of reclaiming an embodied art in words.

As background, I define disability according to the United Nations and World Health Organization to explain the medical model of disability, which seeks cures for what it deems insufficient bodies, and the social model, which seeks infrastructural remediations for bodies innately sufficient as they are. I disentangle the historical incompatibility of the sick and disabled identities informed by feminist philosopher Susan Wendell's notion of the healthy disabled (2013) and weigh the psychic damage done to patients of medically unexplained symptoms who first receive incorrect diagnoses of psychosomatic illness from dismissive physicians.

Next I conduct a Foucauldian analysis of Maud Casey's *City of Incurable Women* (2022), a historical novella that gives voice to nineteenth-century women warehoused for hysteria, a now defunct psychosomatic diagnosis of the era. Philosopher Michel Foucault’s concept of the medical gaze (1963) clarifies the power structures at play in an institution where a captive female population learns to “write” their illness in medical photographs. Finally I engage poet Jim Ferris’s aesthetic of asymmetry (2004) to enable formal reinvention in “crip” poetry. My own poems speak obliquely of mobility impairment until the last section on the neurosurgery I had for a spinal defect that restored my ability to walk longer distances. The third section features erasure poems created from interviews I conducted with ME/CFS patients, whose testimony distills inherent truths about the human condition from their lived experience of chronic illness.

INDEX WORDS: People with disabilities -- civil rights, Women with disabilities, Attitude to disability, Social advocacy, Hysteria -- France -- history -- 19th century -- fiction, Women patients -- France -- history -- 19th century -- fiction, medicine -- history, Medicine -- philosophy, American literature, Literary criticism, Disabled poets, Adjustment (psychology) -- poetry, Poetry

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DEDICATION

To the Millions Missing, all the patients of chronic fatigue syndrome missing from their lives, help is coming.

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Love and gratitude to all.

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INTRODUCTION

“Why don’t you go into disability studies?” she asked.

It was the spring of 2013 or so, and my friend Joey McGarvey had invited me for dinner at her apartment in Inwood Park at the northern tip of Manhattan. We were playing SET, a pattern-matching card game of striped and solid tildes in triplets at which I could not be beaten—until that evening against her husband, Ian, a real-life wizard of mathematics and now a professor of number theory. Joey had been my student in a Nabokov seminar I had teaching-assisted while we were both at Stanford and, since then, had gotten a master’s degree in English at New York University and taken a position as an editor at Random House.

I had no such early-career success to show, having been delayed from Columbia’s doctoral program in Russian literature by a mystery illness and subsequent medical leave. A year and a half later, my health had somewhat stabilized, and I had come back to New York. Joey and I were talking about writing poetry, a practice I took up to survive the PhD while chronically ill. But realization was also dawning that my academic subject, or at least, the area-studies approach to it, didn’t quite suit me. I would sit down at my laptop to work, call my sister, and complain I could more easily write a novel than a dissertation. When, to the faculty’s amazement, I won our department’s internal prize for Russian poetry translation, I took it as my cue to withdraw from Columbia for the translation MFA at Iowa.

There was no discussion of any disability but mine when I was in Russian literature, so if Joey was suggesting I pursue disability as a discipline, I was already on my way out of area studies. From translation, I meant to go all the way to the dark side of creative writing. I told her I needed ten years to get her a poetry manuscript. “All her friends say that,” Ian shrugged. Of course, the wizard was right. The intervening decade came and went without any manuscript from me. Maybe Joey's other friends delivered; maybe they didn't. For me, it has simply taken longer. Only now for this creative dissertation have I assembled a set of poems approaching full length. They map the arc of my learning to write poetry, all the admissible and published or potentially publishable poems of the last decade since I began writing in earnest. A Workshopper I knew at Iowa said it takes a hundred poems to get good. I've written that many now, mostly unprintable juvenilia as befits a beginner, so I might amend his statement to say, it takes a hundred poems to find your voice because good is subjective. At least these poems, to my ear, sound written by someone with an intentional style, and I'm content with that. Whether I need to write a whole set in a stabilized voice to send to Joey, I'll decide next.

But the answer to her question, why didn't I go into disability studies, or why not sooner, is predictably complicated. It will sound defensive to say it's not because of stigma, but I swear it's not. True, I cried at my first meeting with a disability coordinator at Columbia because, in the span of three and a half years, I'd gone from performance dancer to someone who could barely walk a block or climb a staircase without skewering leg cramps. I had only ever prepared for an active life and now found myself undeniably disabled. As it is for all of us who find ourselves suddenly impaired, my new normal was a shock. And yes, at first, I felt ashamed to use a wheelchair in public because I didn't know where to look or how to hold or deflect the gazes I met as I was pushed by. If I stood up out of the chair for any reason, I would get amazed comments on how I actually could walk, and how strange. Most people think wheelchair users are paraplegic at minimum. This vocal amazement would put me on the defensive, and being me, I'd pipe up about how some disabilities are partial and invisible and launch into the whole spiel, yada yada. Maybe I opened some eyes and minds that way. Maybe I only advocated for myself in the moment.

Whatever my public-facing advocacy, whenever I have needed accommodations, I request them. I don't care who sees me get out of my car when I park in a blue bay; in fact, I relish the morbid curiosity certain onlookers must feel when I flounce off without apparent impairment. I gladly use an elevator to avoid stairs if there is no escalator at hand. On one hand, uncharitable, I have never hesitated to identify as disabled if it made my life easier or enabled opportunity, distinction, or funding; on the other, more generous, that's what accommodations are for. Nobody would pretend so-called "reasonable" accommodations replicate an able-bodied experience or justify, compensate for, or otherwise adorn being disabled. They level the playing field as much as it can be leveled, which is not much. Just because I have unofficially adopted the closest blue bay behind our department as My Parking Spot does not make faulty collagen and impact intolerance worth it, even if my access to that parking spot allows me to run almost unpardonably late to campus every day I go in. It's a silver lining at best. I'd rather stride in on time from a farther lot.

Nor would I ever discourage anyone from seeking documentation of disability or accessing accommodations. I tell my students from the jump I have impaired mobility so they feel safe discussing their own access needs with me but also so that, when inevitably I move my office hours online due to mounting fatigue as the semester wears on, they understand. I would call this advocacy but not activism. I have never campaigned for better research funding for any of my illness communities past or present, always too overwhelmed with professional commitments I'm only halfway strong enough to fulfill. In my defense, I do not qualify for government disability insurance or supplemental income because I *can* work part-time and have more than two thousand dollars in assets. In other words, I'm not disabled enough. Until the Social Security Administration adopts a sliding scale for disability, which it should but may never and now no time soon, the system directs my energy away from activism with my reduced ability and increased need to make a living. Ultimately I would prefer to protect my legal ability to work even part-time rather than forgo my vocation. Disabled folks are uniformly devastated to leave their professions for a modest SSDI stipend and the designation of permanent disability.

Nobody sits around shiftless at home and impishly collects the way stereotypes paint. All these individuals, at least those in my illness spheres, want to contribute to society and suffer daily, sometimes hourly, for their lost careers. My best excuse for not working overtime on their behalf is that I've been performing low-wage graduate labor, a service of its own kind.

Along with my capacity to work, I've enjoyed the plausible deniability of invisible disability. For a while, I was very thin, but otherwise, one would not have known by looking at me that my body was excruciatingly unbalanced. My gait is normal enough that only a kinesiologist or physiatrist would spot the scoliosis and sway back, the pigeon neck that now looks to me like a dead giveaway of everything that ails me, even if physicians and physical therapists dismissed it for sixteen years. Even noticeably hypermobile, I'm viewed as able bodied, a fact that mitigates certain challenges because it means I control perception of me as a disabled person. I could be accused of taking the unobtrusive way out, hiding under my cloak of invisibility to pass as abled whenever possible. To ease our already difficult lives, most of us with invisible conditions do. We disclose our status where and when expedient.

But gatekeeping this knowledge only works if we're believed. Invisibility has forced me to beg credulity from doctors, family, and strangers alike. My condition was so thoroughly invisible, it hid on blood tests and MRIs and neuro exams, imperceptible even to specialists until I got in the room with micro-specialists who could detect it. On balance, it's impossible to know whether more or less visibility would have made my life better or worse, saved me pain, grief, or money, or sped my timeline to diagnosis because a more severe and thus more visible presentation would mean I must then live with more severity. Because all counterfactuals are inherently false, I waste my time recalculating the zero sum of my medical luck.

But the real reason I didn't go into disability studies sooner is that I believed I was ill. All signs pointed to primary illness with secondary disability. As a patient of myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), I felt sick, sickly in the first place, disabled in the second. Disability pride revolves around seeking rights rather than cures, and I very much wanted to recover. Even to exhibit a negative attitude toward my limitations felt like a betrayal of the identity group. This is not to say I had nothing in common with the low vision or hard of hearing or electric wheelchair users, just that studying the history of our oppression would not have gotten me diagnosed any faster. I might've uncovered my diagnosis more quickly had I gone into medicine myself: one of my lives not lived, and one I sometimes regret. So in my graduate work, I have hewed more closely to the medical and health humanities for insight into how to bear the burden of chronic illness than I have to disability studies and the history of disability rights.

Even then, I didn't devote myself to narrative medicine. I read dozens of illness memoirs for a doctoral exam in modernist and contemporary illness literature, but I don't have a draft of my own memoir stashed away in a drawer. I didn't write such a memoir for this dissertation. I would say I have dabbled. Maybe I just wasn't interested. Without my condition and all its lived experience, I'd specialize in the environmental humanities. Without the climate crisis and anthropocentrism, I'd have gone toward performance studies. All things being equal, that's where my interests lie.

But all things are never equal. I think, in the end, I just couldn't bear it. I couldn't bear a mystery illness and also study disability. It was too austere to make the fruitless rounds of doctors year after year to no new insight and also study the inhumane treatment of disabled people through the ages. When finally a neurosurgeon diagnosed me with hypermobile Ehlers-Danlos syndrome (hEDS), a genetic disorder of the connective tissue, with occult tethered spinal cord and craniocervical instability, I could not believe that all those years, sixteen years of mystery symptoms, I had never been sick. In my body, there was no ongoing process of tissue damage by pathogens or my own cells, no viral-bacterial-fungal-parasitic infection or teratogenic-autoimmune self-destruction or chemical-toxic poisoning. I never acquired my condition, if acquisition suggests a state before and after a foreign agent gained entry. Neither is it a birth defect, a consequence of the fetal environment. It is congenital, the random chance of genetic recombination that characterizes sexual reproduction, as indivisible from my being as any other encoded part of me. I may feel unwell; still I am and was not ill.

All along, I was disabled at the source by faulty collagen proteins and all their downstream effects: the snapping pain of joint subluxations due to lax ligaments; the fatigue of my muscles doing at the cost of energy what working ligaments do for free; dizzyingly low blood pressure due to blood vessels that insufficiently contract when I stand up; a spinal cord so taut, it played my legs like banjo strings. No cure exists for any genetic disorder. The treatment for mine, degenerative but not fatal, is straightforward enough: take salt tablets, get supportive shoes, avoid impact, take up swimming, get spine surgery. I recovered from surgery with no complications (knock wood during this two-year postoperative interval) and walk fifty percent more than I did before. If any part of my story has been lucky, it is this surgical outcome.

And with that, I was released from my diagnostic quest and the health humanities all at once. At least for this condition, I never have to comb the diagnostic manual again. I'm free to study disability in all its forms without the Atlas burden of my own unknown quantity. For the sake of these poems, so coy about the speaker's impairment until the second half of the collection, I want to understand from a critical perspective what happened to me in the hospital system as an illegible patient of a rare disorder and how contemporary American writers render their disabilities legible on the page for a literary audience. An amateur performance waltzer forced into early retirement by debility, I seek contemporary precedents for reclaiming an embodied art in words. But first, I present a brief history of disability rights and their constructive interference with medical perception.

Modeling Disability

Disability is a legal, medical, and social concept the United Nations first described in 1945 when it began promoting “the rights of persons with physical disabilities”[1] in the form of social welfare. While the UN notes no impetus for this timing, it coincides with the end of World War II. The Paralympics were founded soon after in 1948 with the purpose of reintegrating injured veterans and civilians into rehabilitative and competitive sports.[2] The UN prioritized rehabilitation and prevention until 1971, when their General Assembly progressed to a human rights approach with the *Declaration on the Rights of Mentally Retarded Persons* and, four years later, the *Declaration on the Rights of Disabled Persons*.[3] They decreed 1981 the International Year of Disabled Persons with a call to action for the equalization of opportunities at all levels of society, from the regional to the international.[4]

In the 1982 *World Programme of Action Concerning Disabled Persons*, the General Assembly defines three key terms per the World Health Organization’s 1980 classifications:

- **impairment:** Any loss or abnormality of psychological, physiological, or anatomical structure or function.
- **disability:** Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

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[1] “History of United Nations and Persons with Disabilities—The Early Years: 1945–1955,” United Nations: Social Inclusion, n.d., accessed Feb. 6, 2025, social.desa.un.org/issues/disability/history-of-disability-and-the-united-nations/history-of-united-nations-and-2.

