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The paradox I am/within: Tripping in/towards Hope through a Gendered Disabled Poetics

Le paradoxe que je suis/dans lequel je suis : trébuchant dans/vers l'espoir par le prisme des poétiques genrées et handicapées

Alanna Veitch, PhD student
Queen's University, Department of Gender Studies
23hfb@queensu.ca

Abstract

"The paradox I am/within" is from a poem I wrote during the first year of COVID after sitting with the bad feelings of an enduring and anxious present. The enduring nature of these feelings demanded I return to the poem as a sustaining practice and method of what Couser (2016) terms disability life writing, through which to assess: In what ways can a gendered disabled poetics bear the messy and detached histories of embodied difference? How can "hope" be generated in/out of despair? I proceed by offering the poem that titles this paper to discuss how it registers the hopeless paradoxes that neoliberal culture has made central to disability. Next, I share poems that attend to my feminized disability experience, inviting the reader to assess the discomfort of exposure. I then invoke the trip as a force of disruption and generator of hope, enabling me to engage more closely with Muñoz's (2009) theory of hope. This paper is an experiment in poetic theorizing about the messiness of disability and the need for hope.

Résumé

La phrase « Le paradoxe que je suis/dans lequel je suis » (« The paradox I am/within ») est d'origine d'un poème que j'ai rédigé au cours de la première année de la pandémie COVID-19, naissant d'émotions néfastes liées à un temps présent durable et anxieux. La nature durable de ces émotions a ordonné que je retourne au poème et que je le traite comme une pratique soutenable et une méthode du « disability life writing » (Couser (2016)). Grâce à cela, j'ai pu évaluer les questions suivantes : De quelles manières la poétique genrée et handicapée peut-elle incarner les histoires désordonnées et détachées qui se manifestent de la différence de l'incarnation ? Comment est-ce que « l'espoir » peut être créé durant et en conséquence du désespoir ? Je procède en offrant le poème éponyme de ce texte afin de discuter de la façon dont il incarne les paradoxes désespérés que la culture néolibérale a rendus un point central du handicap. Ensuite, je partage des poèmes qui traite mon expérience féminisée avec le handicap en invitant au lecteur d'évaluer l'inconfort d'être exposé. J'invoque donc le voyage comme une force perturbatrice et créatrice de l'espoir qui exemplifie la théorie de l'espoir de Muñoz (2009). Ce texte expérimente avec la théorisation poétique sur le désordre de l'expérience des personnes avec des handicaps et la nécessité de l'espoir.

Keywords
Embodied difference, critical disability, disability poetry, hope, precarity

Mots clés
La différence incarnée, le handicap critique, la poésie sur le handicap, l’espoir, la précarité

Introduction

This paper originated in response to a call for abstracts on how disabled people interact with a state whose politics are imbued with eugenic logics. Being a disabled woman closely engaged with disability work—for it is deeply personal—I felt a need and responsibility to respond. Because the original paper never amounted to anything, this draft marks my attempt to bring it back to life: as a theoretical meditation on my poetic depictions of disability and white female embodiment. While this is a personal account, I find myself lingering on Cameron Awkward-Rich's (2022) use of "we" to describe both the singular and collective subjectivities of those at the intersections of gender, race/ethnicity, class, sexuality, dis/ability, and difference in times of austerity, oppression, and violence.

Two excerpts prompted the original submission that, now, help me to frame this second version at the outset: the first is by Muñoz (2009) and reads, "…the here and now is a prison house. We must strive, in the face of the here and now's totalising rendering of reality, to think and feel a then and there" (p. 1); the second is by Berlant (2011) wherein they write, "(Optimism) is a scene of negotiated sustenance that makes life bearable as it presents itself ambivalently, unevenly, incoherently" (p. 14). Both are not necessarily writing about disability, but rather about the disabling effects of a violent now that endures and renders diverse realities flat. By highlighting how folks negotiate hardship—to make life bearable—both Muñoz and Berlant rework such renderings toward conceptions of social justice, agency, and hope.

