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The Theory of Breath: Long Covid, Disability Justice and the Right to Breathe

La théorie du souffle : COVID longue, justice pour les personnes handicapées et droit de respirer

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Abstract

This paper develops the theory of breath as an interdisciplinary framework emerging from my lived experience of long covid, a post-viral illness now disabling an estimated 19 per cent of Canadians who contracted SARS-CoV-2. Using autotheory as methodology, I weave together fragments of my shifting bodymind. This inquiry situates long covid within Critical Disability Studies. The theory of breath connects the laboured respirations of long covid to broader struggles for the right to breathe: the asphyxiation of Black men at the hands of police, the burning of forests, and the choking wildfire smoke of a destabilized Anthropocene. Capitalism guarantees unequal access to breath across lines of race, disability, class and gender. Drawing on disability justice, Black feminist thought and Indigenous knowledge traditions, I examine long covid as a mass disabling event marked by epistemic injustice, medical dismissal and the gendered silencing of illness. I trouble the ableism within disability rights movements that leave housebound people behind, and critically examine how whiteness structures both long covid activism and the field of Critical Disability Studies itself. The bed is reclaimed as a site of activism; rest and slow art making as legitimate forms of resistance. I argue that the bodymind of someone severely disabled is not a site of weakness but of methodology, a place from which new knowledge is churned up. Long covid demands urgent attention in our field as a portal to the disability futures we are called to imagine.

Résumé

Cet article développe la théorie du souffle comme cadre interdisciplinaire issu de mon expérience vécue de la COVID longue, une maladie post-virale qui handicape désormais environ 19 % des personnes canadiennes ayant contracté le SRAS-CoV-2. En recourant à l’autothéorie comme méthodologie, j’entrelace des fragments de mon corps-esprit en transformation. Cette démarche inscrit la COVID longue dans le champ des études critiques du handicap. La théorie du souffle relie les respirations laborieuses de la COVID longue aux luttes plus vastes pour le droit de respirer : l’asphyxie d’hommes noirs aux mains de la police, les forêts en flammes et la fumée étouffante des feux de forêt dans un Anthropocène déstabilisé. Le capitalisme garantit un accès inégal au souffle selon la race, le handicap, la classe et le genre.

En m’appuyant sur la justice pour les personnes handicapées, la pensée féministe noire et les traditions de savoir autochtones, j’examine la COVID longue comme un évènement de handicapage massif marqué par l’injustice épistémique, la disqualification médicale et la mise au silence genrée de la maladie. Je m’interroge sur le capacitisme présent dans certains mouvements de défense des droits des personnes handicapées, qui laissent de côté les personnes confinées à domicile, et j’analyse de manière critique la manière dont la blanchité structure à la fois l’activisme lié à la COVID longue et le champ des études critiques du handicap lui-même. Le lit est réinvesti comme lieu d’activisme; le repos et la création artistique lente sont réinvestis comme formes légitimes de résistance.

Je soutiens que le corps-esprit d’une personne sévèrement handicapée n’est pas un lieu de faiblesse, mais un lieu méthodologique, un espace d’où émergent de nouveaux savoirs. La COVID longue exige une attention urgente dans notre champ, en tant que portail vers les futurs du handicap que nous sommes appelés à imaginer.

Keywords

Long COVID, disability justice, epistemic injustice, Anthropocene, intersectionality, care collectives, slow activism, theory of breath, authotheory.

Mots-clés

COVID longue, justice pour les personnes handicapées, injustice épistémique, Anthropocène, intersectionnalité, collectifs d’entraide, activisme lent, théorie du souffle, autothéorie.

Prologue: A Rude Awakening

The sun rose. I had slept for less than two hours and felt ragged, as I often did with long covid. The birds and distant thrum of traffic reminded me there was a world outside my bedroom window. I languished in bed, my thoughts drifting from terror to despair, knowing that once I arose my heart rate would skyrocket and symptoms would worsen. For the past two and a half years my body has refused to cooperate with my wishes and needs.