[2] “Paralympics History,” International Paralympic Committee, n.d., accessed Feb. 8, 2025, www.paralympic.org/ipc/history.

[3] “History of United Nations and Persons with Disabilities—A Human Rights Approach: The 1970s,” United Nations: Social Inclusion, n.d., accessed Feb. 6, 2025, social.desa.un.org/issues/disability/history-of-disability-and-the-united-nations/history-of-united-nations-and-0.

[4] “International Year of Disabled Persons, 1981,” United Nations: Disability, n.d., accessed Feb. 8, 2025, www.un.org/development/desa/disabilities/the-international-year-of-disabled-persons-1981.html.

- **handicap:** A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.[5]

According to the WHO, a loss of function (impairment) restricts normal activity (disability), which in turn limits the normal fulfillment of social roles (handicap), *normal* itself being a relative and contested term. In *The Rejected Body* (1996), feminist philosopher Susan Wendell praises these definitions as "generalized enough to include many conditions that are not always recognized by the general public as disabling, for example, Crohn's disease, which limit people's activities but do not necessarily cause any immediately observable disability."[6] Wendell's interest in visibility surfaces here as concern for disabilities below the *observable* threshold. She admires in the WHO's classifications the growing awareness of disability as a social lack of accessibility, services, income, and civil rights rather than any inherent physical lack. At the same time, she critiques, as I do, the presumption of normalcy according to some "universal, biologically or medically describable standard of structure, function, and human physical ability,"[7] all of which are culturally contextual.

Since 1982, the UN has periodically revised its approach to disability protections[8] such that the contemporary language, as laid out by the 2006 Convention on the Rights of Persons with Disabilities, completely reverses course on earlier notions of prevention and welfare:

> Crucially, article 1 establishes **disability as a social construct** that arises from "interaction with various barriers [that] may hinder [individuals'] full and effective participation in society on an equal basis with others" rather than as an inherent

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[5] "World Programme of Action Concerning Disabled Persons," United Nations: Disability, n.d., accessed Feb. 8, 2025, www.un.org/development/desa/disabilities/resources/world-programme-of-action-concerning-disabled-persons.html.

[6] Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (Routledge, 1996): 13.

[7] Wendell, *Rejected Body,* 14.

[8] "History of United Nations and Persons with Disabilities—The Decade of the Nineties," United Nations: Social Inclusion, n.d., accessed Feb. 6, 2025, social.desa.un.org/issues/disability/history-of-disability-and-the-united-nations/history-of-united-nations-and-1.

> limitation (art. 1). In doing so, the Convention presents disability as a natural and universal phenomenon of human diversity and rebuts the prevailing historical paradigms of disability as a medical deficit, focus of charity, or condition requiring a medical 'cure' or social welfare provision. Further, article 1 conceives of disability as being inclusive of and not limited to 'long-term physical, mental, intellectual or sensory impairments', which reflects a floor rather than a ceiling. *Notably absent in article 2, the definitions article, is any definition of 'disability'.* Instead [...] the treaty '[r]ecogniz[es] that disability is an evolving concept" that results from the interaction between persons with impairments and attitudinal and environmental barriers.[9] (italics and quotes original, bolding mine)

Here the UN Convention declares itself for the *social model of disability,* a theory that frames disability as a social construct in which environments and social stigmas, not bodies, disable individuals, who may or may not be inherently impaired. Adapted from the philosophies of the Union of the Physically Impaired Against Segregation in the United Kingdom in the early 1970s, the social model, in the words of scholar Tom Shakespeare, operates on "the distinction between disability (social exclusion) and impairment (physical limitation) and the claim that disabled people are an oppressed group."[10] Although the UN acknowledges these systemic barriers, they do not go so far as to dignify the disabled as oppressed or marginalized. While many sources, including some from the UN, repeat the oft-quoted statistic that disabled people constitute the world's largest minority group,[11] all these sources cite the WHO, which claims only that an "estimated 1.3 billion people experience significant disability [, representing] 16% of the world's population, or one in six of us."[12] That such a large share of humanity manifests disability does reinforce the Convention's idea of it as a "natural and universal phenomenon of

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[9] Michael Ashley Stein and Janet E. Lord, "Convention on the Rights of Persons with Disabilities," United Nations, 2023, accessed Feb. 6, 2025, legal.un.org/avl/ha/crpd/crpd.html.

[10] Tom Shakespeare, "The Social Model of Disability," *The Disability Studies Reader,* 4th ed., ed. Lennard J. Davis (Taylor & Francis, 2013): 215.

[11] "Disability Stats and Facts," *Disability Funders Network,* n.d., accessed Feb. 9, 2025, www.disabilityfunders.org/disability-stats-and-facts.

[12] "Disability," World Health Organization, Mar. 7, 2023, accessed Feb. 9, 2025, www.who.int/en/news-room/fact-sheets/detail/disability-and-health.

human diversity," although if it indeed arises from external barriers, it is sooner impairment they mean to call natural and universal.

Equally significant, the UN Convention repudiates the prevailing *medical model of disability*, which views impairment as a bodily deficit to correct or cure to normative standards. Implicit within the medical model is the deferred responsibility and even denial of any need to improve systemic accessibility when corrected and cured bodies can reintegrate seamlessly into existing infrastructure. In the medical model, the impaired body takes all blame for access failures; in the social model, the inaccessible environment is at fault. In the convention's full name, "on the Rights of Persons with Disabilities," we see a return to the person-first language that appeared in their earliest mission statement of 1945—*persons with disabilities* instead of *disabled persons*—although in recent years, the person-first prescription has come under fire as euphemistic and stigmatizing of the proudly disabled identity that would name itself upfront. In most minority groups, advocates and activists espouse self-identification so that we leave the choice of terminology and label to the persons themselves.

Claiming Disability

Illness and disability are neither mutually inclusive nor exclusive. Before my definitive diagnosis, I identified as sick before disabled because I believed my disabling symptoms derived from illness. Illness was the supercategory, the meta-genre, or seemed to be. To split linguistic hairs, I wasn't disabled; I had a disabling illness. My denial was a sort of solidarity. In "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities" (2013), Susan Wendell articulates how the contemporary disability rights movement has "fought the identification of disability with illness [for how it] contributes to the medicalization of disability."[13] Dictionary definitions of *sickness, illness,* and *disease* are so general as to blur the lines impractically

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[13] Susan Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," *The Disability Studies Reader,* 4th ed., ed. Lennard J. Davis (Taylor & Francis, 2013): 161.

between malady and disability and necessitate a technical or medical definition here. The WHO distinguishes among diseases based on contagion: noncommunicable diseases such as "cardiovascular diseases, diabetes, cancers and chronic respiratory diseases" oppose such communicable diseases as "HIV/AIDS, tuberculosis (TB), malaria, viral hepatitis, sexually transmitted infections and neglected tropical diseases."[14] Notably, no sensory impairments (of vision, hearing, or proprioception, among others)[15] appear in either list. The International Classification of Diseases categorizes ME/CFS as a "post-viral fatigue syndrome" characterized by "chronic, profound, disabling, and unexplained fatigue."[16] While there is no consensus on its exact pathology, all evidence points to a noncommunicable disease of the nervous system. So for me to identify as disabled when by all accounts I was ill would have confused the priority of structural remediation with medicine. Activists seek access; I sought a cure.

Nearly twenty years before her article on the unhealthy disabled, Wendell took up the question of whether illness or disability, asking, "How concerned should we be to distinguish disability from chronic illness? From life-threatening illness [...]? Of course, even when chronic or life-threatening, illness need not always be disabling [...]. It is also true that many people with disabilities are healthy."[17] Illnesses and disabilities run the gamut from mild to severe, with some disabilities needing more, less, or no medical attention at all. This spectrum, however, has done

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[14] "Communicable and Noncommunicable Diseases, and Mental Health," World Health Organization, n.d., accessed Apr. 8, 2025, www.who.int/our-work/communicable-and-noncommunicable-diseases-and-mental-health

[15] Kristen Ernstmeyer and Elizabeth Christman, eds., "Part VII, Sensory Impairments," *Nursing Fundamentals*, 2nd ed. (Chippewa Valley Technical College, 2024), www.ncbi.nlm.nih.gov/books/NBK610833/.

[16] "Chronic Fatigue Syndrome," World Health Organization, n.d., accessed Apr. 8, 2025, www.who.int/standards/classifications/frequently-asked-questions/chronic-fatigue-syndrome.

[17] Wendell, *Rejected Body,* 20.

little to endear illness to disability. Wendell quotes from Eli Clare's *Exile and Pride: Disability, Queerness, and Liberation* (1999):

> To frame disability in terms of a cure is to accept the medical model of disability, to think of disabled people as sick, diseased, ill people [...]. My [cerebral palsy] simply is not a *medical* condition. I need no specific medical care, medication, or treatment for my CP [...].
>
> Of course, disability comes in many varieties. Some disabled people, depending on their disabilities, may indeed have pressing medical needs for a specific period of time or on an ongoing basis. But having particular medical needs differs from labeling a person with multiple sclerosis as sick, or thinking of quadriplegia as a disease. The disability rights movement, like other social change movements, names systems of oppression as the problem, not individual bodies. In short it is ableism that needs the cure, not our bodies.[18]

Indeed, quadriplegia is a symptom of paralysis,[19] not a disease, and anyone who thinks it a disease has succumbed to ignorance as much as stigma. But stigma has prevailed on Clare too if he accepts MS patients as disabled but not ill when medical science understands the autoimmune process at work enough to call MS a neurodegenerative disease and treat it as one. It seems Clare objects to the negative connotations of *communicable* disease and sickness, insisting on a definition of disability that excludes infection. He seems to want within his ranks only the uninfected. By this measure, someone with a temporary disability such as a broken foot would buttress the disabled cause more than say, a patient of chronic Lyme disease, despite the latter individual's greater need for accommodations and systemic remediation.

Among the disabled, I don't find a disavowal of disease any less stigmatizing than ableism itself; indeed, I find it quintessentially ableist. In the famous opening lines of *Illness as Metaphor* (1977), critic Susan Sontag meditates, "Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the

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[18] Clare as qtd. in Wendell, "Unhealthy Disabled," 161–2.

[19] "Quadriplegia," Cleveland Clinic, Aug. 10, 2022, accessed Feb. 13, 2025, my.clevelandclinic.org/health/symptoms/23974-quadriplegia-tetraplegia.

kingdom of the sick. Although we prefer to use only 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."[20] If the healthy disabled turn away from the unhealthy disabled to circulate only on their good passport, they actively practice the same denial of human frailty that those not in coalition or discourse with the sick and disabled practice passively. Wendell demurs, defending separatists for their "understandable desire to avoid the additional stigma of illness, especially such heavily stigmatized ones as AIDS and cancer."[21] These stigmas are proportional to the perceived suffering and mortality that accompany diagnosis.

At least where medical science understands a given pathology, empiricism has largely dispelled the ancient stigma of disease as a divine punishment or judgment of community or patient. There is nothing wrong with being ill, nor should we imply any untouchability or inadmissibility of the sick in disabled circles or anywhere else. Indeed, there are parables against doing so. Certainly illness *can* be moral*ized,* the way HIV was during the AIDS crisis as a plague sent to eradicate gay men.[22] The diverse profiles of HIV patients, including transplant recipients and some fetuses of HIV-positive mothers,[23] have helped dispel the stigma of sin, as have advancements in treatment that took the virus from a terminal to a survivable affliction and even, in seven rare cases globally, a curable one.[24] The same moralizing occurred during the COVID-19 pandemic, when at first the media took comfort in the idea that most victims of the

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[20] Sontag, *Illness as Metaphor,* 3.

[21] Wendell, *Rejected Body,* 21.

[22] Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (Farrar, Straus and Giroux, 1989): 134.

[23] "How Is HIV Transmitted?," HIV.gov, Feb. 7, 2023, accessed Mar. 2, 2025, www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/how-is-hiv-transmitted.

[24] "Seventh Case of HIV Cure Reported at AIDS 2024," World Health Organization, July 25, 2024, accessed March 2, 2025, www.who.int/news/item/25-07-2024-a-seventh-case-of-hiv-remission-reported-at-aids-2024.

virus had underlying conditions, as if they deserved their fate more or life less. Then we heard reports of complications and death in those without preexisting conditions, and we grew properly scared and cautious in reaction.

