LONG COVID AND THE RIGHT TO BREATHE

HELEN ARMSTRONG

Supervisor's Name: **nancy halifax**

Advisor's Name: **Geoffrey Rheame**

Supervisor's Signature: _____

Date Approved: _____

Advisor's Signature: _____

Date Approved: _____

Submitted to the Graduate Program in Critical Disability Studies in partial fulfilment of the requirements for the degree of

Master of Arts

Graduate Program in Critical Disability Studies

York University

Toronto, Ontario

M3J 1P3

Date of Submission:

November 11, 2025

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 and air craft 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 year and a half my body has refused to cooperate with my wishes and needs. The pages about my bodymind and life routines that I had composed two years ago for this essay are discarded as I struggle to write a new script.

The threat of long covid was always a fear lurking in the background, knowing that I was at risk due to being immune compromised and asthmatic for decades. 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 and caused my heart to race repeatedly during the night. More disturbingly this state of sympathetic overdrive has a physical manifestation of ongoing anxiety. 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 Lazy Boy 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 and praise worthy 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. I could not long play the capitalist productivity game, on display even in my program in Critical Disability Studies at York University.
I was unpredictable, unreliable and began to frequently leave things undone, to take the easiest way out. This was shocking behaviour for a woman raised in an affluent white Protestant family which praised workaholism and composure. Relatives quickly disappeared in their discomfort over my messy idleness.

Disability scholar Rosemarie Garland-Thomson says the disabled body forces us to grapple with our inherent vulnerability and its inescapable fragility. (2011) The author calls on us to find our personal agency and unique disability knowledge through the process of misfitting into the environment. They claim this engagement can lead to political awareness and a new praxis to engage in for liberation. I acknowledge this

practice can be painfully slow and fraught for me. Any hard won silver linings heard about from other people with long covid on YouTube and Spotify interviews feel small and amassed through profound suffering, often only when there is already partial recovery. Learning through reading and writing is not how I will acquire any knowledge; rather it is more likely that through breath work and time in nature that I sometimes find my place in the world. Ableism impacts me daily through microaggressions, which often immobilize me and thus seem to prevent me acquiring new knowledge informed by disability liberation. I have wallowed in grief and debility, reckoning continually with my new unreliable corporeal form. I feel like my mother in her 99th year, fragile and dependent; except I am 64. I could have easily been diagnosed with a mental health disability as panic attacks, surprisingly common with long covid, assaulted me in the first year of my illness.

I struggle to accept Garland-Thomson's assumption that somehow we can find a new sense of power and praxis, a sense of agency, through this isolating protracted health crisis of long covid. I query the subjugated knowledge she references. Meanwhile many of us must contend with medical authorities and our own internalized ableism, as we often willingly accept the label "patient". Wendell (1996) details how we internalize the epistemic and social authority of medicine which increasingly is accepted as having all knowing power in our society. This power extends even to doctors being able to decide whether we get disability benefits, are allowed to get accommodations and stay at work and get other daily living supports. Garland-Thomson has been critiqued for being privileged and too fixated on identity politics, which may inform their assumptions about

disability being a liberating experience. Mollow (2004) notes that Garland-Thomson excludes the weakened body from their definition of disability, which is highly problematic for those us dwelling in the weakened state of long covid.

People with long covid often fixate on cure from both allopathic and alternative sources, which all neatly fit into the realm of capitalism. Rarely do we discuss with each other ways to bring about personal and collective power. I look to Foucault (1980) and Bacchi (2010) who discuss how we internalize governmentalism, a form of self policing which makes us adhere to dominant health and other power structures. We often do not look further to define who we are and discover our own emergent power. Bacchi reflects on Foucault, noting that we can internalize the confines of ruling structures to such an extent that we do not realize they are a form of oppression, which we in turn act out in our lives. We often do not interrogate this situation as we often do not realize it is happening.

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? Even the institution of friendship, especially with nondisabled people, makes me unable to explore my emerging new identity as friends cannot hear my struggles without fixating on cure. Any interaction in an institutional setting including my faith community feels oppressive, and even more so in work situations trying to navigate nonexistent accommodations in a gradual return to work.

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. Perhaps she is part of the

institutional framework of the oppressive illness/health institutional framework. Such coaches have little formalized training or accreditation and are proliferating with many ads and promises on social media. (York, 2024 and Suleta & Hemendinger, 2024) Coaches often claim to have been cured of a similar illness and typically charge high fees. Most problematic, they often peddle in false hope which many are desperate for. I recall that at my worst in 2024 I read a long blog by Gill Deacon, a well known former CBC radio host who is otherwise quite respectable. (Deacon, 2025) She promoted the services of a $3,000 highly controversial recovery method called The Lightning Process, which tells people with energy limiting illnesses to stop thinking about their symptoms and do whatever they want. This process, which Deacon claims cured her, has led to huge setbacks for some people with ME/CFS. Anecdotally I have read on social media site Reddit that some have significantly worsened and even committed suicide after taking part in these three-day sessions and following the advice to live their lives without pacing for energy expenditure. I had two free long zoom sessions with coach Amanda, who completely ignored the oppressive structures of capitalism when she told me I was not yet ready to embrace positive thinking from this illness. She then told me of a man who believed her when she said that he was holding onto his long covid because it kept him safe and not having to go out and engage in the world. I hung up in a rage. This scourge of positive thinking under capitalism is heavily critiqued by Ehrenreich (2009), who views this mandatory optimism as discouraging critical thinking and promoting consumerist views of happiness. This enforced positivity can make those of us who are ill blame ourselves for our illness, rather than engaging in discussion about structural

change.