When the test showed positive I knew things could be dire. When I did not recover I feared the worst. First came the anxiety, the confusion, racing heart and tight chest. Suddenly I could only walk less than a minute without my chest constricting. I developed dysautonomia, a nervous system disorder which rendered me supine much of the time. The dreaded post exertion malaise surfaced gradually, a hallmark of Myalgic encephalomyelitis/Chronic Fatigue Syndrome, which leaves people with the illness worried that any form of exertion can cause a “crash”. This limited my activity to the point where there was little left to do but recline and focus on my breath. One of my only remaining activities was weaving on a small loom in one of the three recliners placed strategically around our home.

I was not prepared for my sudden disintegration and disappearance. I had suddenly shifted into the status of “extreme disability”, absent from work spaces, friendships and hard won identities of warrior activist and faith community volunteer. Friends were confused, reassuring me that I would get better, except I did not. Colleagues continued at a frenetic pace while I appeared on zoom calls trying to look “normal”. Doctors told me they found nothing wrong. I had been moderately disabled with a hidden digestive disability

for 13 years, but suddenly I existed in a new complicated and constantly shifting terrain. I used a scooter to get around and depended on my partner for most activities of daily living.

Disability scholar Rosemarie Garland-Thomson says the disabled body forces us to grapple with our inherent vulnerability and its inescapable fragility (2011). I struggle to accept their assumption that somehow we can find a new sense of power and praxis through this isolating protracted health crisis of long covid. Garland-Thomson has been critiqued for their privilege and fixation on identity politics. Mollow (2004) notes that Garland-Thomson excludes the weakened body from her definition of disability, which is highly problematic for those of us dwelling with the weakened state of long covid. Meanwhile many of us must contend with medical authorities and our own internalized ableism, as we accept the label “patient”. Wendell (1996) details how we internalize the epistemic and social authority of medicine, which can limit our agency in the world.

People with long covid often fixate on cure from both allopathic and alternative sources, which all neatly fit into the realm of capitalism. I look to Foucault (1980) who discusses how we internalize governmentalism, a form of self policing which makes us adhere to dominant health and other power structures. How in my understanding of this illness have I internalized the stigma, disbelief and victimhood that are part of the dominant narrative around long covid?

I have in desperation paid too much money for a recovery coach who tells me that even my worsening of symptoms are positive signs of recovery. Such coaches have little formalized training and are proliferating with many ads and promises on social media. Most problematic, they often peddle in false hope which many are desperate for. This

scourge of positive thinking under capitalism is heavily critiqued by Ehrenreich (2009), who states that this mandatory optimism discourages critical thinking as it promotes consumerist views of happiness.

A theory takes shape from my words, with my altered bodymind. I no longer develop a crisp, argument cleanly embedded on a page. Instead fragments are written in the midst of brain fog and confusion. The theory of breath emerges yet remains elusive, much like the lives I and other folks with long covid live. We prioritize daily living and reach out to each other in Twitter (X) chat rooms during sleepless nights to discuss treatment and government and societal betrayal. I hope my prologue hints at my being remade after being dashed apart like a smashed teacup. Yet I resist silver linings and morals that our society is so eager to hear: no inspiration porn will be written on this page.

Long Covid: A Contested Definition

“Long covid” is a post viral illness which includes up to 200 plus symptoms. This disabling condition can appear weeks or months after acquiring SARS-CoV-2 and can be ongoing or relapsing (Raveendran et al., 2021). The World Health Organization reports that long covid can continue or develop three months after the infection and last for two months or more (WHO, 2025). I will examine the illness using autotheory and scholarly research to situate the disability of long covid within Critical Disability Studies. My literature review reveals that long covid, while often accepted as a disability qualifying for financial benefits in Canada, remains poorly understood by many medical doctors. Au et al (2022) label this poor treatment “epistemic injustice”.