Even within the disability community, stigma dictates a hierarchy of more and less desirable disabilities, with physical disabilities ranking above cognitive ones even before disabling illness blurs the lines. In the physically disabled, post-polio symptoms were historically preferred to those of cerebral palsy.[25] Moreover, Wendell continues, "[p]eople with physical disabilities often insist that they are not mentally disabled because of the additional stigma of psychological or developmental disabilities in most societies."[26] Stigma accrues in proportion to the perceived distance from normative identity groups. To refuse coalition with variously disabled individuals to avoid the stigma relative to our own micro profiles of cause, duration, severity, and thus to our perceived superiority or preference within a normative hierarchy, we diminish our strength in numbers to enact social change of all kinds.

To appeal to the slippery slope fallacy, where then does the stigma end in the line for medical care? Do we prioritize cancer patients by who lived healthier versus more indulgent lives before diagnosis; people who contracted HIV sexually versus intravenously versus in utero; amputees who lost limbs in war versus sporting accidents versus car accidents? Medicine already does: you will get a liver transplant faster for non-alcoholic cirrhosis than for alcoholic cirrhosis. By indulging any stigma with respect to illness or disability, by assigning any value judgment to either phenomenon, we contribute to the medicalization of both. It seems a convenient and ironic regression into the medical model to deny solidarity with those disabled by disease only because the word invokes connotations of communicability and contagion.

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[25] *Crip Camp: A Disability Revolution,* written and directed by Nicole Newnham and James LeBrecht (Higher Ground, 2020), streaming.

[26] Wendell, *Rejected Body,* 21.

Such pathogens occur as naturally and universally in the environment as any other impairment and can also be helped by structural initiatives such as vaccine campaigns, sex education, and drug rehabilitation.

But therein lies the problem: if we speak of preventing, rehabilitating, or curing disabling illness, we stumble into the original eugenicist agenda of the medical model of disability long since debunked and abandoned by the United Nations. The only answer I can descry to the question of whether illness or disability is a metric of primary or secondary impairment: does an individual have a sensory impairment like congenital blindness or limb difference, or a disabling illness like Crohn's disease or multiple sclerosis? But such a division fails along the fault line of communicable versus noncommunicable disease. In that case, if one's condition derives from genetics, the in vitro environment, or accident, then primary impairment; if by infectious disease, then secondary impairment. Disability therefore can only remain a critique of structural inaccessibility, whatever the nature of the impairment.

Identifying foremost as disabled or entertaining hope of a cure for my disabling mystery illness therefore felt like a betrayal of the disabled cause, even though everyone I know with chronic fatigue wishes for the same. The ME/CFS community prays daily for the powers of medical science to deliver them. All day long from bed, they campaign for research funding. Herself a patient of ME/CFS, Wendell notes, "[D]isability movements have criticized spending enormous amounts of public and donated money searching for 'cures' while neglecting to provide the most basic services and opportunities that would improve the lives of people with disabilities,"[27] something she calls elsewhere "medicine's preoccupation with life-and-death issues."[28] The same amount of money earmarked for research might fund considerable

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[27] Wendell, "Unhealthy Disabled," 172.

[28] Wendell, *Rejected Body,* 10.

structural remediation, but it won't create the knowledge that is the lifeblood of science, where inconclusive and failed results are a matter of course. Equal federal, state, or municipal disbursements would seem to be the only equitable solution. ME/CFS finds itself at a double exclusion from both medical and disability initiatives as a disabling illness that kills few except by suicide, demoting it to a stigmatized, psychologized, overlooked, and under-researched condition. Some individuals are so severely disabled by ME that access to opportunities would not make a meaningful difference in their lives. Access to basic care services would, but such services would not offer a possible future thriving the way research can.

For patients of mystery illness, the enigma of our conditions preserves hope of a cure until accurate diagnosis reveals medicine can offer nothing more at that time. At that point, says critic Susan Lonsdale, "For those people whose disability is a chronic illness such as arthritis or multiple sclerosis, the notion of being cured or made well [...] may be less relevant on a daily level, where adaptation and accommodation to the disability is necessary."[29] Wherever a patient takes medical science to its limits, the goal posts move from cure to accommodation. So perhaps I was justified in identifying as ill while I sought a cure and can relax into the social model of my disability now that I seek only to manage it. Perhaps the real test of disability is not how impaired or sick or handicapped we are, but whether in our sick and impaired handicap, we seek a cure.

One of my disability rights heroes, the painter and scholar Sunaura Taylor, whom I had the privilege to meet here at UGA last autumn when she was on tour for her second book, describes in her first book how, in 2012, she had the chance to meet one of her animal rights heroes, the utilitarian philosopher Peter Singer. Singer takes a dim view of disability as a force for good in the world because he believes humanity already endures enough diverse suffering in

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[29] Susan Lonsdale, *Women and Disability: The Experience of Physical Disability among Women* (St. Martins, 1990): 53.

the form of, say, poverty.[30] Taylor pressed him on whether that meant he believed those who advocate for the positive sides to disability were “just kidding ourselves [by] making the best out of a bad situation,” and he countered with a thought experiment often posed to disabled folks:

> “You know, I do ask people when they say something like that, I say, ‘Does that mean if somebody offered you a pill that could cure your disability or cure your child’s disability and it would cost two dollars and there were guaranteed to be no side effects that you would not use that?’ And I think most of them would use it. Virtually all of them would use it. And if so, I think they are saying they are making the best of a bad situation.”
>
> “You see, I think most parents would use it, but most disabled people would not use it,” I replied confidently.
>
> “So you wouldn’t use it?” Singer was clearly surprised.
>
> “There’s no way I’d use it!”
>
> “Really?” he asked, even more surprised.
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> “Disabled people are asked that all the time,” I said. “I think the fact that disabled people may answer ‘no’ is a really complicated thing for able-bodied people to understand.”
>
> “So try to tell me more about why you wouldn’t use it,” Singer said, genuinely trying to figure this out.
>
> I hesitated. *What do I find valuable about disability?*[31]

In 1982, Taylor was born with arthrogryposis, congenital joint contracture,[32] in all four limbs from military waste that leaked into the drinking water in her hometown of Phoenix, Arizona, during her mother’s pregnancy. Taylor uses a power wheelchair and has limited use of her arms and legs. She can walk a few steps and hold a brush to paint. Often she uses her mouth instead. The average able-bodied person would likely consider her severely disabled, and yet, she rejects Singer’s cure out of hand. I think of my friends Nancy and Jessie Romer, sign language interpreters who introduced me to the concept of *Deaf gain,* which describes the sensory,

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[30] Sunaura Taylor, *Beasts of Burden: Animal and Disability Liberation* (New Press, 2017): 133.

[31] Taylor, *Beasts of Burden,* 134.

[32] “Arthrogryposis Multiplex Congenita,” National Organization of Rare Disorders, Nov. 12, 2024, accessed Jul. 15, 2025, rarediseases.org/rare-diseases/arthrogryposis-multiplex-congenita/.

cognitive, linguistic, and cultural gains of diminished or absent hearing.[33] These are the intangibles we gain when we join the community. Not every aspect of disability, even hearing loss, is synonymous with loss.

Taylor finally refutes Singer in her capacity as an artist, claiming disability as a creative constraint that invites continuous innovation. Because the disabled body works in nonstandard ways, the disabled person is liberated from having "every aspect of [their] body already defined"[34] by normativity. She declares, "When I told Singer that disability is creative, I was thinking about disabled dancer, artist, and poet Neil Marcus, who has said, 'Disability is not a "brave struggle" or "courage in the face of adversity." [...]. [D]isability is an art. It's an ingenious way to live."[35] The affordances of disability are Taylor's artistic medium, and there is no art not somehow restricted by its medium, not even multimedia. There is no total art, just as there is no universal accessibility. An oil painting is not a sound installation; cinema is not live theater. The Deafblind can use braille but not audio tours; cane users and I can take escalators, but wheelchair users and stroller pushers need elevators. So while her disability constrains her, Taylor lives and works happily within those creative constraints.

Here in 2025, I no longer seek a cure because no cure is forthcoming from contemporary medicine. Until gene therapy becomes commonplace, we cannot speak of curing genetic disorders. If however I could obtain that two-dollar panacea, admittedly I would take it because of what psychologists call *loss aversion,* the phenomenon by which losses have

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[33] H-Dirksen L. Bauman and Joseph J. Murray, eds., *Deaf Gain: Raising the Stakes for Human Diversity* (University of Minnesota Press, 2014): xv.

[34] Taylor, *Beasts of Burden,* 135.

[35] Taylor, *Beasts of Burden,* 136.

approximately twice the psychological impact as gains of the same size.[36] As a teenager, I twice climbed Yosemite's Half Dome trail, a strenuous all-day hike of sixteen round-trip miles up steep stairs past two gushing waterfalls and across sun-beaten backcountry flats to pine-edged switchbacks and finally the infamous cables by which we scale, hand over hand, the bald granite pate that backs the dome's sheer face, like one hemisphere of a cerebral cortex surveying all Yosemite Valley. The thought I will likely never manage that hike again sends a mortal frisson of deprivation through me and has for sixteen years. I feel almost entitled to the superior health I've courted my whole life—but good habits are no match for genetic destiny (or environmental exposure). Post-operatively, I can hike a little bit again: I set out from the Half Dome trailhead last summer and made it twenty minutes uphill before I precipitously pooped out and turned around, leaving my able-bodied family, including my spritely sixty-nine-year-old father with bad knees, to continue without me. But twenty minutes of pedal-metal after twenty years of zero was mettle enough. At some point during my illness, I told my sister I'd count myself lucky if I could hike again by age fifty. "Hey," she says now, "you're ten years ahead of schedule!" But what I feel most keenly, in a case study of loss aversion, are the twenty years gone, not the ten saved.

So if parents would administer the panacea to their disabled child, I'd wager it's because they relate to their child's disability as a loss of function by proxy rather than a proud identity category outside the able-bodied cis-het White male norm, the way most ways of being are. When I came out to her as queer, my mother voiced regret that it would make my life harder because no parent wants their child's life to be hard. But wishing away one identity for another easier one only shores up the majority and entrenches the barriers that minoritize us. Taylor's point in denial is that, if disability is a social phenomenon, disabled folks largely identify with

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[36] "What Is Loss Aversion?," *Scientific American Mind* 27, no. 4 (2016): 72, doi:10.1038/scientificamericanmind0716-72b.

their disabilities to the degree that they would not trade them for an able-bodied identity of greater convenience. They cannot be simultaneously themselves and able bodied; an abled version of their bodies would no longer be theirs. For all the associated difficulties, non-normative ways of being are valid and valuable; they are ours: they are us. By refusing the panacea, Taylor advocates for the creative constraint of disability because there is nothing wrong and much joyous in it, even if it makes for certain greater life challenges.

Great ruminator that I am, I wish I had grown up on the water in a fish family who spent the weekends swimming and surfing and boating and that I had swum competitively in high school because I could've stayed active all these years and maybe figured out my condition sooner. As an ME/CFS patient, I never adjusted to my housebound reality; I missed ballroom dance every day. I lived in a constant state of not-me. So when, with the hEDS diagnosis, swimming became not only an option but an order—"You swim like you don't miss a meal," said Dr. Patel—I regained my identity as a jock without so much as a bicep curl. If influence and interest had conspired to start me young, by now I'd speak water natively like all the delphine swimmers at Ramsey gym. The pool is the one place I aim to terrify. I want to look lethal in the lane, like a shark, sleek and inevitable. Instead, I look like a doggy, like any other recreational swimmer paddling my no-butterfly medley of forty laps twice per week. But I don't mind. I was and am impaired by hEDS and tethered cord syndrome, but I'm a sportsperson again. And the cloud of my self-alienation lifted, at least what hung over the zone of inactivity.

Even as I hold these seemingly contradictory identities—mobility impairment and athletic pursuit—I still live with pain and fatigue. I take a strong drug cocktail and sleep extra hours, and I feel no solidarity with anybody while doing it. It is isolating at best. It will probably prevent me from having biological children. So after twenty-three years able bodied and eighteen disabled, not yet the balance point of my life, I would take the panacea. I would mountaineer again. And for this, I apologize to my disabled community. But among the chronically ill, the dream is not uncommon. As Wendell sagely says, both a refutation of and capitulation to Singer:

> I do not think that those of us who appreciate having become ill are making a mistake or deceiving ourselves. Illness is not by definition an evil, but people fear and try to avoid illness because of the suffering it causes. Some of that suffering is social and could be eliminated by social justice for people with disabilities, but some of it is not. Solidarity between people with chronic illnesses and people with other disabilities depends on **acknowledging the existence of the suffering that justice cannot eliminate** (and therefore on our willingness to talk about impairment). It also depends on acknowledging that illness is not *only* suffering. Like living with cerebral palsy or blindness, living with pain, fatigue, nausea, unpredictable abilities, and/or the imminent threat of death creates different *ways of being* that give valuable perspectives on life and the world.
>
> Thus, although most of us want to avoid suffering if possible, suffering is part of some valuable ways of being. If we could live the ways of being without the suffering, some of us would choose to live them. Some of us would choose to live them even if they were inseparable from the suffering. And some of us are glad to have been forced to live them, would choose to be rid of the suffering even if it meant losing the ways of being, but would hope to hold on to what we have learned from them. There are, I think, many versions of disability pride.[37]

I take disability's point: I've gained many wonderful spoonie[38] friends, health literacy, two academic fields, an enviable bodily insight, and untold sympathy, the essential moral of any tale. And I do pride myself on being a swimmer, however unintimidating. But do these gains counteract what I lost? Performance dance, early career advancements, half the social markers of adulthood, half my days spent housebound for fifteen years? I'm grateful I can never know.