I have come across many long covid narratives in social and news media, some fixated on recovery but many about erasure and ongoing grief and terror layered over with an overwhelming sense of societal abandonment. These stories somehow fit into the dominant narratives of either victimhood or inspiration porn/cure. I have listened to many podcasts from our mentors, the 2020 “first wavers” who have been sick for more than five years who had no guideposts early on to make sense of their illness during lockdowns. An energy limiting illness prompts confusion from friends and others, and erases all our carefully constructed identities. We are separated from time when bedbound, our social and economic value discarded. I have gradually had some partial recovery but often still sink into the grasp of the nightmare chimera. In this liminal state, I somehow still resist. I try to embrace our much professed disabled crip time, somehow slowing down to escape the capitalist forced frenzy.

A theory takes shape from my words, unlike those that developed methodically as a crisp argument cleanly embedded on a page, but fragments 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 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 (Ayers and Reed, 2022, Young 2014) 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. New symptoms can arise at any time. (Raveendran, Jayadevan, & Sashidharan, 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. (World Health Organization, 2025) I will examine the illness using autotheory and a review of scholarly research to situate the disability of long covid within the realm of Critical Disability Studies. My literature review including academic and grey literature reveals that long covid, while often accepted as a disability qualifying for financial disability benefits in Canada, (Government of Canada, P. H. A. 2024, October 22). The illness remains poorly understood by many medical doctors especially when diagnosing and proposing treatment options. (Au, Capotescu, Eyal & Finestone, 2022) The above authors label this poor treatment "epistemic injustice". (P. 3) My research will focus on Canada and to some extent the USA when examining treatment of people with the illness.

Many long covid advocates critique the recent federal Canadian Guidelines for Post COVID-19 Condition (CAN-PCC) for their promotion of exercise as treatment:

"The CAN-PCC Collaborative suggests activity, movement, or exercise-based interventions for adults with confirmed post COVID-19 condition who do experience post-exertional malaise (PEM) post-exertional symptom exacerbation (PESE)". (Alexander et al, 2025) However, exercise should not often be prescribed to treat this condition, since research has shown, and many people have anecdotally reported that it

worsens long covid. (Davis, 2024) Additionally, the illness is still treated by many medical professionals as an anxiety disorder/mental health illness. This is 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 tied in, as increasingly we struggle to breathe in growing parts of the world due to poor air quality from wildfire smoke. How can we use the international legal system to insist that clean air is a human right? (Rönnberg, 2020) There are many parts of the world especially in lower income communities impacted by industrial air pollution. In Mexico City children have weaker lungs (Hernández-Garduño et al, 1997) and Los Angeles still struggles with smog impacting many.

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. This often very disabling condition is not well understood, with doctors often stating it is too new to understand. (Au et al, 2022) 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

I propose the theory of breath, a concept evolving in the destructive era of the Anthropocene. This is the current novel era of ongoing accelerating human domination over all aspects of the planet, causing increasing destruction. (Lewis & Maslin, 2015, P. 77)

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) In 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 distribution of the right to breathe. (Sharpe, 2016; Puar, 2017) The theory of breath as articulated in this essay weaves together thinking from movements including disability justice, Black Lives Matter and environmental justice. I explore who has the right to breathe, and who is often denied that right.

Many with long covid fixate on the breath, something many ignored until now. I close my eyes, inhale, exhale in ragged delivery. Terror overcomes me as I catastrophize about my life going forward. The requirement to stop and rest feels impossible for a

compulsive achiever and woman recently diagnosed with Attention Deficit Hyperactive Disorder (ADHD). 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, centering on strained respirations. The theory is ages old, beginning when I took my first breath. I recall my early days as an asthmatic starting at age 6. My years of laboured breathing manifested my first experience of prolonged suffering, a state that reemerged when wildfire smoke choked our city two years ago and returned in June 2025 with more smoke alert warnings singling out those of us who are immune compromised. Breathing is exertion, demanding effort. The reminder of early suffering is perhaps something I can build on to strengthen me in my new corporeal unraveling. I can calm my earlier child self when I practice careful controlled breathing in and out. This young one who still resides in me needs care and soothing, not just my adult self suffering with this disorienting illness.

The emergence of the covid 19 virus and increasing wildfire smoke are connected to the growing disruptions of our climate. These otherwise horrific 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” (Foucault, 1979) so entrenched in much of our lives and realize the old ways did not make sense for so long and now this is clear. There is something stark and revealing about wildfire smoke on our doorstep and long covid raging in my body that connects me profoundly to the Anthropocene, urging a profound societal change. The climate crisis of course impacts poor disabled people of colour in much worse ways, as many

communities of colour dwell in zones with poor air quality and in countries that have few limits on toxic extractive processes. Indigenous peoples frequently deal with ongoing colonial extraction on their land.