Many long covid advocates critique the recent federal Canadian Guidelines for Post COVID-19 Condition for their promotion of exercise as treatment. Exercise should not typically be prescribed to treat this condition, as it will worsen long covid (Davis, 2024). Additionally, the illness is still treated by many medical professionals as an anxiety disorder, largely due to those living with the condition being mostly women, who continue to experience sexism and disbelief from health professionals (Duckworth, 2022).

Many people with long covid struggle to breathe and breath work is proposed as an approach to heal and recover (Saskatchewan Health Authority, 2021). This focus on breath ties into other struggles to breathe and live including the rights of people who face risk of asphyxiation by law enforcement. I look to the research by Mbembe (2021) who examines the experience of Black men in this area. All of us are implicated, as increasingly we struggle to breathe in growing parts of the world due to poor air quality from wildfire smoke.

We are seeing a massive number of people in Canada now disabled by long covid. A 2023 Public Health Agency of Canada report states that 19 per cent of people who contracted COVID 19 came down with long covid, which clearly makes this illness a mass disabling event. Texts on long covid have not been widely published in the field of Critical Disability Studies, due to the recent development of this disability within this past five years, but will be more discussed in years to come.

Introduction to the Theory of Breath

The theory of breath is a concept evolving in the destructive era of the Anthropocene, the current novel era of ongoing accelerating human domination over all aspects of the planet,

causing increasing destruction (Lewis & Maslin, 2015). Breath is necessary to life on all levels, and can also be viewed as an interdisciplinary framework encompassing the social, political and philosophical. Breath is a radical and elusive act for many communities, especially those marginalized by race, disability and poverty (Gumbs, 2020). Experiencing long covid we can view breath as part of our isolated yet collective struggle and our embodiment. Capitalism guarantees that racism, income disparity, ableism and environmental catastrophe result in unequal access to the right to breathe (Sharpe, 2016; Puar, 2017). The theory of breath I articulate weaves together thinking from movements including disability justice, Black Lives Matter and environmental justice.

Many with long covid fixate on the breath, something many have ignored until now. I close my eyes, inhale, exhale in ragged delivery. Terror overcomes me as I catastrophize about my life going forward. Theory takes place in my wheezing efforts to breathe, outside the academic journal, textbook or Zoom classroom. This is a theory of survival and existential reality, centring on strained respirations. I recall my early days as an asthmatic beginning at age 6. Breathing is exertion, demanding effort.

The emergence of the covid 19 virus and increasing wildfire smoke are connected to the growing disruptions of our climate. These climate disasters must open a portal, and force us to observe diffraction (Barad, 2007), a bending which somehow produces new ways of thinking. Foucault calls on us to relinquish the “conservatism” so entrenched in much of our lives. There is something stark and revealing about wildfire smoke on our doorstep and long covid raging in my body that connect me profoundly to the Anthropocene, urging a profound societal change.

Belser (2020) illuminates a thinking process which makes me realize that the denial of long covid is connected to climate change denial. This form of silence unfolds in strikingly similar ways to widespread patterns of disability denial. I wish to find an opening with others to discuss my own environmentally disrupted bodymind but often sensing none I retreat.

Breathing is an exertion, a reckoning, a way of being that now demands concentration and care. The theory of breath is embodied, related to its Latin root theoria, meaning contemplation. With uncertain and laboured breath all else remains abstract and liminal. I feel somehow connected to the many others who struggle to breathe, and ponder the deaths of Black men asphyxiated at the hands of police in North America, leading to the Black Lives Matter rallying cry “I can’t breathe!” The lungs of the world are on fire in the Amazon, and in the Boreal forest, further uniting all living beings who suffer in the Anthropocene.

My worth as a long covid survivor (I eschew the widely used label “patient”) is now measured by how well I rest and deeply breathe. The bodymind of someone “severely” disabled is a contested site, unstable and constantly shape shifting. I frame this positionality not as weakness but as methodology. What knowledge am I churning up from this altered state?