If I follow Wendell's lead, the real betrayal would seem to be regret I ever experienced disability: that I was born with Ehlers-Danlos and had to modify my lifestyle to accommodate impairment. I do wish I'd discovered the nature of my condition sooner, but I don't regret the fact

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[37] Wendell, "Unhealthy Disabled," 171. (italics original, bolding and paragraph break mine)

[38] Christine Miserandino, "The Spoon Theory," *ButYouDontLookSick.com,* 2003, accessed Mar. 16, 2025, butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/. At lunch with an able-bodied friend, Miserandino grabs a handful of spoons from a nearby caddy to represent her quota of daily energy, passes the spoons to her friend, and asks her to plan a day around their limited number. As her friend lists activities, Miserandino subtracts spoons from the handful, and their quickly dwindling number leaves her friend in tears at the implied sacrifices Miserandino must make. Thus was coined the term "spoonie" for the chronically ill and disabled who budget their energy and activities to get through a day.

of it. To do so would be as pointless as regretting any other genetic attribute—big forehead, bumpy nose, average height, predisposition to diabetes—which plenty of us do all the time, and me most of all. But there's nobody but natural selection to blame for the genetic lottery. Such regret is a scream in the void. I've always been extra gumby and sat like a pretzel, all tied in knots, and now I know why. Even if it makes me eccentric, it's a quirk that amuses me. In a fatalist sense, there was no other way to be me than with this genetic complement, and being me is okay most of the time.

Pointlessly I *do* regret, since my first hospitalization for undiagnosed allergies at the age of seventeen, that I have outpaced medicine on multiple occasions and had to wait for science to catch up with me and lost a lot of time dwelling in depression and anxiety meanwhile because I am such an empiricist and research moves so slowly. I wish in the meantime I'd written a seven-volume epic while lolling on my chaise-longue like Proust. I wish, when my legs started to fail me, I had been diagnosed right then and there with hEDS and sent for neurosurgery and emerged at twenty-four years of age a postoperative merperson and gone on my aquatic way. Instead I made the rounds of dismissive doctors for fifteen years while laboring as a graduate student on decent health insurance and a poor salary. It's a considerable portion of a human life, fifteen years, especially timed to what would've been one's prime.

But in the scope of medical science, fifteen years is quick, not even long enough to complete the clinical trials for two new drugs, and I take two. In the span of human history, fifteen years is nothing, not even a generation, and I am just one person of billions. Had I been born in any previous era, I would've lived my whole life tethered on land and not had the education even to conceive of a sprawling epic from my sick bed, let alone pen it. So my disability pride is intact, even if my transhistorical timing wasn't perfect.

I *also* regret, equally pointlessly, that all my current diagnoses and treatments were known to medicine in 2008 when my symptoms began. The issue was the rarity of my presentation, a rarity of a rarity, a stripeless zebra among industry-standard horses. Until 2023, two dozen doctors and specialists in four states failed to read my symptoms into a recognizable form. For the purposes of medicine, the illness I presented was illegible, what philosopher Michel Foucault might call an “impenetrable shape.”[39]

Disability Illegibility

In the early days and months of my symptoms, physicians examined my clinical results to arrive at a diagnosis of exclusion, the one that remains after all other possibilities have been ruled out.[40] They settled on fibromyalgia, then five years later, added ME/CFS. Both conditions are popularly called *wastebasket diagnoses:* collections of medically unexplained symptoms “held to be ambiguous, in terms of their nature, causes, and treatment.”[41] The wastebasket is an apt metaphor for how most patients feel so labeled: discarded by physicians as if in censure for how resistant our suffering is to treatment. In 2020, sociologist Erik Børve Rasmussen proffered a different term: “Unlike waste in a wastebasket, unexplained symptoms are not discarded but *contained,* not ejected but *managed.* [...] I propose we instead think about it as a ‘junk drawer.’ A junk drawer is an ordering device whose function is the containment of things we want to keep but have nowhere else to put.”[42] So in the last five years, patients with unexplained symptoms have been promoted from waste to junk! Useless thrown out to useless reserved. Physicians like to see results and grow exasperated or lose interest when patients fail to improve.

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[39] Michel Foucault, *The Birth of the Clinic: An Archeology of Medical Perception* (Routledge, 1989): 117.

[40] Daniel J. Bell, “Diagnosis of Exclusion,” *Radiopaedia.org,* 2020, accessed Mar. 5, 2025, doi.org/10.53347/rID-80338.

[41] Erik Børve Rasmussen, “Making and Managing Medical Anomalies: Exploring the Classification of ‘Medically Unexplained Symptoms,’” *Social Studies of Science* 50, no. 6 (2020): 901, doi:10.1177/0306312720940405.

[42] Rasmussen, “Medical Anomalies,” 901.

Impeding my accurate diagnosis was not a lack of clinically significant results but the inability of doctors to correlate them into the Occam's razor of a unified pathology. Without a diagnosis, the chronically ill are unlikely to recover because diagnosis indicates treatment and, in the age of the insurance industry, brokers access to it. Even with a cut-and-dried diagnosis, optimizing a course of treatment takes trial and error. Without a biomarker, that is, "a biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease,"[43] insurance companies may refuse to cover what they deem experimental treatments, and a hypothetical diagnosis can't be tested for an individual patient. This is an affront to desperate people willing to try anything, but insurance companies are not in the business of reimbursing hope. For my part, the hundred-thousand-dollar-a year immunoglobulin treatment one neuromuscular specialist ordered for me in 2009 would *not* have helped, but I did not know for sure for over a decade. It's a lot of what-if to carry over ten years. In parting, that same neuromuscular practice, my first, advised me, "You'll have to get sicker before we can diagnose you." This dismissal underlines, not inaccurately, that mild illnesses all look the same within a given specialty: sneezing and a runny nose could be any rhinovirus, a cough could be any chest infection, vomiting and diarrhea in children could be flu or norovirus. The practitioner must look closely to differentiate.

But it's the towering arrogance and even marginal danger of their advice that strike me now, the obvious obverse to their proposal being that I was already sick enough, but they *didn't know enough* or *they needed to learn more* or *medicine must advance before we can diagnose*. After a lumbar puncture, repeated nerve conduction studies, a muscle biopsy, and six thousand dollars' worth of bloodwork, the possibility they had missed anything did not occur to them. Much later, when I asked my operating surgeon whether my case of tethered cord was severe,

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[43] "Biomarker," NIH National Cancer Institute, n.d., accessed Jul. 14, 2025, www.cancer.gov/publications/dictionaries/cancer-terms/def/biomarker.

she told me with all the delicacy in the world that tethered cord was always severe when present, wherever a patient might fall on the spectrum of more or less.

Under the panoramic view of the modern medical gaze, doctors assume a pose of total bodily insight that leaves the patient lacking where diagnosis is not forthcoming. According to historian and philosopher Michel Foucault in *The Birth of the Clinic: An Archeology of Medical Perception* (1963)*,* advancements in anatomy and magnification in early nineteenth-century medicine meant that doctors could at last describe

> what for centuries had remained below the threshold of the visible and the expressible [...]. [I]t meant that the relation between the visible and the invisible—which is necessary to all concrete knowledge—changed its structure, revealing through gaze and language what had previously been below and beyond their domain. A new alliance was forged between words and things, enabling one *to see* and *to say.*[44]

Microscopes, x-rays, and other imaging technology raised pathologies invisible to the naked eye to the level of detectability and thus describability, enabling correlation with visible symptoms. Once seen, a sign, in the semiotic parlance of the day, could be said to signify. But when the vanishing point of medical sight advanced to the cellular scale, medicine's self-awareness vanished with the enhanced scrutiny. The practice of medicine suddenly appears so transparent that "there emerges on the horizon of clinical experience the possibility of an exhaustive, clear, and complete reading: for a doctor whose skills would be carried 'to the highest degree of perfection, all symptoms would become signs,' all pathological manifestations would speak a clear, ordered language."[45] If doctors failed to diagnose me, it was the fault of my symptoms for not articulating their meaning clearly, not the doctors' inability to interpret those subtle articulations. In effect, they accused my symptoms of mumbling when my body declaimed rare complaints.

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[44] Foucault, *Birth of the Clinic,* xii.

[45] Foucault, *Birth of the Clinic,* 94–5.

Any system that admits no weakness invites such blind spots, a figure of speech disability scholars would protest as ignorance rather than blindness. To rephrase: a field that claims infallibility will have that much more trouble identifying and correcting the inevitable faults that accompany human endeavor. As Foucault writes, “the gaze is not faithful to truth, nor subject to it, without asserting, at the same time, a supreme mastery: the gaze that sees is a gaze that dominates; and although it also knows how to subject itself, it dominates its masters.”[46] Increased magnification imbued doctors with a sense of omniscience rather than proportionally increased powers of sight, which consequently negated the validity of inscrutable pathologies in their estimation.[47] In 2009, my second neuromuscular specialist told me if I had pain where nerve studies detected only normal electrical conductivity, the problem was in my central nervous system because peripheral nerves are too simplistic to report damage in the absence of it. Where there is pain in the absence of damage, it is the misfiring of the central nervous system: the brain and spine. These organs are so complex, however, he assured me we would never locate the problem. He advised me to stop looking for biological causes, to medicate the pain and get on with my life. Years later, I learned this too was arrogance when my operating surgeon ordered an MRI of my thoracic spine because surgeons never cut a spine before examining its whole length. In the center of my spinal cord, she found a syrinx, a small cyst considered a biomarker of congenital tethered cord, although other doctors had ruled the condition out on lumbar images alone. Nobody else in a decade and a half of diagnostics on my central nervous system had thought to chart the territory between my neck and low back.

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[46] Foucault, *Birth of the Clinic,* 39.

[47] In contrast, patients cannot afford such single-lens inflexibility. In “[Frame Fragment]” from *Veil and Burn* (2008), poet Laurie Lambeth Clements, an MS patient, confides, “People ‘in my condition’ lose vision gradually, sometimes without noticing. I want to notice, if it happens. I close each eye periodically to monitor change” (23). She takes her own notes on the progressive loss of her vision; she does not wait for external monitors, nor does she presume herself monolithic, above or beyond revision, unlike the medical gaze.

For diagnostic ends, my condition was illegible insofar as doctors could not interpret a clear pathology from abnormal test results and invisible insofar as doctors did not look where they might have found additional abnormalities or could not identify certain results as abnormal in the first place. In Foucault's words, the "projection of illness onto the plane of absolute visibility gives medical experience an opaque base beyond which it can no longer go. That which is not on the scale of the gaze falls outside the domain of possible knowledge."[48] The doctors at the university hospitals I visited could not perceive me as diagnosable or treatable. Disability scholar and poet heidi andrea restrepo rhodes reads Foucault to mean that, as a discourse, "medical science invests belief in its own representational terms as the most comprehensive and legitimate route to establishing the real of disease."[49] If our bodies do not speak its diagnostic language, medicine regards us as unreal. In search of legitimacy, I considered applying to the Undiagnosed Diseases Program at the National Institutes of Health, where patients undergo extensive genomic testing to distinguish rare presentations of known diseases and, more rarely, novel diseases.[50] Since 2008, the program has identified more than thirty new diseases, but more than half of accepted patients leave with no diagnosis at all.[51] Had I suffered more acutely throughout my mystery years or been completely unable to lead a semi-normal life, I would have applied, but I had not yet exhausted my diagnostic pathways when one gave way.

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[48] Foucault, *Birth of the Clinic,* 166–7.

[49] heidi andrea restrepo rhodes, "Bed/Life: Chronic Illness, Postcolonial Entanglements, and Queer Intimacy in the Stay," *Disability Studies Quarterly* 43, no. 1 (2023), doi.org/10.18061/dsq.v43i1.9664.

[50] "Focus on the Undiagnosed Diseases Network," National Institute of Neurological Disorders and Stroke, Jan. 2, 2025, accessed Mar. 9, 2025, www.ninds.nih.gov/current-research/focus-disorders/focus-undiagnosed-diseases-network.