Revisiting these excerpts and several poems I wrote during, and immediately following the peak of COVID restrictions, the questions I now strive to address are: what might happen when my feminized disabled poetry encounters Muñoz's and Berlant's texts? What might this encounter illuminate, shift, blur, and/or leave in shambles? In what ways can a gendered (or feminized) disabled poetics bear the messy and detached histories of embodied difference? What capacity is there for hope in disability when it is unexceptional, impervious, and vulnerable to crisis? In what ways can a gendered disabled poetics build (or fail) alliances of care across individuated spaces of neoliberal rule?

In what follows, I share insight into the reasons I gravitate toward poetry as a critical, methodological, and sustaining practice that works together with the method of disability life-writing put forward by Couser (2016). I then offer the poem that titles this paper to reflect on its use of poetry as a form of life-writing to register the paradox, paranoia, and hopelessness that neoliberal culture provokes regarding disability. Next, I share several poems that address some of the discomforting feminized experiences of having a disability, which expose more than I originally hoped to reveal. From the limits of my exposure, I invoke the trip as a force of disruption. Rather than ending on a disparaging note (as a narrative trope I try to resist getting caught up in), my last section engages more closely with Muñoz's (2009) work on hope to think theoretically about the hope my poems gesture towards. I recognize (and warn) that this paper's ambition might lead it to, or be interpreted as, a form of neoliberal failure. Nevertheless, by failing, this paper does some of the necessary work of attending to the messy, uncomfortable, and hostile conditions facing disabled and multiple marginalized folks in Canada and globally, while modeling how hope might be generated through the embodied act of poetry.

Methodological Framing: Poetry, Disability Life Writing, and Poetry as Illumination

In the field of feminist disability studies, poetry is a method for (1) exploring, analyzing, theorizing, and making sense of embodied differences (Bartlett et al., 2011; Fenge et al., 2016; Ferris, 2004; Lorde, 2007); (2) attending to and/or challenging structures of oppression and exclusion that bear on different bodies and minds (Clare, 2015; Price, 2015; Schalk, 2018); (3) stripping down language and unsettling literary form in ways that centre experiences of disability and diverse embodiment (Ferris, 2004; halifax, 2023; Kuppers, 2007; Rinaldi & halifax, 2016); and (4) refusing to be totalized or exceptional (unlike a good neoliberal subject who should always strive for exceptionalism) (Johnson & McRuer, 2014; Rice et al., 2017). Some of these qualities are what distinguish disability poetry from conventional approaches, particularly when disability itself becomes an analytic lens through which stereotypes are exposed, challenged, and redefined (Bartlett et al., 2011; Ferris, 2004; Quayson, 2007). In disability poetry, there is an insistence on self-definition that is also attentive to the social fabric from which the self emerges, with attention to what and how experiences are shared—and whether they can, or should, be—in an effort to complicate standard conventions that shape how the world is understood and lived in.

On the surface, a disability poem might appear in ways that subvert standard poetic practices, or in ways that seem so conventional that disability cannot be easily perceived; one must examine what the poem or literary work is doing in relation to the context, much as Quayson (2007) and Titchkosky (2007, 2009) reveal how disability figures in literature and everyday life. The disregard for normative literary traditions is part of the work of writing the non-normative bodymind into text (Couser, 1991; Simplican, 2017; Tsiokou, 2017); the subtlety of the poem's subject is one of its aesthetic strengths

(Ferris, 2004; Leggo, 2007; Vernon, 1979); never only autobiographical, the “I” never fixed, the poem negotiates its subject (Battiste, 2012). Rather than fixating on what makes a poem “good” or “bad,” I fixate on what a poem does: the way it breathes as the body does, with and against the currents of everyday life; and its capacity to falter unapologetically. For those of us with a tendency to trip, the poem is where stumbling takes shape, is differently embodied, and is activated anew.