Autotheory as Methodology

Autotheory provides a methodology for my journey and will be used as a tool to disrupt current narratives that label catastrophic disability only in terms of loss. McNamara (2021)

describes autotheory as disrupting the scholar’s reproduction of hierarchies of power which privilege white and especially male academics. In using autotheory I resist the need to explain everything, instead using a montage effect to create different learnings. Autotheory has not been widely employed in the realm of disability studies according to Samuels (2023), who looks to earlier women of colour feminist writers who pioneered this form, in particular Lorde and Anzaldua, bell hooks and the Combahee River Collective.

This methodology allows me to string together fragments of my lived experience, arising from my shifting bodymind. People with long covid are an uncomfortable reminder of the possibility that more will be disabled by covid; we are an inconvenient truth. To find some meaning I build on the lineage of scholars like Audre Lorde, whose Cancer Journals (1980) showed the suffering of illness as intentionally political. Eli Clare (2017) offered the wisdom of the body as home, even when dwelling in pain and confusion.

How did I suddenly become a statistic in the global neoliberal hegemony that produces debility, the slow violence that disables mass numbers of people forcing them to suffer but not die quickly? (Puar, 2017) I see myself as a casualty of the war of neoliberal urgency which demands that at all costs we reopen economies and end masking to pretend we are back to “normal”.

The Bed as a Site of Activism

My writing silently mimics an activist scream, internal and unheard by those whose voices yell at energetic protest marches. This writing is an act of survival that can only imagine a bed in protest in the spirit of John and Yoko’s 1969 hotel actions for world peace. I

compose in bed and reclining. I silently protest the betrayal of the social contract to keep us safe. In Sick Woman Theory (2016) Joanna Hedva is pictured reclining in a bed surrounded by pill bottles, raising her fist in the air, too sick to attend a march to protest against the racist death of George Floyd. Mine is activism stripped to its basic survival, the act of conscious breathing. Hedva reminds us that the most anti-capitalist protest is to engage in care for oneself and others. Care work is often framed as women’s work and is dismissed. Hedva proclaims the bodies of women in pain as marked by cultural invisibility.

I hearken back to the 2014 UK activism of disabled artist Liz Crow who also had an energy limiting illness. Crow staged a 48 hour bed-out in the Salisbury Arts Centre, streamed online and on Twitter. The artist activist made public the private secluded existence of many who are disabled at home. In the tradition of Yoko and John, the activist concept of a bed-in has a rich potential to build on.

Disabled artist Frida Kahlo’s emancipatory practice to make art about her bodymind in pain includes lasting images of her painting in bed. Kahlo had a rich imagination that flourished in her art making often from bed, affirming the bed as a site of creativity, a space where we can imagine disability futures. At her first solo art show in Mexico in 1953 Kahlo appeared lying down on a stretcher, insisting on her right to be celebrated.

Being as Radical Activism

Beyond the bed, I struggle with the need to do nothing, to close my eyes and meditate and slow down. How do I declare my worth when idle? The right to exist without productive

action must be reclaimed as radical activism. Hersey (2022) insists that rest is resistance, especially for women of colour who have been pummeled by ongoing demands to focus on constant work. Taylor (2004) amplifies this right to not work and reclaim our power as disabled people.

This right to resist and rest counters most performative activism, with its focus on marching, yelling, standing up and expending energy. Our bodies with long covid are fatigued; we are disrupted at the cellular level. Writing years before Hersey, Lorde stated: “Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare.”

I struggle to embrace the call to embody radical rest.

How do we sick women become more visible in a world so terrified of our rich brokenness? Lorde reminds us:

> “that visibility which makes us so vulnerable is that which also is the source of our greatest strength. Because the machine will try to grind you into dust anyway, whether or not we speak…we can sit in our safe corners mute as bottles, and we still will be no less afraid.” (Lorde, p. 22)

We must continue to break the silence from our beds and couches.

There is a vulnerability to coming out with chronic illness. Butler (2016) says “the very meaning of vulnerability changes when it becomes understood as part of the very practice of political resistance.” We can collectively mobilize vulnerability which embodies agency instead of the binary which places agency as its opposite.