[51] "Undiagnosed Diseases Program (UDP)," National Human Genome Research Institute at the National Institutes of Health, Jan. 12, 2025, accessed Mar. 9, 2025, www.genome.gov/Current-NHGRI-Clinical-Studies/NIH-Undiagnosed-Diseases-Program.

In 2017, the year after I was diagnosed with ME/CFS, the documentary *Unrest* by Jennifer Brea brought visibility to a subset of ME/CFS patients who reported extreme fatigue and dysautonomia,[52] in which the automatic functions of the body misfire: heart, breathing, temperature, blood pressure. A chain of informed viewers who saw the film and Brea's subsequent TED Talk led her to a diagnosis of tethered cord syndrome and craniocervical instability (CCI), also known as bobblehead, in which the ligaments that affix the skull to the spine loosen and cause cranial settling and thus brainstem compression, cascading bizarre neurological symptoms into the lower body.[53] Because ME/CFS is believed to be a post-infectious illness, no physicians sought diagnoses of CCI, tethered cord, or hEDS in that patient population until Jen Brea and her kith appeared with symptoms so severe, they could not be ignored. Most frighteningly, Brea developed central apnea, which stopped her breathing whenever she turned her head or lay on her back even while awake.[54] My first neuromuscular specialists sought such a smoking gun in me. The year I was diagnosed, I learned I had one; they just weren't looking in the right place.

By 2019, Brea's subset of ME/CFS had been folded into hEDS, an insight that triggered a flurry of diagnoses and corrective surgeries by a small group of hyperspecialized neurosurgeons. That same year, I made the acquaintance of Steve, a former assistant professor here at UGA who was waylaid from the tenure track almost overnight by a severe case of post-viral ME/CFS. When I first met him, Steve was one of the sickest people I have ever known, a ghost of a man in corporeal form. Rather than get up off the couch to let a

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[52] "Dysautonomia," Cleveland Clinic, Sept. 11, 2023, accessed Jul. 13, 2025, my.clevelandclinic.org/health/diseases/6004-dysautonomia.

[53] *Unrest,* directed by Jennifer Brea (2017, Shella Films), streaming.

[54] Jennifer Brea, "CCI + Tethered Cord Series," *Medium.com,* Mar. 26, 2019, accessed Mar. 16, 2025, jenbrea.medium.com/cci-tethered-cord-series-e1e098b5edf.

stranger into his house, he texted me the door code. Piled under blankets, he wore sunglasses against the afternoon sun setting through the front window blinds and spoke to me in a whisper, not because he couldn't use his voice but because the resonance of his vocal cords through his skull would aggravate his status migraine, his unceasing headache.

Over the next couple of years, still living independently in Athens, Steve retraced all Jen Brea's diagnostic steps at great financial cost and eventually received her same diagnoses from a neurosurgeon at the Medical University of South Carolina. To get there, he purchased a van so that, sunglassed and ear-plugged, he could lie on a mattress the whole ride there and back. Faced with someone so sick when comparatively I could do so much, could still work part time and speak aloud and take a walk once a week, I could not believe my case shared any features with his, but he insisted I consult his surgeon. For two years, I could not muster the strength until a fellow patient (not a physician but a psychologist) recommended salt tablets for low blood pressure. At two grams a day, my stamina improved immediately, and all the water weight I could not hold onto came back. I became a boxer in the ring no longer sweating it out. Due to the unusual mechanics of my metabolism and the usual mechanics of osmosis, I had probably been dehydrated since 2008 when my leg symptoms began. When at last I had enough blood in my head to drive the five hours to Charleston on my own power, I too left with the same diagnoses as Steve had. "Your friend was right to send you to us," said Dr. Patel. "Yes, he's much smarter than me," I agreed.

Tethered cord is usually diagnosed by a low-lying conus, in which the base of the spinal cord nerve bundle appears to sit too low in the spinal column and often off center, as visible on a traditional supine MRI. But in hEDS, the conus sits at normal height, and untutored neurosurgeons exclude the diagnosis. Instead, one must take an upright MRI at a specialty imaging center to reveal how the spinal cord, instead of curving gently down the mountain roadway of the spinal column, pulls tight like a Formula 1 car racing the shortest path down the lumbar to the sacrum. This tension activates only under the force of gravity—another reason we spend so much time off our feet—so a supine image disguises it.

As if to console with a dash of mysticism, medical conditions "hidden, concealed, difficult to detect; unaccompanied by readily discernible signs or symptoms"[55] are called *occult,* as is tethered cord in cases such as mine, Steve's, and Brea's. According to Foucault, when the locus of medicine moved from the house, where doctors came to call, to the clinic, where patients sojourn to doctors, institutions systematized medicine into a "corpus of knowledge that can be said to be, quite literally, blind because it has no gaze. [...]. Such is the *occultation* that has made possible the long history of systems, with 'the multiplicity of different sects opposing and contradicting one another'" into an illusory, almost metaphysical medicine (italics mine).[56] The dismemberment of the human body into specialties and subspecialties—sects—particularly occludes diagnosis in the case of multisystemic illness. To instrumentalize another animal and another ableist metaphor of blindness, hEDS and its comorbidities invoke the parable of the elephant and the blind men, each of whom imagines a different whole based on the portion of the animal they can reach: trunk, tusk, ear, flank, foot. In the author's note to her debut poetry collection *Gaze Back* (2022), a grimoire of the feminine grotesque, poet Marylyn Tan uses "occult (literally, 'unknown') technologies as a vehicle to explore new ways of manifesting the embodied, esoteric desires of the self, whether because or in spite of the systems of hierarchy we are made to operate within."[57] It requires magical thinking to conceive of my body as desiring an invasive surgery only advanced imaging technologies could reveal as salutary and only contemporary medicine could perform safely; the surgical treatment of "sectioning" or resecting

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[55] *Oxford English Dictionary,* "occult (adj. & n.)," Mar. 2025, doi.org/10.1093/OED/7501505460.

[56] Foucault, *Birth of the Clinic,* 56.

[57] Marylyn Tan, *Gaze Back* (Georgia Review Books, 2022): 36–7.

the filum terminale—the non-nerve tissue at the base of the spinal column, a vestige of our embryonic stage that in hEDS shrinks and tightens—has existed only since 1976 when Dr. Harold J. Hoffman described it in *Child's Brain.*[58] I don't believe my body willed that surgery; I believe my body existed as it was genetically programmed to exist, partially crippled by nerve impingement, until the deus ex machina of a surgeon's scalpel intervened on the prophecy of that DNA. Thenceforth I believe the body adjusted accordingly, as the body does after any major injury, which that neurosurgery undoubtedly was. It just so happens that the injury relieved more pain than it caused.

I was referred to orthopedics, physical therapy, neurology, endocrinology, rheumatology, epidemiology, psychiatry, dermatology, colorectal surgery, neurology again and again, and genetics before I was referred to neurosurgery, the department that treats both CCI and tethered cord. And I had to refer myself; not one physician ever suggested it (though Steve has a PhD). To paraphrase Dr. Theodore Woodward's advice to his interns at the University of Maryland in the 1940s, "When you hear hoofbeats, think horses, not zebras."[59] So medicine allows zebras exist but makes no provision for them. Yet here I am, a medical zebra, the mascot of the Ehlers-Danlos community in protest to this reductive rule of thumb. Happily my CCI is mild enough to respond to exercise. A neurosurgeon here in Athens dismissed it, but Dr. Patel at MUSC could see it on the x-rays. In the hands of the right specialist, or subspecialist to be fair, my diagnoses were obvious. He said never to operate on my neck; the tethered cord, however, would have to go. I went for a second opinion with the most renowned tethered cord surgeon in the West and probably the world: Dr. Petra Klinge, MD, PhD, of Brown University in

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[58] Luke J. Weisbrod and William Thorell, "Tethered Cord Syndrome," NIH National Library of Medicine, Jul. 31, 2023, accessed Mar. 29, 2025, www.ncbi.nlm.nih.gov/books/NBK585121/.

[59] Ann Marie Hart and Karen S. Moore, "When You Hear Hoofbeats, Think Horses—But Be Prepared for Zebras," *Journal for Nurse Practitioners* 15, no. 6 (2019): PA10, doi:10.1016/j.nurpra.2019.03.025.

Rhode Island. After examining me for all of ten minutes, although we talked for much longer, Dr. Klinge said my case of tethered cord was “textbook.” To her, I was as legible as the manual of occult tethered cord she and her research team are writing.

Had I not found my way to Dr. Klinge when I did, I would have remained one of those chronically ill individuals, most of them women, who develop secondary depression and anxiety, which unwitting physicians target as first-line concerns in the absence of legible physical symptoms. Etiologies of the mind relieve doctors of the responsibility for our failure to thrive because the institution of medicine accords a degree of volition or control over mental illness to patients who thus must be electing a state of illness in the case of persistent and/or resistant depression. In Wendell’s words,

> The diagnosis of psychosomatic illness props up the myth of control in two ways. First, it contributes to the illusion that scientific medicine knows everything it needs to know to cure us [...] because there is no physical problem for which it cannot provide a diagnosis. Second, it transfers responsibility for controlling their bodies to the minds of those patients who cannot be cured; the problem is not that medicine cannot control their bodies, it is that their minds are working against them.[60]

If only we could get into our right minds, medicine insists, our bodies would correct themselves. Doctors can thus deflect responsibility from themselves as individual practitioners and the institution of medicine at large. Ironically, the myth of control implies a single determined mind can overpower all of medicine’s studied recommendations. Rather than a directly proportional relationship of mystery symptoms to psychosomatic illness, Sontag proposes an inversion: that psychological theories chart “an index of how much is not understood about the physical terrain of a disease”[61] and so “assign to the luckless ill the ultimate responsibility both for falling ill and for getting well.”[62] The contemporary practice of psychology does endow the patient with

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[60] Wendell, *Rejected Body,* 100.

[61] Sontag, *Illness as Metaphor,* 55.

[62] Sontag, *Illness as Metaphor,* 57.

ultimate responsibility, as I learned in my first year of therapy. Only oneself and not one's therapist, counselor, psychiatrist, partner, caretaker, or anyone else is responsible for one's mental health. Thus psychiatry means to empower the mind to mind itself as much as physical medicine urges surrender of the body to medicine's prescriptions. Wherever doctors dismiss symptoms as mental, they demand patients reject their own reality for alternate ones in which they not only suffer all the same ailments but must metabolize their suffering as the self-imposed barrier to treatments they would not need without those ailments. Medicine abandons the mystery patient.

Psychosomatic brushoffs moreover compound the distress of living with indefinite mystery symptoms because patients feel infantilized and gaslit by authority figures supposedly tasked to help. In a recent survey of more than three thousand rheumatology patients, those initially misdiagnosed with psychiatric or psychosomatic conditions reported damage to their self-worth (over eighty percent), lingering upset even after corrected physical diagnosis (seventy-two percent), and overall lower mental wellbeing, higher depression and anxiety, and less trust and satisfaction in all healthcare services than those never misdiagnosed with mental health conditions.[63] Ironically the psychosomatic brushoff seems to enact itself by heightening the patient's emotional distress. Equally ironically in the case of hEDS, my dismissive doctors were right: whatever illness I had throughout my diagnostic quest *was* mental because hEDS is not an illness: it is a genetic disorder. Even so, they erred insofar as depression, anxiety, and lapsed exercise routines did not account for most of my pain and fatigue. It is some consolation, even while rheumatologists correctly dismissed me from the specialty because I had no

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[63] Melanie Sloan et al., "'I Still Can't Forget Those Words': Mixed Methods Study of the Persisting Impact on Patients Reporting Psychosomatic and Psychiatric Misdiagnoses," accepted manuscript for *Rheumatology* (2025), doi.org/10.1093/rheumatology/keaf115.

inflammatory markers, that I still lick the wounds of dismissive neurologists who might've helped sooner if they had not been so quick to scapegoat my reasonable depression.

ME/CFS is perhaps the primest contemporary example of misunderstood, feminized, and psychologized conditions in a lineage including tuberculosis (a bacterial infection), queerness (an identity category), and hysteria (a pseudo-pathology). Maud Casey's historical novella *City of Incurable Women* (2022) gives voice to the nineteenth-century women institutionalized for hysteria, many for life, at the Salpêtrière Hospital in Paris, where they vied for the attention of watchful male doctors. Gilles de la Tourette, the same for whom Tourette syndrome was named after he published an account of it 1885,[64] described the female hysteric as "an extraordinarily complicated type, of a completely particular and excessively versatile nature, remarkable for her spirit of duplicity, lying, and simulation. With an essentially perverse nature, the hysteric seeks to fool those around her, in the same way that she has impulses that push her to steal, to falsely accuse, to set things on fire."[65] In fewer words, Tourette describes a pathological attention seeker. In 1928, doctors revised the description to something closer to an artistic temperament, "not a pathological phenomenon [but] a supreme means of expression."[66] While inherently performative in both framings, the condition need not have been faked. It took another sixty-two years to eliminate the term from the Diagnostic and Statistical Manual of Mental Disorders III in 1980.[67] Today the same symptoms are diagnosed as conversion

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[64] Clara Lajonchere et al., "Gilles de la Tourette and the Discovery of Tourette syndrome," *Archives of Neurology* 53, no. 6 (1996): 567, doi:10.1001/archneur.1996.00550060111024.