The method of writing the body into text works within the literary genre known as life writing, or more aptly, disability life writing (Barrett, 2014; Couser, 1991, 2016; Mintz, 2003; Simplican, 2017). Such narratives are autobiographical writings that reckon with our human embodiment as vulnerable subjects, of which we are made acutely aware in illness and disability (Couser, 1991, 2016). Having emerged alongside feminist and disability rights movements, life writing uses personal experiences to understand and critique patterns of oppression (Mintz, 2003; Simplican, 2017). However, central life writing is to feminist and disability studies; it has also been critiqued—met with hostility—for calcifying the abled/disabled binary, perpetuating the desire to view disability as a tragedy and/or story of overcoming, individualizing structural forms of oppression, and being incompatible with a community ethos (Barrett, 2014; Mintz, 2003). The paradoxical relationship life writing has with feminist disability studies is, according to Mintz (2003), what “stimulates the possibility of a different sort of community…, unbounded by the very divisions that fracture [one’s] sense of relatedness to others” (p. 135); it necessitates that ambiguity (see Simplican, 2017) become central for negotiating, and making legible (see Barrett, 2014), a fluid and multilayered self embedded within diverse social networks.

As a fluid methodology, life writing takes many forms (see Couser, 2016; Mintz, 2003), casting a wide net capable of holding the elusiveness of disability, through which poetry can witness and critique the complexities of human embodiment in disability, illness, and structural oppression (Battiste, 2012; Ferris, 2004; Rinaldi & halifax, 2016). Poet Audre Lorde (2007) imparts how vital poetry is to existence, forming the light with which to scrutinize our lives, survive, and hope for change. As a woman disabled by the cruelties of this world, and pathologized for being a woman with an unruly body and mind, I feel Lorde's words resonate through my fingertips as I articulate how poetry is a form of life-writing for inhabiting, understanding, and altering the structures that exploit my vulnerability. As an embodied practice that eludes form (see halifax, 2023; Leggo, 2007; Vernon, 1979), poetry charts the courses that make up the work of living; it nods to those of us who trip in poorly lit areas (see Chaudhry, 2017, on tripping), reanimates the swerve of our gait (Retallack, 2003), and allowing us to tend to our wounds and see part of the world in each scar. Poetry is a critical act of illumination, an affirmation of life, and a refusal to be (re)solvable.

The Paradox of Disability

When I first sat down to write this paper, I found myself reflecting on an encounter with a friend I had not seen for nearly ten years. We were congenial, enjoying reminiscing, and like clockwork, the topic of my having multiple sclerosis (MS) surfaced. Perhaps to reassure or congratulate me for managing to walk to the kitchen and back on my own—aided (un)noticeably by the wall—or for simply getting up in the morning, he told me that I do not look disabled and that I seem to be doing quite well. I seem to have fooled him; I was passing (too well?) as the physically capable person he knew many years earlier. Of course, part of me wanted my disabled self to remain disguised; part of me enjoyed living in the fantasy that my disability was no more interesting than the colour of my hair (a mousy light brown shade), or to return to my past, less/disabled self. I appreciated his surprise and, perhaps most of all, his acknowledgement that I was *still* a person. I also did not want to sour a perfectly good conversation with a curt response: *"What did you expect me to look like… be like?"* Yet, I berate myself for feeling so flattered and offering a painfully uncritical response that went something like, “Thanks! Yes, I’ve been doing really well … I’ve been walking a lot, doing yoga, you know … still dancing in the confines of my tiny apartment.” While this is all true, it is only part of my reality because every day differs, and the future is never inevitable.

You see, in 2015 I was diagnosed with relapsing-remitting MS (RRM) after several years of rapid physical and psychical decline—physical and psychical because they are not distinct from one another (Patsavas, 2014; Price, 2015). I was 24 years old, in the prime of my (re)productive years. However, instead of securing a stable job, getting married, and having children like a good neoliberal subject (as my twin sister was doing), I faced an uncertain, potentially lonely future. Three years earlier, at 21, I was performing on a stage out at sea, but now, ten years after my diagnosis, I dare not use the stairs without railings or someone to hold onto. Yes, I can walk independently for about 2 kilometers, but a short break and a supportive arm are often necessary. As such, my independence is always in question. But then again, I have never been completely independent; independence is a fantasy, one that often reinforces the belief that any dependence—especially if it is the result of a societal issue, like poverty—is an individual failure and the result of a bad attitude (Bê, 2019; Johnson & McRuer, 2014; Titchkosky &

Michalko, 2017). Please forgive my cynicism and the bad attitude I have towards the unlivable conditions disabled people are often expected—forced—to endure.