Problematizing Cure

When I was moderately disabled I did not yearn for cure. However, long covid has proven to be an untamable beast, ensnaring me in its tentacles. For the duration of my illness I have spent many hours seeking cures, listening to recovery podcasts throughout the night to calm myself and assuage my terror. At my lowest I flirted with assisted suicide, whereas before I was ideologically opposed on the grounds that it would put disabled people at risk. Things have become very murky. Kafer (2013) says that cure culture can erase disability futures, eliminating difference rather than embracing and accommodating it.

Yet I embrace this possibility of cure, understanding that competing ideas can dwell within me. Eli Clare (2017) urges disability studies to better acknowledge cure narratives for their complexity. They call on us to enact “a politics where the longing for cure and the resistance to cure can live side by side” (p. 65). I prefer this duality as it allows for a more fulsome understanding of my suffering while embracing disability humanity. We must reimagine cure as something that will be sought by many who experience pain and suffering, as a possibility within disability realities.

Our Sick Histories Haunt Long Covid

Many long haulers are aghast that we are often dismissed by health care providers, written off as having anxiety and mental illness. But this form of erasure has been experienced by many, especially women, who have experienced medical and social silencing for having ME/CFS, fibromyalgia, Lyme disease and other chronic illnesses. Our bodyminds are entangled in a medical model narrative that pathologizes those who are considered too

complex to understand. Much of this erasure can be traced to the centuries of sexist treatment of many women’s illnesses, often portrayed as “hysteria”.

Sontag (1978) reminds us that illness is a real part of our lives, not a mental health disorder that we can be blamed for. People with long covid are part of a historical lineage of patients who are epistemically marginalized, whose complex suffering defies medical categories. The Cartesian binary of body and mind are challenged by long covid, which afflicts us on all levels, with up to 200 symptoms. Clare (2017) urges us to grapple with the greater complexity; our bodyminds are not separate from the forces of oppression that shape us.

More attention must be given to the ongoing long covid epidemic, as it points to systemic institutional failure on all levels. This failure harkens back to the HIV/AIDS era, which was entrenched in queer stigma and thus abandonment until AIDS ACT UP activists fought to legitimize their illness and successfully demand treatment (Schulman, 2021). We must situate long covid on this continuum and cultivate grassroots resistance with allies.

Art as Slow Activism

Those who are most debilitated can reach for art as a form of activism, to proclaim our belonging. “Craftivism” was coined by Betsy Greer in 2003, using crafting to call for justice. This art as activism was popular with Greenham Common women in the 1980s, who created beautifully stitched peace banners at nuclear missile sites.

Craftivism is rising in popularity, partly because it can circulate easily on social media. This making is not the stereotypical passive feminine activity of quiet sewing.

Instead it is a force for change that skillfully subverts and appropriates crafting to construct a better world. I have found joy in knowing that much of my fibre art done in lockdowns is being displayed to help build community at my Unitarian congregation building. The slow methodical act of lap weaving mirrors my slow deep breathing and allows me to enter meditative space. This is slow activism. This visible yet tenuous connection across space with my faith community reminds me that I matter, I am not forgotten.

Let this art making be the blueprint for the revolution, a life force that counteracts the planetary destruction we are mired in.

Disability Futures and Those Who are Silenced

The revolutionary future I yearn for remains intangible, but my gentle art making strives to bring in a disability imaginary. Kafer (2013) views disability as containing the seeds of possibility through allowing us to reimagine and resist. If around 19 per cent of people in Canada live with long covid, I wonder about the racialized, Indigenous and queer people, who I do not observe anywhere on Twitter or in the news. Those who dwell in the non-normative bodies of race and gender face even more extreme barriers to being believed that they have long covid and being treated respectfully by doctors.

Many disability scholars including Schalk (2022) demand that disability justice embrace this intersectionality or it will fail. The struggle for justice will require strong allyship. Together we must confront the structural failures which make it hard to prioritize

an illness that affects so many more women than men. There must be a correction, to put those of colour and working class, queer disabled people with long covid at the centre.