In the midst of this upheaval the stories of disabled agency and care work must be centered. Is this impulse to help and the possibility of rebuilding all we are left with in our climate disrupted era? Piepzna-Samarasinha (2022) and Berne and Raditz (2019) document another recent history and possible future, showcasing the importance of fierce committed disabled people who engaged in mutual aid during the 2020 climate disaster fires in Seattle. This aid network expanded into the covid pandemic with mask sharing and checking in on those who were vulnerable and needed groceries and other necessities of life. These rhizomal networks of disabled people are creating a map for a disability inclusive future in our climate changing world, reaching out through sharing what they have with each other, including masks and medication, a modern form of bartering. In the Anthropocene these skills will be increasingly in demand, as the natural world collides with our constructed one. My sliver of hope is that disability futures will increasingly be imagined in the global north where many in places like Toronto currently live in a denial, which seems largely brought on by being lulled by consumerism. I have observed that through indulging in comfortable material abundance, such as vacations and social media, people are soothed and distracted from the terror of climate change. I notice that many people who hold economic and social power deny or at least downplay climate change, perhaps worrying that they may have to give up some of their comfort. Disability and environmental destruction are common and can't be concealed in the

already disrupted global south and in many locales in Canada which have already burned and flooded.

Belser (2020) illuminates a thinking process which makes me realize that the denial of long covid is connected to climate change denial. Climate change is overwhelming and frightening and has parallels with what I experience as a person living with long covid. Those with little economic comfort can be overwhelmed by daily demands and often must only deal with urgent matters. “This form of climate silence unfolds in strikingly similar ways to widespread patterns of disability denial.” (Belser, n.p.) 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, in this instance 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. Several years ago large swaths of land in Australia burned, destroying ecosystems filled with many animals and other life forms. Drifting smoke now makes breathing laboured for increasing numbers of people in our world.

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, not on how many household chores my limited energy allows me to accomplish in the family compact. The basic acts of living have become highly troubled every day, hour and minute. 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? What theory arises in my incoherent confusion?

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:

“Autotheory...has been regarded as a way of dismantling… these barriers, and is more horizontal. It centers and legitimizes individual, bodily experiences as a means of processing knowledge production — basically, a way of thinking through “high” cultural theory via our physical, embodied selves.” (McNamara, n.p.)

In using autotheory I resist the need to explain everything, instead using a montage effect to create different learnings. This opacity mirrors my own murky shape shifting self. I invite the reader to embrace contradictions and to join me to pause to breathe. Autotheory has not been widely employed in the realm of Disability Sudies according to Samuels (2023), who looks to earlier women of colour feminist writers, who pioneered this form of writing in feminism and disability studies, in particular Lorde and Anzaldua, bell hooks and the Combahee River Collective. Samuels urges us to employ the methodology in the service of multiple liberations.

This methodology allows me to string together fragments of my lived experience, arising from my shifting bodymind. I am a written tome detailing the unraveling of long covid, which society now desperately tries to shut out and deny. People with long covid are an uncomfortable reminder of the possibility that more will be disabled by Covid 19; we are an inconvenient truth. My frequent scans on Twitter reveal that covid continues to be a mass disabling event. Yet mainstream media prefers to ignore this growing cascade of suffering. To find some meaning I build on the lineage of scholars like Lorde, whose Cancer Journals (1980) showed the suffering of illness as intentionally political. Clare (2017) offered the wisdom of the body as home, even when dwelling in pain and confusion, weakness and exhaustion. I struggle to embrace the combined theory and lived experience of these writers.

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, often from war which arguably Covid 19 has become? (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", something that conjures the normate man, who our society envisions at the pinnacle of power. Early on this white male has been imagined as prevailing in the wide expanses during colonization of this continent. (Ray, 2017) This ideal male seems to rarely be struck down by serious viral events.

My body is now inconvenient to capitalist and even community support systems, my exclusion extending beyond my workplace to my faith community. In an attempt at crip

reconstruction, I insist on weaving together fragments of the narratives of people I know with long covid, now virtually through empathy, humour, anger and struggle. I resist being disposable and instead honour our connections and insistence to live. Syrus Markus Ware (2025) posits that disabled people are the mycelial networks of crip kin joined across the universe. These networks are inspired by the fungal branching below ground in nature, being decentralized and cooperating and mingling in unique ways. Markus Ware is here referencing Solnit's (2020) observation that mushrooms are just the visible parts tangled up with a larger underground fungus that remains a mystery. Our own Disability Studies forays are rhizomic, branching off in manys directions to engage in sociology, medical humanities, education and literature, among other disciplines. (Egner, 2023, P. 17) "Uprisings and revolutions are often considered to be spontaneous, but less visible long-term organizing—or underground work—often laid the foundation."

Jure. (Jan. 31, no year).

These are the seeds we bring home to build our crip kinship, to nourish us.

The Bed as a Site of Activism

My writing silently mimics an activist scream, internal and unheard by those whose voices yell at an energetic protest march. 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.