Since speaking with my friend, I have mulled over what I could have otherwise said: “What did you expect me to look like … *be* like?” I could have attempted to satirize my physical limitations: “If only you could see me stumble down the stairs!”—though this is not very funny. My question might have invited a fruitful discussion that gently pushed against common assumptions about disability, which have been theorized in great detail by scholars like Garland-Thomson (2005), Puar (2017), and Johnson and McRuer (2014), to name a few. On the other hand, humour might have been a different way for me and my friend to engage with the uncomfortable subject of my disability, demonstrating my willingness to make light of the situation that is so often associated with tragedy, while exposing how often disability is used for comedic relief (Anesi, 2018). Ridiculing my disability might, nevertheless, have done little more than reproduce (as my initial response might have done) the belief that disability is burdensome, unnatural, and a situation to simplify, mock, degrade, pity, or overcome. Nevertheless, my preoccupation with what either response might have reproduced or failed to challenge about disability assumptions suggests that I am caught up in the “anxious paranoid determination that no horror…shall ever come…*as new*” (Sedgwick, 2003, p. 146). In other words, I was overcome by the need to know how my words and bodily movements would be interpreted and understood by my friend.

The difficulty I have navigating the tensions between normalcy and difference, control and surrender, tragedy and wit, independence and dependence illuminates the paradoxes of living differently as a white disabled woman in a society. Though I am afforded protections as a white woman (Ahmed, 2007), under the neoliberal spectre which demands independence, a high level of productivity, and a well-functioning body and mind, I am neither socially nor economically viable (Garland-Thomson, 2011; Rice et al., 2018; Shildrick, 2019). I am not worth the social or economic investment that affirms my being here. In the poem that follows, I divulge how living with/in such paradoxes bears profoundly on my social relations and my sense of self.

The paradox I am

Well, I've been
sitting here for hours,
thinking (not knowing)

of the words
that passed between us and
the ones that never did

I sit here and I wait
for something to touch
or to leave me

for I've come to believe
that a withering self is
not (always) worth being

so, how do I – explain
the life that I've been living, while
trying to keep it hidden?

the paradox I am
within has no way out
for I am *it*

People look,
but few will say the things
I've heard, and meant to:

"She's doing well."
Yes, well, I've been, but
I've seen time and what it's done, and
I fear it as do you.

but few will speak
and watch me wither
each year, a little slower

So, well, I've been
sitting here, not knowing
what to do with myself
anymore
than you do

The poem begins and ends with the idea that I am well, while conveying the irony of not being well at all. As earlier stated, I embody the paradox of health and illness as a disabled patient whose body has responded as well as can be expected to medical treatment (thus far); of wanting and not wanting to be seen as a disabled object; of being lonely and not alone, caught between living and not living in a way that is compatible with the social and political world. I am at a point where my disability and medical diagnosis have become so imbricated that I no longer cohere to one category of person (Awkward-Rich, 2022; Clare, 2015; Garland-Thomson, 2005). Living with/in these contradictions, I find it increasingly difficult to disentangle myself from them and these ready-made categories I had been trying to fit into, let alone understand my place among them, for what can a disabled subject do with oneself when they do not *fit*?

As the poem suggests, I spend a great deal of time sitting, thinking about my encounters with others, about what was and was not said, and about whether something better is possible. However necessary it is to write about one's life, it is challenging and, as Mintz (2003) notes, requires a patient and trusty reader. It is difficult to articulate something truthful and poignant about living differently than one initially envisioned or hoped, and to be understood, to avoid cycling into a tragic tale or whirring over the narrative arc that keeps everyone comfortable with its happy ending. So, while I do not intend for this to be a site of tragedy (for any of us), I am drawn to Awkward-Rich's (2022) insistence on thinking with the terrible feelings that he considers endemic to trans life, because there are *bad feelings* that I consider endemic to my disabled life. What, for instance, do I mean when I write, "to believe / that a withering self is / not (always) worth being"? Why make such a troubling statement? There are many reasons, one of which is why poetry is my preferred method of writing; it permits me to apply ambiguity as a literary salve to the wounds I am writing open (see Simplican, 2017, on estrangement). In part, I am giving space to the real possibility of progressive decline that characterizes conditions like RRMS (Dutta & Trapp, 2014). I am also naming the loneliness and abandonment that a disability diagnosis and treatment might mean for disabled folks, as Clare (2015) and Piepzna-Samarasinha (2023) each detail. Most of all, I am being honest about becoming emotionally labile, cycling through feelings of sadness, anger, and anxiety that are irrational, explainable only with an assessment and MRI, and so there is not always room for them. My life is not entirely sad; in many ways, having to contend with my embodied self (as Crouser, 2016, notes about life writing) has enabled me to live by writing, but not in the ways one might assume.