I feel unease in trying to engage in long covid digital activism as I sense a white middle class dominance. While I hear anecdotally that a local Black friend has several relatives disabled by long covid, these voices are absent in spaces I frequent online. In Canada we need to join the call for intersectional mutual aid networks, diverse education campaigns and health models that reflect diverse communities’ knowledge of illness and disability.

Disability Studies: A Contested Site for Intersectional Activism

As a privileged white woman I must trouble the history of disability activism and disability studies. I acknowledge that I, like other white disability scholars, must respond to Chris Bell who asks “White Disability Studies” to redress the white supremacy in our field and decentre ourselves in conversations about racism and ableism (Bell, 2006). I must acknowledge that engaging in auto theory, I can perpetuate the problem of centring my own whiteness.

Long covid activists and writers as well as disability studies scholars must reckon with the continual promotion of whiteness, what Chen (2014) labels “disability nationalism”, which formulates disability identity and pride in a Western rights based construction. In Canada and the U.S. throughout the second half of the 20th century our field has centred white middle class disabled people. This is only now beginning to shift. White disability activists have not often called out “the ongoing forces of colonial war,

impoverishment, and pollution” (Hutcheon and Lashewicz, p. 696) which disproportionately target Black and Indigenous peoples.

I question whether my auto theory project is centring the views of a white normate. This whiteness is most obvious with the centring of white super crips, as much of white disability culture is more readily accepted into white supremacist society than that of racialized disabled people. We must critique this systemic problem and examine how long covid discussions further contribute to the white nationalist disability project.

Ableism in the Disability Rights Movement: Sick People Left Behind

One of my many realizations since contracting long covid is that of ableism within our own disability rights movement. I no longer can show up at a disability pride rally and march in a crowded, noisy space, sit for one hour in hot sun listening to speeches, then march through noisy and visually overstimulating downtown Toronto streets. Our voices are thus often left out of the disability rights movement, which is historically built on showing up and joining together. Those who are ill remain often structurally invisible within the disability activist community.

Hedva (2016) in Sick Woman Theory turns this exclusion on its head, loudly proclaiming that we belong even if relegated to our beds. They loudly proclaim that all those who cannot show up, including those people of colour in working class jobs, must be acknowledged in the movements and that we matter.

Wendell (2001) frames “the social invisibility of illness” to explicate how many of us with chronic illness are erased from both medical and disability discussions as we are too sick to advocate collectively. Digital activism may afford some possibilities, but even these platforms can be ableist. Those of us with chronic illness must be included, and this will not be easy. We need slowness, mutual aid and care collective approaches and acknowledgement of our needs in the wider disability movement.

The Right to Breathe and Black Lives

Structural violence embodied in the contested right to breathe can arguably connect those of us who are white with Black lives. I acknowledge that my white privilege makes this conjecture problematic and risks racist appropriation, but will nonetheless attempt to make these linkages. The precariousness of Black lives centres on the right to breathe, as represented by the deaths at the hands of police of Black men, including Eric Garner in 2014 and George Floyd in 2020. Floyd uttered his final words “I can’t breathe” 20 times. This statement became the global rallying cry of the Black Lives Matter movement.

The ease of breathing in safety is never a given for those oppressed like Floyd and Garner. Sharpe (2016) speaks of Black life as lived “in the wake,” a historical aftermath of slavery where breathing is never guaranteed. The breath can be traumatic as well as an act of defiance.

I often labour a lot to breathe, as I sit hooked up right now to an oxygen concentrator, having been through a severe wildfire smoke event. The right to breathe is increasingly contested, as more of us are impacted by worsening air conditions across the

world. This precarious right to be links me to others both human and to other life forms who struggle and often perish in wildfires across the globe.