[65] Maud Casey, *City of Incurable Women* (Bellevue, 2022): 25.

[66] Casey, *Incurable Women,* 23.

[67] Cecilia Tasca et al., "Women and Hysteria in the History of Mental Health," *Clinical Practice & Epidemiology in Mental Health* 8 (2012): 110, doi:10.2174/1745017901208010110.

disorder,[68] the psychosomatic diagnosis Jen Brea first received that, in her case, could not have been more inaccurate.

Lacking biomarkers to confirm the diagnosis of hysteria, doctors kept the incurable women warehoused as “a kind of living pathological museum”[69] at the Salpêtrière, wrote the father of neurology, Jean-Martin Charcot,[70] so that he and his colleagues could carry out clinical trials on a captive and thus dehumanized population. Dumped together into the wastebasket of hysteria, the incurables live at the whim of physicians intent on instrumentalizing them as examples of a type that medicine has not yet precisely identified. Foucault might have been speaking of hysteria asylums when he claimed that “[t]he clinic was a science of cases to the extent that it proceeded initially to the diminution of individualities.”[71] In Charcot’s pathological museum, patients subsume their individuality to exhibit a type.

The physicians, on the other hand, subsume nothing and fabricate much. In a sort of reverse case study of multiple sclerosis, an autoimmune condition characterized by *visible* plaques of the brain and spinal cord that was first identified and named by Charcot himself in 1886,[72] the collective narrator of *Incurable Women*, a lyric *we,* explains how “[t]he proof of our illness was an *invisible* lesion on our brains.”[73] For physicians to enlist an invisible and here

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[68] Vaughan Bell et al., “Dissociation in Hysteria and Hypnosis: Evidence from Cognitive Neuroscience,” *Journal of Neurology, Neurosurgery, and Psychiatry* 82, no. 3 (2011): 332, doi:10.1136/jnnp.2009.199158.

[69] Casey, *Incurable Women,* 12.

[70] Tasca et al., “Women and Hysteria,” 110.

[71] Foucault, *Birth of the Clinic,* 168.

[72] Bernard Zalc, “One Hundred and Fifty Years Ago Charcot Reported Multiple Sclerosis as a New Neurological Disease,” *Brain* 141, no. 12 (2018): 3482, doi:10.1093/brain/awy287.

[73] Casey, *Incurable Women,* 27. (italics mine)

unverifiable symptom as proof lends form to Foucault's notion of "opaque transparency" in the clinic:

> The structure, at once perceptual and epistemological, that commands clinical anatomy, and all medicine that derives from it, is that of *invisible visibility.* Truth, which, by right of nature, is made for the eye, is taken from her, but at once surreptitiously revealed by that which tries to evade it. [Thus] the aim of the anatomists 'is attained when the opaque envelopes that cover our parts are no more for their practiced eyes than a transparent veil revealing the whole and the relations between the parts.'[74]

Where signs of disease resist being seen through "the opaque envelopes that cover our parts," a physician's supreme sensitivity will penetrate through to the invisible that becomes, under the dominion of the medical gaze, not only proof of disease but the ultimate proof of his qualification as a physician. His conjecture attains to authority, not science but a faith-based venture in which, having trained on visible signs, he may now declare (rather than conjecture) invisible signs whose validity patients must suffer to test in clinical trials. The doctors never suffer; they decree, test, conclude, revise, and repeat: a science without method or consent.

In hopes of better amenities throughout these unofficial trials, the sorority of patients at Salpêtrière strives to manifest on the visible plane the unevidenced signs of their hysteria, effectively bribed into performing their diagnosis as the doctors describe it. The narrator envies the "best girls" who enunciate their suffering clearly, "fluent in the language of hysteria, the language of our pain—amorous supplications, eroticism, ecstasy, hallucinations, crucifixion, mockery, menace, the cry, etc.—." and, for their articulated suffering, receive private rooms with windows like the *payantes;* meanwhile, the "unfluent, the unbest" remain jumbled together in dirty, malodorous dormitories.[75] The reward of accommodations equal to those of a paying resident would have incentivized a kind of indentured servitude in which poorer residents earn their keep by performing hysteria for the medical gaze. A superior patient will perform to doctors'

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[74] Foucault, *Birth of the Clinic,* 165–6.

[75] Casey, *Incurable Women,* 25.

expectations and thereby legitimize the unproven diagnosis and the doctors' own authority in assigning it. But in performing to a pseudo-scientific standard, the best girls physically *and* scientifically distort their clinical trials and thereby compound their own suffering and that of their sister patients with further inconclusive results. In performing an unscientific diagnosis in service to their quality of life, they produce more art than medicine.

The end goal of the best girls' ecstatic performances isn't clear to the collective narrator of *Incurable Women*, who receives no special attention for poor articulation of hysteria and will entrap herself in a lifetime of hospital observation if she performs too well. The narrator explains, "They wake us from our trances, *What actresses! As successful with comedy as with tragedy on the dull stage of reality.* We understand the competition, but what is the prize? [...]. To be hypnotizable is proof of the invisible lesion on our brains and so proof of our hysteria."[76] Shoring up his conviction with more faith, Charcot postulated the hysteric's susceptibility to hypnosis, "a form of heightened attention combined with […] voluntarily lowered resistance to suggestion" whose efficacy is almost as difficult to test[77] as an invisible lesion is to prove. In the hypnotic state, the incurable women convincingly enact the full range of theatrical emotions.

So too do they dance them. The narrator remarks of the Moulin Rouge can-caner Jane Avril during her stay at Salpêtrière[78] that "*[t]he luxurious pain of a body in the throes of its symptoms* has been likened to a dance, and when she, a dancer, was a body in pain, it was something to behold."[79] In a sense, as a professional dancer, Avril is a superlative hysterical. A

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[76] Casey, *Incurable Women,* 31.

[77] "Hypnotherapy," *Salem Press Encyclopedia of Health*, 2025.

[78] Michel Bonduelle and Toby Gelfand, "Hysteria Behind the Scenes: Jane Avril at the Salpêtrière," *Journal of the History of the Neurosciences* 8, no. 1 (1999): 35, doi:10.1076/jhin.8.1.35.1778.

[79] Casey, *Incurable Women,* 13.

diagnosis well performed will earn one's keep, just as the state of normalcy well performed will earn release. This was known to happen; Avril was deemed recovered within two years and left the Salpêtrière in 1884. Thus a Goldilocks performance, neither hot nor cold, becomes the goal of the competition and the art the incurables must hone as they practice their way through clinical trials if they seek to rejoin civilian life.

As the stage of these performative articulations, the living pathological museum of the Salpêtrière becomes a theater of pathology as much as a clinic. On the theatrical nature of pain, Foucault elaborates:

> Can pain be a spectacle? Not only can it be, but it must be, by virtue of a subtle right that resides in the fact that no one is alone, since [...] disease can be cured only if others intervene with their knowledge, their resources, their pity, since a patient can be cured only in society, it is just that the illnesses of some should be transformed into the experience of others; and that pain should be enabled to manifest itself [...]. If he refused to offer himself as an object of instruction, the patient would be guilty of ingratitude.[80]

Foucault would insist, by dint of their living on social welfare at the Salpêtrière, that the incurable women owe a debt of spectacular pain to society in payment for the interventions of medical science. They owe their bodies to science as test subjects, and they should feel gratitude in submitting to these uses as dependent members of a society that stands to derive some value from their clinical type. This "compensation," says Foucault, is of "objective interest for science and of vital interest for the rich. The hospital became viable for private initiative from the moment that sickness, which had come to seek a cure, was turned into a spectacle. Helping ended up by paying, thanks to the virtues of the clinical gaze.[81] Like animals in a zoo, the incurable women must exhibit their symptoms so that doctors may study them and the rich whose tithes fund the hospital may someday recover faster from the same ailments thanks to the experiments performed on lower-class women's bodies.

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[80] Foucault, *Birth of the Clinic,* 84.

[81] Foucault, *Birth of the Clinic,* 84–5.

A language spoken, a tragicomedy acted, and a dance performed at the behest of doctors bent on teaching demonstrations in the Salpêtrière, hysteria is likewise a phonetic tableau for medical study. The narrator remarks how the best girls who speak fluent hysteria also stage and inscribe it in clinical photographs:

> Photographs of the doctors' best girls making shapes that spell hysteria (*arc en cercle,* ecstasy or some other passionate attitude) hang in the hospital corridors [...]; in the amphitheater, where those best girls make the shapes; in the offices of the doctors who teach the best girls how to make the shapes. When we first arrived, we did not know how to write the illness with the jumble of our bodies. We, the unbest girls, never learn.[82]

The incurable women enter the hospital a jumble of illegible limbs, whereupon the doctors school them in how to "write the illness" of hysteria like an embodied penmanship. Where doctors succeed, they pose the best girls like puppets on a stage, dolls in a pantomime of a diagnosis. If their admission photographs don't show the signs of hysteria, their progress photographs will. Such *doctoring* of images would not only distort the historical records of an illness, it would dead-end clinical trials with falsified data; moreover, it instrumentalizes female patients in service to a misogynist pseudo-pathology whose very name, *hysteria,* "from Latin *hystericus*, from Greek *hysterikos*, from *hystera* womb; from the Greek notion that hysteria was peculiar to women and caused by disturbances of the uterus," so used since 1772,[83] compounds their exploitation by the patriarchy. By performing to medicine's standards, the best and unbest girls alike doom themselves to lives lived as hospital test subjects.

Ultimately, the incurable women compromise their integrity with medical performance, however legible. As the collective narrator reflects on her time spent in hospital, she observes on the walls of the named rooms "photographs of our bodies on the platforms like a stage set. Photographs taken when we first arrived (here, someone) and the ones taken after (here, what

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[82] Casey, *Incurable Women,* 36.

[83] *Merriam-Webster.com*, s.v. "hysteria," accessed Mar. 26, 2025, www.merriam-webster.com/dictionary/hysteria.

she became)"[84] Here we encounter most literally Foucault's reminder that to submit to a physician's gaze at all is to subordinate oneself (literally and typographically) to one's ailment: "Paradoxically, in relation to that which he is suffering from, the patient is only an external fact; the medical reading must take him into account only to place him in parentheses."[85] With the parenthetical turn from "someone" on intake to "what she became" during her residency, the collective narrator of *City of Incurable Women* admits an erosion of identity, a reduction from animate subject to medical test subject and inanimate object. In her quest for absolution, she searches her past for sins she must expiate and decides of her estrangement from her family that "what I wanted most of all was to become imaginary so that I might be forgiven. In this, I have succeeded."[86] Speaking for the incurable collective, the narrator, even as an unbest, unfluent girl, attains to the conceptual through medical performance: the figment, the artifice of in the art. In this dissolution of self, she cures herself of physical ailment as her doctors cannot.

Maud Casey's *City of Incurable Women* tells a cautionary tale of medical abuse in which the narrator achieves authenticity through dematerialization from the physical. Whether acted, danced, photographed, or written, her art made within the medical model of disability fails to restore her to her body. This is not the disability writing I seek. And when I submitted myself to the medical gaze as a dancer in pain, it was no substitute for joyous theatrical performance. Since manifesting the visible symptoms of certain diagnosis, I no longer pantomime legibility in yet another illness history for the medical gaze. From within the social model, I now inscribe language from within the creative constraints of disability, whatever that sounds, looks, and reads like.

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[84] Casey, *Incurable Women,* 36.

[85] Foucault, *Birth of the Clinic,* 8.

[86] Casey, *Incurable Women,* 84.