I do not wish to make anyone uncomfortable with my sad thoughts, though they are part of living with RRMS—a 50% lifetime prevalence (Siegert & Abernethy, 2005). I do, however, wish to draw attention to aspects of living that have been made unbearable through debilitating histories of racial and colonial violence, which have linked disability to racialized and feminized categories of identity (Al-Saji, 2023; Dhanvantari, 2024; Erevelles, 2011) and the austerity that such individuals now face under neoliberal capitalism (Smith-Carrier et al., 2020; Stapleton, 2013). Not only have these systems continued to make life unbearable for those debilitated by them, but they also target the lives of those living with severe disabilities. In addition to austerity measures that aim to cut welfare system costs by cutting access to its services, another way this has taken shape in Canada is through the legalization of medical assistance in dying (MAiD) in 2016. In March 2021 (during COVID), Bill C-7 received Royal Assent, which, beginning March 2023, expanded MAiD eligibility to include those with a grievous and irremediable condition, such as severe mental illness and depression (Brassolotto et al., 2023; Stainton, 2023; Thomas, 2022). While I have no intention of shaming those who have found dignity in medically assisted death, I am troubled by the contradictions in social policy decisions which intrude upon the ways I live and view myself—and my future—as a disabled woman and member of society. Rather than make conditions conducive for life through income support and affordable housing (Smith-Carrier et al., 2020; Stainton, 2023; Stapleton, 2023). The Canadian Government is making assisted death easier to access for those worn out by the act of living in an inequitable world.

COVID is part of an enduring period of precariousness for disabled, racialized, queer, trans, female, elderly, and multiply marginalized folks who already face intense austerity, stigma, and exclusion from social and economic services (Abrams & Abbott, 2020; Linton, 2021; Stienstra et al., 2021). With mental health-related disabilities (including depression) having risen sharply among youth, working-aged women, and racialized minorities between 2017 and 2022 (during which time COVID took effect) (Hébert et al., 2024), the expansion of MAiD eligibility in lieu of public provisions is not only worrisome but also illustrative of a deeper ethical issue related to how populations are controlled. Disability ethics educator Heidi Janz (2023) makes clear how the simultaneity of inadequate COVID responses and expanded MAiD eligibility is illustrative of how ableism and eugenics—a movement to 'improve' the human species by eliminating those deemed unfit for society—figure prominently in Canadian medical-legal systems, forming what Garland-Thomson has termed eugenic logics (i.e., medical-legal reasoning used to determine who lives and who dies).

These same logics are also imbued with racist and classist sentiments, which require careful thinking about the various ways that life, death, and illness are distributed across persons (Erevelles, 2011; Puar, 2017; Stapleton, 2023). The resulting practices (exemplified by MAiD and intense socio-economic inequality) are especially troubling because those deemed unfit are more susceptible to conditions like depression—which are made severe by the systems and services that shape the course of their lives (see Brassolotto et al., 2023, on vulnerability)—and are often members of historically oppressed and economically disadvantaged groups. Though I am white (an identity marker that offers me some protection), as a permanently disabled woman who also deals with profound sadness, it feels nearly impossible to evade the eugenic logics that pervade the very systems allegedly designed to support and protect individuals with disabilities. What can a depressed, disabled subject do with themselves in such a system?