The right to breathe is highly precarious due to capitalist extraction, which is burning up our planet. The lungs of the Earth in the Amazon and the Boreal forests are under attack and burning at this very moment. The universal right to breathe joins us together in a quivering chain of frailty, as all life forms are threatened (Mbembe, 2021). Nixon (2011) states the violence is gradual and often hidden with effects that accumulate and are devastating.

Indigenous peoples are on the front lines of many climate disasters, as many are often land and water keepers. Indigenous Peoples make up just five per cent of our population, yet manage up to 25 per cent of Earth’s land. Hillier & Vorstermans (2024) situate the ongoing decimation of Indigenous lands within broader frameworks of disability and disablement in settler colonial states, connecting environmental destruction to the denial of Indigenous breath, spirituality and community.

Connection to Sea Breathers

As I lie in my bed in the middle of the night, unable to sleep and worrying, I practise the slow calm breath I have learned in my long covid breathing class. I suddenly remember a conversation about whales and the awe many of us have when hearing them breathe rhythmically through their blow spouts. Seventeen years ago visiting friends in Rivière-du-Loup, Quebec we set out in a canoe to mingle with the belugas. Magically they swam

alongside us. I now understand this interplay as a lesson in life and breath, joined together with these threatened creatures.

Gumbs (2020) recalls those Black survivors captured and held on slave ships who are

> “under each other under unbreathable circumstances, are the undrowned. Their breathing did not make them individual survivors. It made a context of undrowning. Breathing in unbreathable circumstances is what we still do every day in the chokehold of racial gendered ableist capitalism. We are still undrowning.” (Gumbs, p. 2)

We are called on to apprentice with these marine mammals, to learn a new way of breathing. These creatures are our guides. Gumbs brilliantly makes the links between the transatlantic slave trade and marine mammals, who in both cases given the violence should have died but often did not.

The Possibilities of Healing through Community

There are many untold stories of mycelial disabled resilience and care work during these health and climate crises. Twitter chat rooms hold up to 46 people gathering to share and build connections.

The revelation about the composted renewing of all life pairs well with Haraway’s concept of the timespace of the Chthulucene (2015) which calls us to manifest ongoingness through generative and collaborative processes and “multispecies assemblages”. Haraway centres this regenerative process in a reimagining of the earth’s destiny, in which the Anthropocene period of human ecological domination is supplanted by a reintegration of all life.

The Right to Care and Connection

Coupled with the need to breathe is the need for care. Many of us with long covid have unmet basic needs for help with shopping, cooking, laundry, cleaning, but also social connection. I read in surprise that in Victorian days and often in Indigenous cultures the solution has been care collectives, a transformative alternative offering spaces where disabled people can find support, understanding, community and empowerment.

We also see examples of care collectives in early Black communities, which Piepzna-Samarasinha (2018) shares have always had to do their own care work due to the life danger imposed by slavery and its legacies of incarceration. The famous former Black slave and activist Harriet Tubman gave speeches in the 19th century to fundraise for her own collective care home for disabled and elderly former slaves (Bell, 2011). The experiences of early Black and Indigenous communities, which both manifest reciprocity and mutual aid, offer a compelling way forward for disability futures.

My own experience with care collectives is sparse. Instead I rely on my partner for help. My lack of a community of care has its roots in capitalist individualism and is harmful to all who cannot maintain this illusion.

Possibilities for Entangled Connections: Learning from Indigenous Knowledge Keepers

Many people with long covid yearn for total health, or at least a return to much of what we had before this devastating illness. But what of other potentiality for healing? I look to

Indigenous models of wholeness and health, readily accessible and often generously offered to settlers. Hillier & Vorstermans (2024) assert that healing must prioritize Indigenous land and water based knowledges. This work is pre-colonial and based on holistic approaches to the environment.

Professor Sean Hillier and Leanne Betasamosake Simpson reveal a more common focus on community ties among disabled people in Indigenous community, and less on the experience of impairment. I made these observations in 2012 during a water walk to stop a mega quarry near Shelburne Ontario. Water is the “lifeblood of ecosystems” (Simpson et al., 2009), a sacred foundation of life in many Indigenous cultures. During this Indigenous-led walk I spent time with three Elder women water walkers, all of whom spoke of physical disabilities in a calm matter of fact way.