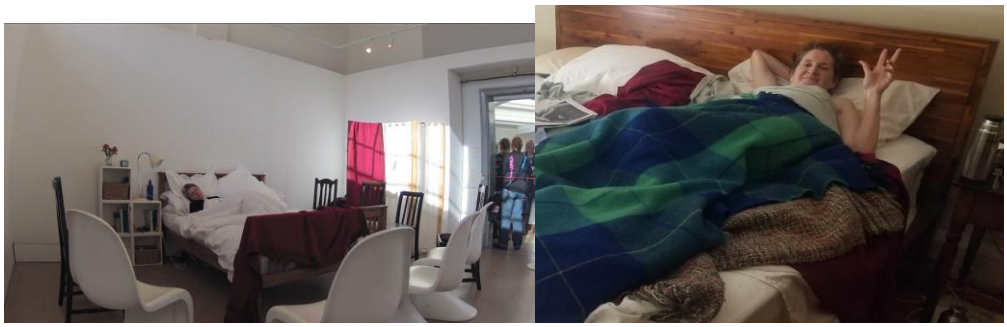
(Wikimedia)

I compose in bed and reclining. I silently protest the betrayal of the social contract to keep us safe. In Sick Woman Theory (2016) 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. Can I somehow embody such rage? Mine is activism stripped to its basic survival, the act of conscious breathing. My power is found in the refusal to engage in that which harms me. Hedva reminds us that the most anti-capitalist protest is to engage in care for oneself and others. Care is something that chronically ill folk know intimately; we care for each other on the phone and online, understanding not judging, acknowledging the suffering of our lives. This quiet radical

activism is invisible, yet so integral to our societies, it takes place in diffracted spaces and goes unnoticed. It happens in our quiet breathing in the recesses. Care work is often framed as women's work, and is dismissed. Many people with long covid are women, as with Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Hedva proclaims the bodies of women in pain as marked by cultural invisibility. Our bodies do not behave, they are unruly and nonproductive. We are a "problem" and thus ignored.

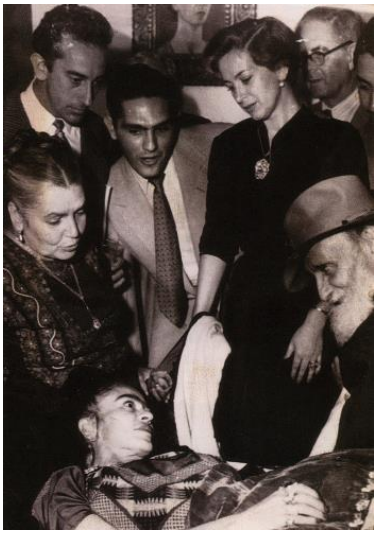
I hearken back to the 2014 UK activism of disabled artist Liz Crow who also had an energy limiting illness. Crow left her home to stage a 48 hour bed-out in the Salisbury Arts Centre, streamed online and on Twitter. (Guardian News and Media, 2013) The artist activist made public the private secluded existence of many of us who are disabled at home. Crowe was also protesting the impending shredding of the social safety net for disabled people on social assistance in the UK. In the tradition of Yoko and John, the activist concept of a bed-in has a rich potential to build on.

Disability Performance artist Liz Crow at her 48 hour bed out. I imagine a similar act.



Disabled artist Frida Kahlo's emancipatory practice to make art about her bodymind in pain includes some lasting images of her painting in bed. Kahlo had a rich imagination

that flourished in her art, 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, insisting on her right to be celebrated. The artist arrived on a hospital stretcher at the opening, (Scott, 2022) refusing to miss out on her triumph. Kahlo and those around her in this photo appear to manifest an ethics of care.



Galak (No date)

I struggle to learn from younger more intersectional racialized activists how to embrace the bed as a site of creativity, love, possibility and activism. Baldwin describes their life in bed: “I choose to reimagine the bed as more than a physical artifact, but as a portal to new worlds and vibrant disabled futures.” (Baldwin, 2025, their statement referencing Nishida (2022) on bed activism) Nishida acknowledges all the forms of activism the bed embodies, including cuddling with our loved ones and animals, engaging in interspecies collective care. Beds as a locus of resistance, sites to learn about our bodyminds and engage in creative activism are, as Nishida points out, spaces where many have endured

violence and oppression. Reclaiming these spaces for care and connection is crucial to disability futures. As a privileged sick white woman I was recently able to spend much money buying a new adjustable bed with a sturdy base, likely anticipating that my life engagement would largely be centered in this site.

More radical forms of viewing the bed can be imagined. Khanmalek & Rhodes (2020) view the bed as an expanding space which queer disabled people can embody to counter capitalist productivity, connecting with others who are embedded (my word play here) in spaces near and far away:

> "In the spirit of Lugones's notion of playfulness, we consider queer play as a methodology of ever- unfolding liveliness that also takes seriously and honors the gravity of queer chronic illness life. This, we propose, affirms a politics and poetics of illness that is antithetical to coloniality's hold on the body as only of value while productive and profiting for itself and for another."
>
> (Khanmalek, & Rhodes, P. 35)

The positivity of the bed eludes me, but these authors view beds as sites of endless imagination, writing, eating, having sex and connecting with those we choose for closeness.