On this issue, Rice et al. (2018) highlight the pervasiveness of neoliberalism and its endorsement of welfare retrenchment under the guise of a free, more equitable market economy. They impart how, under a system built on contradictions, one becomes a paradoxical self: "upon our bodies rules of governance are inscribed and through our bodies these rules are enacted" (Rice et al., 2018, p. 667). Rules of what is/is not normal are transmitted through societal institutions (such as employment or marriage) that dictate how one should live or else risk becoming a failed neoliberal subject. Bombarded by contradictory messages, I feel I have become the paradox I wish to escape, “for I am *it*” (quoted from the poem, “the paradox I am”). Of course, one must not forget the agency of those whose bodies and minds contradict normative scripts and, in doing so, offer new ways of understanding and reclaiming disability. Perhaps I am headed towards this realization at the end of the poem, but I am neither certain nor confident; I must sit longer with the discomfort.

Sitting with Discomfort Longer

The following poem I offer is another confessional piece, a third-person account of the despair and fatigue that accompany chronic illness, and the uncertainty that so often plagues my thoughts about the future. However autobiographical the piece is, I write to escape myself; here, the poetic “I” is up for negotiation (Battiste, 2012), its subject trusted to the reader who comes to embody the moment by bearing witness to it (see Mintz, 2003, on the embodied reader). Through the poem, I dissociate, handing my discomfort over to the reader who might make something more of the subject’s situation than the hopeless tragedy that is so often read into disability (see Quayson, 2007, p. 49, on “*disability as inarticulate and enigmatic tragic insight*”). By handing discomfort over to the reader, the poem functions as an intervention into the ethical implications of such framings (see Quayson, 2007, p. 24).

Where some mornings go

The morning came, and she lay there, naked
tired, though not yet out of bed
The sheets beside her strewn about,
while hers rested neatly around her body.

> The sun had already risen, and the day was moving
> her mind ran while her body lay still, breathless.
> Today is a difficult day without reason,
> though it's just another day when the living is
> empty but still occupying.
>
> Really, it has been a rather rough season
> with changes abound that may drown her existence
> What is its name? This looming disappearance.
> Death? But the memories
> must so too rest.
>
> "Goodness," she breathes aloud, her hand resting
> on her forehead, fishing for her hairline, thinning as it is,
> and she summons her bottom that continues to grow
> though her clothes become baggier
> over blush skin and throws.

As an intervention, then, the poem's reading might summon questions concerning: What is it to be naked, vulnerable to one's own judgement? What is it to be visible to others and vulnerable to public scrutiny? How do beliefs about disability bear upon our bodies and minds to make them undesirable? What strategies are available to help limit the extent of our exposure?

With these questions in mind, one way to read the poem and the nakedness of its female subject is as a wrestling with the objectification of female and disabled bodies (Clare, 2015; Garland-Thomson, 2005). No matter how much is disclosed or made visible, the issue of objectification extends beyond her physical body, and toward the body as a socially negotiated site of vulnerability and ambiguity: remaining concealed under the sheets and undescribed in the text, the poem's reader has the freedom to sketch the contours of the subject's body, limited only by the mention of her receding hairline and tired frame. Her frame is tired because social expectations about the appearance and comportment of one's body are tiresome, unrealistic, and fatiguing; they shape the body and determine its social worth (Garland-Thomson, 2005). We—women, in particular—are construed as assemblages of parts that can be literally or figuratively altered or removed. Nevertheless, by disclosing very little about the subject's situation, the poem also limits what can be known about her body, giving the reader permission to visualize both her shape and situation; it might even imply that her body deviates in function and form from the idealized normative body. Her nakedness, then, might signify some risks of self-disclosure: what is protected or given up should she refuse to be seen, stripped down, and prodded by needles, medical images, wandering eyes, and curious mouths and hands?

On the limit of consent, Saketopoulou (2023) discusses the issue one faces when consent (which I consider intimately related to disclosure) can no longer be limited or retracted, after one has shared more about themselves than they are comfortable sharing. How affirming and threatening consent is for those of us still navigating the contours of our own selves. You will have to excuse me for realizing that I may be oversharing; I cannot help but share and ask you, my reader, to consider what the poem is doing: what it discloses, limits, and makes (un)clear about disability. Is there something especially notable about that morning, of all mornings? At what point does discomfort become so overwhelming that it itself becomes illegible, past the threshold of consent?