Reclaiming Disability

With the birth of disability studies in the 1980s, anthologies of work by disabled writers began to appear alongside the critical treatises. *Toward Solomon's Mountain: The Experience of Disability in Poetry* (Temple University Press, 1986), edited by Joseph L. Baird and Deborah S. Workman, collects unsentimental poems on the disabled experience; *Staring Back: The Disability Experience from the Inside Out* (Plume, 1997), edited by Kenny Fries, collects fiction, nonfiction, and drama in addition to poetry. Contemporaneous with these general anthologies were intersectional ones elevating the disabled women’s experience. *With the Power of Each Breath: A Disabled Women's Anthology* (1985), edited by Susan E. Browne, Debra Connors, and Nanci Stern, resists “institutionalized silence,”[87] as does *With Wings: An Anthology of Literature by and about Women with Disabilities* (Feminist Press at CUNY, 1993) edited by Florence Howe and Marsha Saxton. By the 1990s, queer disabled writing appeared in volumes like *Pushing the Limits: Disabled Dykes Produce Culture* (Women’s Press, 1996), edited by Shelley Tremain, to question the “corruption and convenience that governs the medical profession”[88] and *Queer Crips: Disabled Gay Men and Their Stories* (Harrington Park, 2004), edited by Bob Guter and John R. Killacky, includes interviews.

The rise of identity poetry documented in these anthologies likewise spurred the creation of identity-based literary organizations to champion and preserve minoritized voices. Lambda Literary for LGBTQIA+ writers was founded in 1989, Cave Canem for Black poets in 1996, Kundiman for Asian American writers in 2004, and CantoMundo for Latinx poets in 2009. Not

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[87] Susan E. Browne et al., eds., *With the Power of Each Breath: A Disabled Women’s Anthology* (Cleis Press, 1985): 10.

[88] Shelley Tremain, ed., *Pushing the Limits: Disabled Dykes Produce Culture* (Women’s Press, 1996): jacket.

until 2019 did Jennifer Bartlett, Sheila Black, and Connie Voisine establish Zoeglossia,[89] an "inclusive space for poets with disabilities [...] to create an open and supportive community that welcomes and fosters creativity."[90] I joined the inaugural year along with ten other fellows and have contributed to several associated publishing opportunities, including disability folios in *Tupelo Quarterly* and the Poetry Foundation archive. Jennifer and Sheila wrote the introduction to the latter.

In their prefatory note to "Collection: Disability Poetics" (2023), Jennifer Bartlett and Sheila Black propose a crip poetics of liberation based on poet Jim Ferris's idea of "a world that underst[ands] asymmetry as a prime characteristic." In ""The Enjambed Body: A Step Toward a Crippled Poetics" (2004) for *The Georgia Review,* Ferris, whose legs grew at unequal rates to a six-inch difference in maturity, tells us he loves "set forms and strong meters [, b]ut I've never been very good at coloring within the lines, let alone walking them. Mine is not the backbeat but the offbeat, the irregular, the freelance, the dropped stitch, the dappled."[91] None can know whether his artistic sensibilities would have developed otherwise without his disability; as they stand, they predispose him to the formal asymmetry he brings physically to the world.

Ferris interrogates the often ableist metaphors of the leg and foot embedded in poetic devices and refashions them for his crip purposes. He quotes poet Robert Wallace, who claims in *Writing Poems* (1982) that "beginning a poem with anacrusis—omission of an unstressed syllable—can push the poem off to 'a sharp, confident start.' But: 'When such a defective foot occurs *within* a line, it is called a *lame foot* and usually suggests disorder or a dramatic break.'

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[89] In 2024, Zoeglossia imploded under accusations of racism and transphobia on the board of directors and has paused operations to reassess their mission and values, but that's another story.

[90] "Who We Are: About Zoeglossia," Zoeglossia.org, n.d., accessed Mar. 28, 2025, www.zoeglossia.org/who-we-are.

[91] Jim Ferris, "The Enjambed Body: A Step Toward a Crippled Poetics," *The Georgia Review* 58, no. 2 (2004): 231, www.jstor.org/stable/41402415.

Just like a cripple to beg for attention," Ferris editorializes.[92] One weak syllable in a line, and the poetic foot becomes defective, disorderly, and lame in Wallace's estimation. On the other hand, Wallace explains "'[l]ines that end without any parallel to a normal speech pause are called *run-on* or *enjambed.* [...].' Enjambment: from the French *jambe,* leg," Ferris adds.[93] Again, Wallace's language stereotypes—*normal* speech—such that the run-on or enjambed line suffers foot problems. In contrast, the *Oxford English Dictionary* defines the term simply as "[t]he continuation of a sentence beyond the second line of a couplet;"[94] the *New Princeton Encyclopedia of Poetry & Poetics* describes it more complexly as "the overflow into the following poetic line of a syntactic phrase (with its intonational contour) begun in the preceding line without a major juncture or pause. The opposite of end-stopped,"[95] definitions that avert all normative biases. Ferris intends his titular "enjambed body" as a powerful step, however lame in the literal sense: "I'm not sure if I want all poems to limp, but I know this: all the interesting ones do, all the lovely ones do, in one way or another."[96] Art may embrace any style it pleases, but for Ferris's part, broken forms, irregular rhythms, and abnormal speeches (perhaps a stutter or a lisp) appeal more than the rigid metrics.

But Bartlett and Black caution that to write while disabled is not enough for a crip aesthetic; one must also advocate. They expound:

> [A] 'crip aesthetic' seeks to unmake or overturn the historic stigma, erasure, and oppression of disabled people by valuing and privileging what is off-center, liminal, derided, or unseen. A crip aesthetic centers what has been in the margins while charging those marginal spaces through repurposing, redirection, and a frankness in

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[92] Robert Wallace as qtd. in Ferris, "Enjambed Body," 230.

[93] Wallace as qtd. in Ferris, "Enjambed Body," 220–1.

[94] *Oxford English Dictionary,* "enjambment (*n.*)," Dec. 2024, doi.org/10.1093/OED/3965092856.

[95] T.V.F.B., and C.S., "enjambment, (*n.*)," *New Princeton Encyclopedia of Poetry & Poetics* (Princeton University Press, 1993): 359.

[96] Ferris, "Enjambed Body," 232.

> including and forging new art out of the pieces or traces or symbols, linguistic and otherwise, of the historical oppression of disabled people. The crip aesthetic prides itself on recycling and repurposing the objects and furniture of organized ableism, taking a lively, inventive approach to overturning aesthetic conventions, such as "classical beauty."[97]

By this definition, the crip aesthetic must engage with the marginalization of disabled folks to amplify disabled voices on the theme of disability in writing that eschews or innovates on traditional forms: Ferris's limping poetics. The disabled writer must write toward disability to harness a crip aesthetic and thus liberate crip identities in art. When speaking of books, the margin is clear, and we place our poems—anywhere we please.

Lyricizing her experience of multiple sclerosis soon after Ferris published his manifesto, poet Laurie Clements Lambeth imbues the grace and imbalance of her symptoms into her poems on horseback riding, her favorite pastime. In "*5. Reluctant Pegasus,*" she considers the glorious but risky potential of navigating the world on a leg numb with relapse:

> My poor cane is wounded, but I'm all right;
> another chip in the handle. No longer
> a three-legged woman, I'm a gimp,
> a limper with a numb leg, no sense
> of *enjambement,* no stride, except
> at the wrong moments, maybe a near
> fall to scare me, or the sense of a skirt
> against the skin where there is no
> skirt, so it comes as no surprise
> when that numb leg sprouts a tiny wing
> at the ankle, another at the knee,
> a fluttering one gracing the calf—
>
> and look, up it goes, into the air,
> out the window over fountains
> where I find myself dancing,
> doing a can-can without the right
> costume, but I'm still kicking[98]

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[97] Jennifer Bartlett and Sheila Black, "Collection: Disability Poetics," The Poetry Foundation, 2023, www.poetryfoundation.org/collections/159065/disability-poetry-and-poetics.

[98] Laurie Clements Lambeth, *Veil and Burn* (University of Illinois Press, 2008): 52.

Like Jane Avril in the throes of her symptoms at the Salpêtrière, the speaker dances on her numb leg, characterizing herself as a gimp incapable even of poetry that runs: while the line spills over onto the next, it hitches instead of gathering speed, inopportune: "no sense / of *enjambement,* no stride, except / at the wrong moments." But like Pegasus the winged horse born of his mother Medusa's beheaded neck, Lambeth creates immortal beauty from horror; like the god Mercury on winged sandals, she brings us the message of defiant cripped poetics. She's still here, kicking her cancan. But as it was for Icarus who flies too close to the sun in his ambition, "the bruised world attracts,"[99] and she falls at last. To think of the world itself as bruised distributes the impact from her leg where it reckons with gravity, not an antagonist here but an attractant. The world beholds her air dance and brings her closer, moves her toward itself in a loving embrace.

Activist and poet Leah Lakshmi Piepzna-Samarasinha picks up where Sunaura Taylor leaves off on the intersection of environmental toxicity, disability, and chronic illness with a polluted river that offers a third variation on an enjambed overspilling of disability poetics. In "dirty river girl," the speaker mourns how the Blackstone, an underground river running through Worcester, Massachusetts, where they grew up, fills with industrial pollutants from Rust Belt runoff and cascades in its wake a secondary

> underground river of kids who went away.
>
> The girls and boys who got sick and tired, spent hours curled up sleeping.
> An underground river swilling its banks,
> filling the riverbed
> carrying us away
>
> *Fibro*
> *chronic fatigue*
> *lyme disease*
> *epstein barr*
> *cancer*
> *endometriosis*

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[99] Lambeth, *Veil and Burn,* 53.

> *MS,*
> *multiple chemical sensitivity*
>
> We were all just too sensitive.[100]

Even in an obvious case of industrial poisoning from "all those dyes, all that cement, all those computer chips rinsed with acid,"[101] capitalism installs the medical model of disability to deflect blame onto the bodies of children who are "just too sensitive." Such critique implies that industrial pollutants would not affect more robust individuals; the fault lies with the body and not the toxic system that pollutes. Where the underground river "swill[s] its banks, / fill[s] the riverbed / carr[ies] us away," Piepzna-Samarasinha's lines are not enjambed but end-stopped on commas, "natural" or "normal" speech breaks. The meaning here is controlled or contained, unlike the industrial pollutants leaching into the Blackstone. But as the speaker contemplates how to redress the situation, their meaning begins to cascade:

> What would it take for a river that polluted
> to be loved?
> What would it take for us to know our bodies beautiful?
> To wash them clean?
>
> Nah—not washed clean
>
> What if our working-class, fucked up, sick, survivor bodies
> were beautiful just like they were?[102]

For my part as an environmentalist, I would never excuse industrial toxicity or ecological fallout based on serene self-acceptance. Although the speaker advocates for uncritical self-love, pauses in the rhetorical questions signal disconnect: the line break in "a river that polluted / to be loved?" and the internal tab in "survivor bodies / [that] were beautiful just like they were?"

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[100] Leah Lakshmi Piepzna-Samarasinha, *Bodymap* (Mawenzi House, 2015): 38.

[101] Piepzna-Samarasinha, *Bodymap*, 40.

[102] Piepzna-Samarasinha, *Bodymap*, 41.

Enjambed spillovers of meaning show this love takes work to achieve; it does not conclude when or where expected, and there is distance to overcome.

Certainly Piepzna-Samarasinha and Sunaura Taylor speak truth to power that, once disabled or poisoned, a body needs no cleansing to merit love: that no innate or acquired impairment makes us unlovable. Piepzna-Samarasinha's speaker tells us how to move forward from a place of chemical sensitivity:

> all it takes to love a river that polluted
> a body that full of story
> is to surrender
> to love it
>
> I
> give
> in[103]

Their surrender need not be a capitulation to capitalism: it might be a care for ecological well-being so great, it overwhelms all other forces, reducing the poem to one-word lines in an excess of feeling. By way of giving in, the speaker commits to restorative justice: both disability and environmental. Rather than dreaming of or bargaining for bodies restored to "normalcy," the speaker invites survivors to accept ourselves as we are.[104]

Poet Tea Gerbeza accepts herself to the point of joy in her debut collection *How I Bend into More*, released in February of this year. Her book makes the boldest entry into embodied crip poetics surveyed here with its calligrams and black-and-white photographs—some of

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[103] Piepzna-Samarasinha, *Bodymap*, 42.

[104] As for loving polluted rivers, nonjudgmental self-acceptance cannot restore good faith where humans have inflicted damage on nonhumans. From the river's perspective in a social model of degradation, humans are the disablers; the river, the disabled. Accommodating a river demands more than a resolution to go forth and toxify no more. Only a commitment to ongoing cleanup can begin to approach ecojustice. Aesthetic potentialities aside (iridescent oil slicks on water, for example, and arresting photographs of bird corpses full of plastic), if there is such a thing as "pollution gain," it must entail the example of the damaged ecosystem that offers more as a site of recovery than as a memorial to devastation. We must accommodate—cleanse, detoxify, undam, regenerate—whatever we can. What damage we cannot reverse will remain as a parable against environmental overreach and abuse.

herself, others of text and image collage, still others of paper quilling—all arranged along an eighty-degree curve that mirrors her severe scoliosis. Gerbeza includes multiple photographs of her bare back without any of the posturing of the best girls in *City of Incurable Women:* these photographs are altogether revealing. Other poems hinge around a dashed vertical line bisecting the page, a typographic representation of a ram-rod straight spine orderly with vertebrae, whose symmetry she unbalances with irregular lines of text that branch left and right from the slim central trunk. Still other poems, the sparest in the collection, feature a solid horizon line to represent the surgical table where she lay during her spinal fusion and where during the operation she flatlined into a code blue, a critical status indicating cardiopulmonary arrest. In "Pain," a poem of sparse text and plentiful dotted lines like undecipherable Morse code, she represents the titular feeling as "an ellipsis /// these small punctures /// [that] alter my body's syntax //// these marked echoes /// [that] punctuate my movement."[105] We poets claim to write on only three themes—love, death, and poetry itself—but to the crip poet's palette, we must add the body as written record, as grammar and syntax, the body as language.