Being as Radical Activism

Beyond the bed, I struggle with the need to do nosthing, to close my eyes and meditate and slow down. Unlike many other long haulers I do not often feel fatigue or brain fog. But how do I declare my worth when idle? The right to exist without productive action must be reclaimed as radical activism, contrasting with my internalized pride as a

performative agiator in much of my adult life. Hersey (2022) insists that rest is resistance, especially for women of colour who have been pummeled by ongoing demands to focus on constant work and continually look after others. She offers radical advice to women of colour who have grown sick from white supremacy and capitalist productivity demands. She insists that women resist through embracing rest and find joy and freedom in not submitting to these demands. 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. Our activism must be slow yet no less potentially transformative. 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.” (Lorde, 1988) I embrace the call to embody radical rest, following these wiser ones.

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, show our sick and angry selves; the alternative is to become part of the background wallpaper.

There is a vulnerability to coming out with chronic illness. I tend to isolate rather than share these intense feelings and the accompanying frailty many of us sick ones must manage. Although disability scholars ask us to query "vulnerability", it is hard in personal life. Can vulnerability be considered a source of strength, not in the ableist way that disabled folks are called "brave" and "inspiring"; how do we crip vulnerability? Can we view this often unwelcome state of being to propel us into power? Butler (2016) says "the very meaning of vulnerability changes when it becomes understood as part of the very practice of political resistance." (Butler, P. 15) Some political movements do mobilize vulnerability. Butler sites the participants in a Turkish riot in 2013, who stand unarmed and "manifestly vulnerable (which) offsets the brutality of the police." (Butler, P. 15). We can collectively mobilize vulnerability which embodies agency instead of the binary which places agency as its opposite. I attempt to imagine how in our isolated homes we can mobilize together yet apart. There are of course online protests and forums some find meaningful, but even these actions can elude us when illness and pain make us retreat to bed, an activist movement of one.

Problematizing Cure

When I was moderately disabled and could leave my home whenever I chose and do all activities of daily living on my own I did not yearn for cure. Instead I made peace with my disability, knowing that I was on a very restricted diet and thus somewhat limited in my social activities. However, long covid has proven to be an untamable beast, ensnaring me in its tentacles and continually sending jolts throughout my entire being which severely limit my engagement in life. For the duration of my illness I have spent many

hours seeking cures, listening to (white middle class centric) recovery podcasts throughout the night to calm myself and assuage my terror about this debilitating illness. 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 of being forced into this end of life practice. Things have now become very murky and I am unsure of everything. Kafer (2013) says that cure can erase disability futures, eliminating difference rather than embracing and accommodating it. This writer is critical of "curative time," (Kafer, P. 27) a space many of us dwell in which looks to a future when we are healed and corrected, rather than being valued in the present. Yet I embrace this possibility of cure, understanding that competing ideas can dwell within me. I feel relieved that many others with long covid share my path. 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, not as an erasure of disability but a response to our embodiment and located within our framework for disability justice.

Our Sick Histories Haunt Long Covid

Many folks wit long covid 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. This is a shocking history where many are treated as disposable and it informs our present. Our bodyminds are entangled in a medical model narrative that pathologizes those who are considered too complex to understand. The lack of research into our conditions speaks to sexism and the medical wall, which I run up against frequently with doctors who claim they don't yet know enough about long covid. Much of this erasure can be traced to the centuries of sexist treatment of many women's illnesses, often portrayed as "hysteria".

Sontag earlier (1978) reminds us that illness is a real part of our lives, not a mental health disorder that we can be blamed for. Sontag reveals illness to be the night time of our lives and references it for being a very common yet taxing experience of being human. She highlights the yin yang duality of human existence; some are lucky to be awarded health for many years, while others experience extensive time in the suffering realm of the sick. It is troubling to hear some other people with long covid, especially those who are recovered speaking on podcasts, describe a personality type for people with the illness, that of the perfectionist, overly functioning people pleaser. I bristle at this stereotyping, looking to Sontag who compared cancer prone stereotypes with early 19th century theories of depression applied to those who contracted tuberculosis. Psychological explanations of disease threaten to marginalize us and subtly affirm that it is all in our head. Sontag seeks the realities of illness beyond metaphor, suggesting that the way we talk about and understand illness can affect how we experience it.

People with long covid are part of a historical lineage of patients who are epistemically marginalized, whose complex suffering defies medical categories. Wilkerson (2002) Ehrenreich, & English, 2005) documented that female born bodies have been seen as having emotional excess, a form of hysteria. The Cartesian binary of body and mind are challenged by long covid, which afflicts us on all levels, with up to 200 symptoms. These are not psychogenic, despite what ill informed doctors would have us believe when our tests come up negative. Clare (2017) urges us to understand the complexity; our body minds are not separate from the forces of oppression that shape us. No body is pure observes Clare, and no cure can heal the trauma that racism, classism and other oppressions inflict on humans. These are systemic forces and point to how many of us are viewed as unworthy of trust. More attention must be given to the long covid epidemic, as it points to systemic institutional failure on all levels. This failure harkens back to the HIV/AIDS epidemic, 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) proclaims the knowledge, anger and deaths of those with AIDS as valid and not be forgotten or sidelined. 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. Our slow art practices can find their way into the wider world, as many creative long covid art pieces have appeared around the world on Long Covid Awareness Day on March 15, visible on Facebook and Instagram posts. These are on display across social media announcing our presence. “Craftivism” was coined by Betsy Greer in 2003, who employed crafting to call for justice. (van der Velden, 2019) This art as activism was popular with Greenham Common women in the 1980s who created beautifully stitched peace/anti-war banners, and strands of fabric to adorn fences at nuclear missile sites, in their ongoing peaceful protests of UK missile nuclear missile sites from the 1981 in Berkshire, England until 2000 when the base was removed. (Dew, 2022)