The ambiguity of that morning also opens questions about the subject's "looming disappearance," and the impossibility of laying to rest the memories of an earlier time, because they stick around: memories of when the world did not feel so heavy, when her body was her own, and before she gave herself unthinkingly to someone who had no intention of keeping her intact. Berlant writes about slow death, but I prefer how Tony

Sandset (2021), drawing from Mbembe's (2003) concept of necropolitics, positions the slowness of death in the context of COVID as an accumulation of everyday exposure "to conditions not conducive to living" (p. 1413)—such as poverty, inadequate housing, and poor nutrition—and how these conditions are disproportionately distributed to, and felt by, particular groups and communities. Worn out by the work of living in an ableist, deathly, and unjust world, the subject's disappearance is not only imminent, but it has also taken hold of her completely. She must already contend with the loss of her former self; now, with the expansion of MAiD, she wrestles with the possibility that those exposed to conditions of slow death might ideate their own passing.

On the idea of one's passing, and the nonlinear passing of time, the following poem reclaims the "I." As an extension of the previous poem, it also gives partial shape to the pain and loss of sensation that living with a chronic neurological condition entails. It can be challenging to explicate a poem about pain and loss, so I trust it to my reader again.

Passing Change

Days pass and I can't place this feeling
I wake early with the sun,
wishing the day would not be done
But the days pass me as the wind does blow

I feel unsettled, rest across my shoulders
my neck warm, my cheeks blush, my legs numb
and I watch the world living in its sonic screen
losing vision and the number of days that have gone

Have I lost the day when the sky burned red?
Its flame now fleeting into an ominous grey
For when I caught it, I was left in awe
transported to a place much different, but the same

And it changed me, though only for a moment
Now the days pass as though they always had

and I wonder where it went, this fiery soul
Is it something or nothing that the day changes so?

I did not want to explicate the poem because explicating requires that I be clearer about an experience that insists on remaining ambiguous, even somewhat blurry (Chen, 2014, on writing with brain fog). Explication asks me to peel back more layers after I am already naked and realizing the extent of my nakedness, unable to limit what has already been exposed—much as Saketopoulou (2023) reflects on about the trouble with (and trauma of) consent when the issue is more nuanced than a simple “yes” or “no” answer. How many layers are left to pull back? How deep should I cut into my wounds so that I might colour this greyness?

From Limits to Tripping in/towards Hope

The act of writing my body into text gets me closer to the answers to these questions, and to the limits of my thinking. Through writing, I can channel the disruption of the trip—of my crooked sway—into astonishment of what the trip awakens within and about this disabled life I am now living. Without falling over the narrative arc which would relieve the reader from the discomfort of uncomfortable stories, and without drudging around in the hopeless mess I may have started to paint with my words—though I endeavoured to make a mess of this essay and how disability is often comprehended (or made to be comprehendible)—I engage the hope that is animated by the trip (nodding to Chaundry’s (2017) “Knowing through Tripping”) as it forces the body and mind to swerve (gesturing to Retallack’s (2003) poetics of the swerve). The poem that follows invokes the trip and its insistence on a crooked gait and uncentered comportment, which swerves and collapses like the walls around an unsteady frame. It is one of the first poems where I play more freely—intuitively—with form, allowing the trip to be present in the spaces which force one to pause. To echo Chaundry (2017), tripping (much like the unanticipated limits of my exposure) “indexes the materiality of risk” (p. 77), forcing a turning inwards (as the poem imparts), in order to venture outward, towards a mode of togetherness—i.e., the “we” noted at the outset of this paper, and the hopes of a collective.

further inwards

there’s something crippling about
indoor spaces

sidewalks, too, are far too narrow
for the crooked sway to which
my body is choreographed

but indoors, the walls collapse and
my throat reins in my vocal performance

my eyes now shifting
down and sideways because
        … because I

am right where I put myself
        a little back and just off centre, but

I’ve not prepared the song that
I’m about to scream, and so I
draw
        further
                inwards