The experience I relate above reflects a common Indigenous view that disability is often not seen as an individual experience, but rather as a gift and something to balance out through kinship ties in communities (Hillier & Vorstermans, 2024). This sense of kinship and community supersedes the need to self identify as “disabled”. Indigenous worldviews which do not fixate on impairment are more generative and relational and can be opportunities to connect many diverse peoples in futuristic healing practices, especially those that tie us back to the lifeforce breath of the Earth.

Robin Wall Kimmerer (Potawatomi) discusses sacred balance, stating that all the living world is comprised of “a set of relationships and responsibilities. We inhabit a landscape of gifts peopled by nonhuman relatives, the sovereign beings who sustain us” (Kimmerer, 2013, p. 27). Indigenous Peoples with the strong leadership of women across

Turtle Island continue to provide hope to me that we can engage in existing communities who are already embodying the futuristic timespace of the Chthulucene.

Where is My Place in the Revolution?

Where do I fit in the revolution? I question how to make change when I am house bound. When the pace of activism becomes unsustainable for disabled bodies, we are left behind even in movements supposedly grounded in justice. I may post on Twitter or make some art for my church as a new form of activism, but still feel invisible and forgotten. Hedva insists on the radical acts of self and other care as strongly anti-capitalist and that we are connected and do matter. We must embrace the slowing down of crip time on our own terms. We have the right to be and to rest.

My own form of activism at present is one of radical refusal. I will not fixate on cure models and will not have my suffering erased. I will find ways to be witnessed, even if it is from my bed. This is an act of reclamation and is legitimate. When our bodies are forced to limit energy we must be quiet, slow and internally focused, not engaged in kinesthetic movement, marching, organizing and disrupting. We can be entwined with the forces of the earth and water when we are still. I feel calm when I engage quietly with nature near my home and this is part of self and Earth care.

Conclusion

Our fragmented lives in this liminal space of the Anthropocene are precious as the past, present and future weave together in increasingly disrupted and complex ways. A

new narrative of connection is showing itself in the diffracted spaces created in this chaos. Canaries were one of the creatures whose death in mines indicated the presence of poisonous toxins. Yet canaries can take flight when they somehow escape the toxic confines, and share their songs and stories with others. I wish to take flight in the emerging Chthulucene. Can humans engage with other life forms including birds and sea mammals to form a new kinship for the coming era, of which we know very little but can now imagine.

I am no longer who I was, as the planet is no longer who they were, but a broiling, seething mass of energy which will continue to unleash at any time. Creating and writing a new story will be necessary for survival. I muse on the decay and circle of life process of salmon who are driven to complete their life journey in the nearby Humber River, jumping upstream to spawn and then die.

The theory of breath is part of the emerging story, continually expanding into many parts of my life and joining me with other living beings. I wept at church last weekend as we sang “Meditation on Breathing”, a song from our Unitarian Universalist hymnal. The sung words soothed and reminded me that the journey towards universal breath continues: “When I breathe in I breathe in peace. When I breathe out I breathe out love. Breathe in, breathe out…”

I return to the meditative motion of my weaving needle as it mirrors the breath I take in and out, and remains an activity I enjoy. Art is my new resistance, insisting I not be erased, that I am here and present in the world, a form of quiet activism that long haulers can embrace as we dwell in our homes, many of us severed from the busy world. In our solitude we reject erasure and devaluation. Through these quiet acts, often in bed, we

announce our complex humanity and place in the world. We demand care and inclusion. Through slow art making we can claim our place in a world that would rather discard us.

Through my art and through my breath I make change. I will be a revolution of one, perhaps not on display but having an ongoing and enduring presence defying erasure. The autotheory process has helped me enter a new space of healing and being to manifest a stronger identity as a person living with long covid. Through this writing I hope to crack open a door to emerging Disability Futures.

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