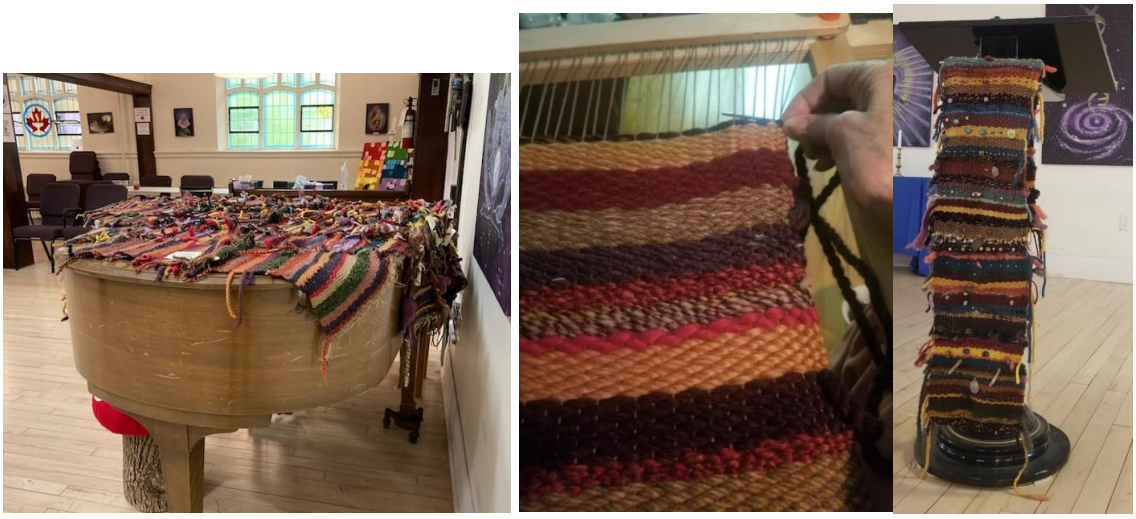
(By permission of Amgueddfa Cymru — Museum Wales)

Pink pussy hats made by me and others in 2017 were used in a unifying but much louder able bodied protest, displayed en masse on January 21 in Washington D.C. against Donald Trump’s first presidency.

(The author with her daughter)

Craftivism is rising in popularity says Greer, partly because it can circulate easily on social media, but also can be used to encourage dialogue. This making is not the stereotypical passive feminine activity of quiet sewing my mother engaged in. Instead it is a force for change that skillfully subverts and appropriates crafting to construct a better world. Such change need not always be boldly insistent, but rather create beauty and comfort in a world with too many harsh edges. I have found joy in knowing that much of my fibre art done in lockdowns, and that I now engage in while housebound, 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. I relax and feel a mycelial connection, knowing that these mellow pieces now adorn the walls and pulpit and soon piano in our church sanctuary. This activity helps mitigate my grief at often being unable to attend the space in person. This is slow activism, in contrast to earlier frenzied making and wearing of pussy hats at a massive march. There is a continuity to this crafting, an adaptable activist form of

engagement that can be done in private at any pace. 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. Will this future be one that is inclusive and complex? Kafer (2013) refers to this time as a future that is not yet here. She views disability in an exciting way as containing the seeds of possibility through allowing us to reimagine and resist. Yet how do I reimagine my increasingly dysfunctional body? If around 19 per cent of people in Canada live with long covid I wonder about the people of colour who I do not meet 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. I shudder when thinking of the medical dismissals that I have faced as a privileged white affluent born heterosexual woman. Many disability scholars including Schalk (2022) demand that disability justice embrace this intersectionality or it will fail. Yet in the intersection of oppression many are silenced. 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 center, in charge of (our) their care and (our) their lives. Women of colour continue to be subjected to a problematic social construction of illness. (Wendell, 2001) Many more people are left to suffer alone without validation and invisibility.

Disability writer and activist Lakshmi Piepzna-Samarasinha (2018) delves deeper, stressing that at the intersections of disability and other oppressions we are continually forced to show proof that we are sick. We are harmed by systems that amass power to decide on our treatments and what economic benefits we are entitled to receive. Many I know feel traumatized by these processes, especially those who dwell in poverty. I think of my friend Bob who is now 41 and was infected early in the pandemic. A former oversees teacher, he depleted his savings and was forced to go through grueling and traumatizing repeated applications and appeals to finally receive the less than poverty level funding on the Ontario Disability Support Program.