For Muñoz (2009), whose work encourages a different way of thinking about hope, hope can be understood as both a methodological tool and a way of being and acting in the world. The kind of hope he articulates is more than a mindset; it is an act of resistance to the sedation and individualized defeat we, as a public, are bound to by a system of austerity that promises so much and yet delivers so little. In this way, hope is generated through the writing of the poem; itself a body taking shape by merging author and reader (Battiste, 2013; Mintz, 2003), tripping at unexpected moments (Chaundry, 2017), and swerving over the page to push against one's consciousness and refuse to accept the unequal burden of structurally created crises (Retallack, 2003; Sandset, 2021). And yet, much like the pain and anxiety that accompany the unanticipated trip (as Chaundry, 2017, conveys), Muñoz (2009) insists that disappointment is a necessary risk one must take if they wish to resist and change a system committed to keeping us stuck, cycling in impasse.

Because I do not claim to be, nor do I want to be, the one "who dreams for many" (Muñoz, 2009, p. 3). I join (in my own capacity) in dreaming forth a world yet to be through body writing. Despite the state's refusal to care by legislating disabled folks into poverty and normalizing the death of specific individuals, we survive. Much like Piepzna-Samarasinha (2023) imparts, I do not always feel equipped to care for myself, let alone anyone else; indeed, we might all be at our wits end, but because we have a different understanding of what care and hope (as resistance) can entail, we will do what we are able, even if that means "setting up care shift Google docs" (Piepzna-Samarasinha, 2023, p. 63), or refusing to be offended by a bad mood that might be the result of unending austerity. As you, my reader, might infer, my vision of hope is incomplete; the work is never over, and so I hope you can forgive me for what is not yet written.

Uncomfortable Endings, in/towards Hope

I am not fond of endings and find them uncomfortable to broach. However, perhaps the discomfort I feel about endings is appropriate for this kind of disability-related work that does not need to be resolved. What follows, then, are two poems I wrote that, for me, foster the hope for living differently in a world that is yet to come (Leggo, 2007; Muñoz, 2009). In both poems, I take a special liking to the sun and the moon (an exhausted cliché, I realize). I find the less exceptional sunsets especially majestic because they have a different kind of aesthetic quality that evokes a feeling of hope and possibility for a future that is unexceptional yet unlike any that came before. The poems, therefore, model a possibility for dreaming and enacting new ways of becoming in the world, while also inviting the reader to think differently about the work: see what is not written, what is omitted; feel the text as it is embodied; let the poem move with and against the current of life. Now, I cannot run, let alone walk in a straight line, without tripping or swerving, so I must trip in/towards a hopeful elsewhere because I cannot remain another day in this enduring and disabling impasse. I hope you can forgive me for placing these poems together, but I do so, trusting that you might stay if you have made it this far.

Catching the Sunset

Bed inside my palm,
the sunset bleeds across the skyline
Across my mind, my hands do bind
to drink in its magnificence

It’s difficult to hold as this
candescent canvas folds
As it transforms across the city stones—
quite real but illusionary

I caught it in my palm that night
we came out of our hiding
to drink this drug that nature owns—
that warms our earthly bodies

We watched as blue skies warmed to red
and became scant of sorrow
Like something real that nothing else
can humanize or borrow

I See Miracles[1]

Give me – the stories you dream
while you wake in a world that exists, but
not as I’ve ever known it

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[1] First published in an anthology of poems, source: Veitch, A. (2024). I See Miracles [poem]. In B. Kauffman (Ed.), *More than a Gathering*, (p. 12). Wet Ink Books.

Tell me – the tales of the day when
you will wake here and relish the living
we’ve had

I see miracles growing and thriving and dying
as the moon wipes the earth with her pale blue face,
and her eyes cast a lonely but lovely loon light
before morning awakens our earthly bodies

Lend me – the thoughts in your beautiful mind
that wrestle with me and my
womanly being

Share you – but most of all see
that I do just as the others do

I see miracles growing and thriving and dying
as the moon wipes the earth with her pale blue face,
and her eyes cast a lonely but lovely loon light
before morning awakens our earthly bodies

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