In these visual poems, Gerbeza has transcended enjambment altogether by eschewing the sentence and "em(brac[ing])"[106] the fragment. We surgery patients may do so to symbolize the fragmentary quality of fading in and out of consciousness under anesthesia or the flesh excised from us or what remains of us afterward. For her epigraph, Gerbeza borrows from the amputee and self-declared cyborg Jillian Weise, who, in her own first collection, an aughts-era bible of crip poetics, writes, "This is the spine) // A closing parenthetical. // What did my body mean to say as an aside?"[107] While expressed in two complete sentences, these lines gesture

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[105] Tea Gerbeza, *How I Bend into More* (Palimpsest Press, 2025): 14.

[106] Gerbeza, *How I Bent into More,* 49.

[107] Jillian Weise, "The Body in Pain," *Amputee's Guide to Sex* (Soft Skull, 2007): 41.

to an incomplete sentiment written by the body but closed down before it can articulate itself, unfinished as a fragment of thought. Or perhaps the crooked spine asserts the open-ended potential of its unique curvature outside ramrod posture and Foucault's medical gaze. The possibilities of such an unresolved aside recall Sunaura Taylor's ingenious artistry of the non-normative body, which may engender any new shape. In homage to Weise, Gerbeza adopts the parenthesis throughout her book as the visual cypher for the back brace she hated wearing in adolescence. In "glossary of parentheses," she traces her eighty-degree curve in a cascade of these pedestrian characters:

(   )
(   )
(a Boston Brace)
(   )
(   )
(a parentheses   )
(around my spine   )
(   )
(   )
(   )
(   )
(   )
(a curve   )
(   )
(an aside   )
)
(remaining open   )
)
a spine)[108]

As I look at this poem, I remember the critical writing sample I submitted to UGA English when I first applied to the doctoral program, a literature review on the near impossibility of notating dance on paper because of our too-many articulate body parts and the dynamism with which we move them, quick to slow and slow to quick for each one. I have choreographed a single dance as a gift to a friend, and it looked a lot like this on the page. (The waltz with its erect posture has

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[108] Gerbeza, *How I Bend into More,* 15.

fewer dynamic movements.) If in this introduction, I sought to locate an embodied crip poetics, Tea Gerbeza showcases one in these stills, so full of movement both despite and thanks to the fused vertebrae at their core.

I have pretended to interdisciplinary writing, but as you will read in this manuscript, I'm all words, words, words. Had I gotten my hands on Gerbeza's book sooner, I might've broken out of my stanzas into an expansive body art like hers. I do include one calligram, oddly enough in a curve very similar to the one her book replicates over and over, but to a different end, as you will discover. Still the rigidity of my poems, if that's what it is, captures how restricted, how stiffly immobilized I've felt these long housebound years waiting for my release. Perhaps I will embrace new unbound forms next.

Writing Disability

I've collected the thirty poems of this creative dissertation under the title "Unusual Velvet," a reference to the "unusually soft and velvety skin" characteristic of the connective tissue disorder that, unknown to me, circumscribed my life through the writing of most of them. These are wounded poems of a certain softness, sutured and scarring over, supple but overwrought, unrebounding. The defective collagen in the thirteen Ehlers-Danlos syndromes makes for inelastic connective tissues that cause pathological flexibility and have earned the hypermobile type, my type, a reputation as the contortionist's disease, exploited for show in youth but paid for dearly in later years as the painful wear and tear of hyperextension accumulates. Invoking this double-edged talent, the poems in the first section of the manuscript, "Contortions," bend to the three-ring circus of societal expectation, ableist and otherwise, in a vain attempt to conform before going quietly their own way. The same faulty collagen that lets us tie ourselves in knots to our own degeneration makes the skin of EDS patients susceptible to contusion where normal skin would rebuff impact. The second section of the manuscript, "Easily Bruised," harnesses this metaphor in service to heartbreak poems that offer up words in place of emotional resilience. The fourth section, “Untethered,” in reference to the “detethering” neurosurgery that treats tethered spinal cord, also called *tethered cord release* and, in medicalese, *microsurgical resection with laminectomy,* concludes the manuscript with poems I composed on the eve of the procedure and afterward as the speaker grapples with their renewed freedom in mobility and all the time lost to housebound fatigue.

The third section, “Erasure,” takes a different form entirely. Funded by a Charlayne Hunter-Gault Giving Voice to the Voiceless grant from the UGA Grady College of Journalism, I interviewed seven patients of ME/CFS, my previous diagnosis, to create erasure poems from the auto-transcripts of our conversations and distill inherent truths about the human condition from these patients’ lived illness experiences. The title of this section refers both to the form these poems take and the way this illness in its moderate and severe presentations all but deletes a person from public life; one of the ME/CFS campaign hashtags is #MillionsMissing. Although some of my interviewees may well have had EDS too, none had yet received that diagnosis at the time of recording. I cannot overstate the mental difference between the labels of a contested pathology versus a known if often overlooked genetic disorder. The uncertainty that accompanies the junk-drawer diagnosis of ME/CFS permeates these erasure poems with a spiritual diffusion that eventually condenses around defiance, serenity, hope, or love.

I conducted five interviews via Zoom and two via email questionnaire in response to the McGill illness narrative interview,[109] a health-research standard, which I tailored to ME/CFS. The two poems condensed from questionnaires came together as traditional found erasures by whittling away at longer texts. Instead of blanking lines and leaving the remainder as formatted

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[109] D. Groleau et al., “McGill Illness Narrative Interview (MINI): An Interview Schedule to Elicit Meanings and Modes of Reasoning Related to Illness Experience,” *Transcultural Psychiatry* 43, no. 4 (2006): 671–91.

in the original document, I took the poetic license of reformatting the conserved words for legibility. I preserve typography where possible but at times punctuate or capitalize for clarity.

Rather than transcribe these lengthy verbal exchanges by hand, I proofed the automatic transcription generated by Kaltura against the Zoom audio file. As I learned in the trenches of aughts-era dictation software, automatic transcription can give rise to some sublime misrenderings no reasoning mind could produce (e.g., “mileage I can settle in my life” for *myalgic encephalomyelitis,* the title of the third erasure), and it was no different with Kaltura. Unable to resist these human-computer miscommunications, an apt metaphor for the misinterpretation of images by radiologists, I preserved those homonymous infelicities in parentheses if they contributed a subliminal wisdom to the poem: a bit of machine learning as assistive technology. Not wanting to take full credit for the results and to protect confidentiality, I attribute the poems as afters to the initials of the interviewees.

All told, I find these erasures less effective if more innovative than the traditional narrative journalism the grant was designed for. Even with Kaltura’s transcription, the process of removing timestamps and filler words from two-hour, twelve-thousand-word interviews and condensing them into 250-word poems was grueling, requiring the focus of days to achieve middling results. Thus I cannot recommend the process and have no plans to repeat it. Moreover, these poems have proven impossible to publish in isolation. Perhaps they will work as a micro-chapbook or simply as a chapter of this dissertation. I don’t regret assembling them, especially not my Russian colleague’s soliloquy on the suffering of long COVID I could hardly stand to cut down to three solid pages, but I hesitate to call any of them successful by contemporary poetic standards. Had I pursued a STEM field, they would have borne out in the way of a failed hypothesis, better known as—research.

I’ve been writing poetry for fifteen years now, but I still cannot comprehend how free-verse poets space their lines internally—bump them out from the left margin, pause pregnantly between words—although I believe there's a method to their white space. Where my poems aren't left-justified but stretch (elastic) toward the center of the page, for want of other insight, I use a cheat: I tab them out based on how much movement the verb, if any, conveys to the line. Russian verbs of motion move differently from their other verbs because of the need to specify unidirectional versus habitual, progressive, or multidirectional movement (this is true). One can go home every Friday or be on one's way home on Friday, but one cannot be on one's way home every Friday or, most challengingly for the anglophone, go home on Friday (we have no grammatical analog for the latter). Russian has most tangibly influenced my poetics not via study of nineteenth- and twentieth-century literature but grammar, the reason I first took up the language. I wanted to know how Vladimir Nabokov did it, how he wrote *Lolita;* I wanted to know what he knew, trilingual from childhood in Russian, French, and English. It turns out his genius did not inhere in *the* language but in language itself, and I had to acquire two foreign languages to divine it. In consolation and nostalgia, I tab out my English lines based on how much they move à la russe.

An irregular metrist after Jim Ferris's heart, I composed all four sections, including the erasures, in my dominant mode: free verse inclined to internal rhyme sometimes broken into stanzas and more rarely end-rhymed. Andrew Zawacki once told me I write densely and that without stanza breaks, the reader might miss things, so I include breaks wherever the math works out: couplets for love poems, tercets for love triangles, quartets for narrative, and longer irregular stanzas for speechifying. In "Two Mississippi," I lucked into a repeating pattern of three-two-one-two-three-two-one to end on the one, alone the way the speaker ends up when the underlying love square collapses.

So did I, thwarted waltzer, get my body onto these pages? I found social dance my senior year of college and proved such a quick study at the waltz that I joined Stanford's performance troupe for two years after I graduated. I was never a professional—I thought about going pro right around the time I got sick and had to cut back and then quit—but I was pretty good. We learned several styles of the dance, the most basic being the rotary or turning waltz; a step up from that, the cross-step. (Box step is for crowded weddings, not dance halls.) For Stanford's annual winter ball, we performed the Viennese waltz, a more advanced style that requires turning 180 degrees every three counts so the leg can reach directly back and then directly forward, and your pair can travel along the line of dance. It is a striding style. My favorite style was the redowa, a skipping style that leaps on the two and five counts instead of stepping on the one and four counts and feels like flying. We were so good, we could redowa backwards in reverse, rotate left such that we had to over-rotate in the corners of the room to the clockwise direction of dance, which usually unwinds you in tight spaces, and then transition mid-leap through a spin from an open pair facing each other to the follow hugged flat against the lead's back so we took the same steps together instead of the usual mirrored ones and whipped up a huge centrifugal force we could spin out of just as easily. Twenty-one-year-old me was the most me she could be in those moments.

So this, impossibly, is what I want from poetry: an equivalent flight. Although I danced in closed forms, I tend not to write them because, under my pen, they derail toward the maudlin, old-fashioned nursery rhyme. Maybe because I struggle to make my meaning fit metrically, maybe because I dislike how end-stopped lines clomp to a halt before lurching back into motion or I resist putting a fine point on it or I'm halfway to prose already, I enjamb almost all my lines. End-stopped lines don't allow the duality of breaking negated words and transitive verbs in the middle of the phrase and so tapping into an ambivalence of feeling and experience. I contort lines to break them in the middle so it all cascades down the page like a waterfall, a cup overflowing rather than a restrained one brimming to spill. I wrote this way before I read Ferris's essay because I want my poems to run where I cannot, and enjambment is the best poetic technique for picking up speed. It seems I already intuited this and practiced it subliminally. I'm compensating for what my body can no longer do. Like any form of translation, it's not the equivalence I dream of, but it does bring motion to poems written from a place of physical and emotional stagnation I in my small, housebound, porchstuck reality couldn't move through any other way.

Ultimately there is no one way, style, form, or aesthetic to disability poetry other than some defiance of the norm, some formal breakage modernism, free verse, and prose poetry already gave us. If the disabled body is sufficient however it is, by analogy we may use any form we please to sing our songs. The sea change would seem to be our celebration of these physical differences, our glory in freed, overspilling, enjambed lines instead of a vain wish to be what we're not: tidy writers of set forms, end rhymes, even blank verse.

There are too many wonderful ways to be other than I am, I wish for them often. But I can work with I've been given in addition to what I went out and got. A sea witch to my own little mermaid, I can give my poems legs and voice and let go the time lost. As Andrew Marvell enjambs it, "Thus, though we cannot make our sun / Stand still, yet we will make him run."[110]

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[110] Andrew Marvell, "To His Coy Mistress," *PoetryFoundation.org,* n.d., www.poetryfoundation.org/poems/44688/to-his-coy-mistress.

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