I feel unease in trying to engage in long covid digital activism as I sense a white middle class dominance, much like other health justice and disability movements I have engaged in. This trend is observed throughout the US and is replicated in Canada. 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, especially in long covid chat rooms on Twitter and in long covid Facebook groups. This absence reveals a dynamic of exclusion described by Vazquez (2023), whose organization Body Politic tried to improve the representation of people of colour in long covid discourse. They founded the US based Patient Led Research Collective. Although Body Politic has ceased operations, the need for more intersectionality in long covid activism remains pressing. We must ask: how is research and other funding distributed when privileged white voices are at the center. The strong people of colour movement in the US is bringing this demand to the forefront of long covid activism, while this challenge around anti-racism appears missing in Canadian long covid activist spaces. In Canada we need to join the call for intersectional mutual aid networks, diverse education campaign and health models that reflect diverse communities' knowledge of illness and disability. The disparities extend to who is included in treatment, especially Indigenous and people of colour. (Yong, 2022) This need must be addressed, as people who face more oppressions will be further excluded from financial benefitss and within health and medical systems.

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 have spent much of my adult life advocating on issues of poverty,

disability, anti-racism and climate justice. However, my views are shaped by a white supremacist culture, and 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 decenter ourselves in conversations about racism and ableism. (Bell, 2011) I must acknowledge that engaging in auto theory, I can perpetuate the problem of centering my own whiteness. I am endeavoring to problematize this, but will do so inadequately.

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. Chen, Meekosha (2011) and Hutcheon and Lashewicz (2020) critique disability movements' politics of identity, which by association extends to long covid activism. In Canada and the US throughout the second half of the 20th century our field has centered white middle class disabled people. The vast majority of us have resisted addressing unacknowledged racism and often failed to reach out to disabled people of colour. 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. Underlying structures of oppression began with colonization and slavery. Gorman urges disability and mad studies to adopt a "transnational theoretical approach (to see)…disability as an assemblage of racialized and gendered narratives, national and postcolonial politics" within global capitalism. (Gorman, P. 273) It is very hard for people of colour to claim the contested

and pejorative identity of long covid as it risks erasure and further marginalization. Indigenous worldviews do not historically split disability from identity, but the legacies of colonial and Enlightenment framing of Indigenous people as inferior and unruly has made it hard for Indigenous communities, much like Black communities, to claim the identity of disabled.

I question whether my auto theory project is centering the views of a white normate, as a number of writers are calling out disability nationalism in our spaces. This whiteness is at its most obvious with the centering of white super crips, as much of white disability culture is more readily accepted into white supremacist society than that of racialized disabled people. This celebration of white disability participates in a concurrent erasure of Black and Indigenous disabled peoples. 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

As someone who loves to join others in loud and crowded protest, it has been shocking to witness my inability to participate in these spaces, and thus painfully grapple with how my disabled comrades have not endeavoured to reach out to us sick ones. At a disability pride march on July 5, 2025, I could only make a brief appearance, paying for it with a flare up of symptoms the next day.

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 in a crowded, noisy space, sit for one hour in hot sun listening to a long drone of speeches, then march in my scooter through noisy and visually overstimulating downtown Toronto streets. The disability pride march seems to replicate the dominant culture, and organizers seem to be less than thoughtful about those of us who are mostly housebound and can't join in. Our voices are thus often left out of the disability rights movement, which is historically built on showing up and joining together. In both Canada and the US there have been significant gains made through direct action (Pfeiffer, 2001) for disabled people. Yet those who are ill remain often structurally invisible within the disability activist community and our needs thus not prioritized by this movement. Hedva (2016) turns this exclusion on its head, loudly proclaiming that we belong even if relegated to our beds. This brilliant writer loudly proclaims that all those who cannot show up, including those people of colour in working class jobs, belong in the movements and that we matter.

There are barriers beyond the physical for people like me. 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 for more. Digital activism may afford some possibilities. But even these platforms can be ableist with inaccessible online platforms for those who are challenged by screens and often demanding expectations of continual engagement (Hamraie & Fritsch, 2019). Pandemic open access was helpful to many but much of this has been rolled back with the opening up of much of society (Goggin, 2021). Those of us with chronic illness must be included, and this will not be easy. We need slowness, mutual aid and care collective approaches, peer systems and the opportunity to engage or not 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 centers on the right to breathe, as represented by the deaths at the hands of police by a number of Black men, including Eric Garner in 2014 and George Floyd in 2020. Floyd uttered his final words “I can’t breathe” 20 times. (Singh, July 9, 2020, The Guardian) This statement became the global rallying cry of the Black Lives Matter movement. This insistence on the right to live and

breathe resonates with me as a long covid survivor and brings me back to the theory of breath.

The ease of breathing in safety is never a given for those oppressed like Floyd and Garner. Their words demand justice, and also are linked to the choking of many Black lives throughout history and in present day capitalism. Sharpe (2016) speaks of Black life as lived "in the wake," a historical aftermath of slavery where breathing is never guaranteed (P. 9). 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 this weekend. The right to breathe is increasingly contested, as more of us are impacted by worsening air conditions across the world. At present wildfire smoke is making many of us stay indoors, as we are not part of the privileged crowd of "normal" healthy individuals. This precarious right to be links me to others both human and other life forms who struggle and often perish in wildfires across the globe. Let this be a loud protest for all life forms to live and breathe easily. (Bergmans, Rachel S., et al (2024).

The universal right to breathe is the connector for all of us who struggle. Garner lived in a low income community impacted by industry which may have worsened the asthma the coroner reported he had. (Kola, 2019) This condition may have contributed to his suffocation in an officer's hold. The right to safe air is contested for many of us who live in fear when we are in public, due to the ongoing airborne Covid 19 virus which can invade again and worsen our condition.

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 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) Our skies are laden with excess carbon and hazardous chemicals. Those most vulnerable are more at risk: racialized communities, disabled people like me, elders, those most impacted by colonization including in the global south. Nixon (2011) states the violence is gradual and often hidden with effects that accumulate and are devastating. This slow suffocation of the Earth takes all creatures and life forms with it, as we all become increasingly breathless. Mbembe shouts to us, demanding to understand how humans can ignore the damage we are wreaking on the lungs of the Earth and its body.

Indigenous peoples are on the front lines of many climate disasters, as many are often land and water keepers. Indigenous environmental knowledge systems are intricate and much older than that of white settlers. This knowledge is manifest around the world: Indigenous Peoples make up just five per cent of our population, yet manage up to 25 per cent of Earth's land. These lands contain 80 per cent of our biodiversity and around "40 per cent of all terrestrial protected areas and ecologically intact landscapes." (United Nations Department of Economic and Social Affairs, 2021). Many Indigenous peoples embrace land and water stewardship. Whyte (2017) insists that environmental destruction decimates the Indigenous breath of spiritual connection, and ties this assault to ongoing colonialism. They reveal that for Indigenous peoples the Anthropocene began centuries ago. Many Indigenous communities have a sacred connection with land and creature life,

a connection clearly speaking of the breath of life in ceremony. This destruction is an attack on Indigenous interdependence and a sacred way of life.

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 earlier in the day about whales and the awe and amazement many of us have when hearing them breathe rhythmically through their blow spouts. Seventeen years ago visiting friends in Rivière-du-Loup, Quebec we dragged a heavy canoe to a shore of the St. Lawrence and set out to mingle with the belugas. Magically they swam alongside us, a mother and gray calf and several other creamy white adults. We all heard their breathing, listening quietly in awe. I now understand this interplay as a lesson in life and breath, joined together with these threatened creatures who seemed happy to mingle with us in the wake of our boat. My daughter, then 9 years old, was frightened but mesmerized. I began to weep at the beauty of this exchange. 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. To tie in the many strands of this essay I look to Gumbs, who brilliantly makes the links between the transatlantic slave trade and similarities to marine mammals, who in both cases given the violence should have died but often did not. The writer magically calls on us all to learn to breathe together, using undrowning as a form of collaboration in which we learn from these sea creatures, especially in the area of vulnerability, during the increasing climate crisis and rising sea levels: “I took my cues from the many marine mammals who echolocate. I had to focus not on what I could discern, but where I was in relation, how the sound bouncing off me in relationship to the structures and environments that surround me locates me in a constantly shifting relationship to you.” (Gumbs, Pp. 6-7) Strangely Gumbs has summarized the need many of us with long covid have to constantly be aware of the surrounding sounds as we try to navigate the world with our distressed nervous systemss.

Churchill Polar Bears. (No Date)

The Possibilities of Healing through Community

Beyond the sea mammal connections which most of us have little access to except through books and online videos, there are other ways to manifest community and healing. 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. Is this impulse to weave frayed threads together and build a fragile connection all we are left with in the climate disrupted era? Solnit (2020) challenges our media driven narrative of nihilation and deliberate nihilism, critiquing the thinking which claims life is doomed, using a counter narrative she develops through extensive research on community resilience and hope in times of unravelling. Her examples of community building after an earthquake disaster in Nicaragua are inspiring, but somehow leave me unconvinced as I dwell at home alone in sickness.

I turn to Darwin to discover transformation, regeneration and hope in the changing world. Studying worms performing the act of compost by digesting and creating soil for the web of life, working silently together, he realized that their disruption can be transformative. (Phillips, p. 38) Despite the popular perception that Darwin focused on the survival of the fittest, his thinking about evolution is poetic in its observation of the interconnectedness, symbiosis and sublime creativity found in the natural world. Nature shows us life is mutable and has potentiality. I am reminded of this constant regeneration of life in my own garden where wild ginger blooms quietly every year, close to the ground and Darwin's worms.

The revelation about the composted renewing of all life is hopeful. It 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, P. 160) Haraway centers 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. This space would surely find ways to entangle humans with those animals and other lifeforms so at risk in these dangerous times. Haraway muses on the Chtulucene:

"the diverse earth-wide tentacular powers and forces and collected things with names like Naga, Gaia, Tangaroa (burst from water-full Papa), Terra, Haniyasu-hime, Spider Woman, Pachamama, Oya, Gorgo, Raven, A'akuluujjusi, and many more… I think our job is to make the Anthropocene as short/thin as possible and to cultivate with each other in every way imaginable epochs to come that can replenish refuge. Right now, the earth is full of refugees, human and not, without refuge… Maybe, but only maybe, and only with intense commitment and collaborative work and play with other terrains, flourishing for rich multispecies assemblages that include people will be possible."

(Haraway, P. 160)

If I verge into the realm of speculative fiction be patient, as this is one of the only ways to imagine our disability futures.

I yearn for these future possibilities, to use technology and the knowledge of animal species to pair with our humanness, to help create a livable time space. How much will we listen to those species who are silenced and killed by the rampant wildfires, the scorched pandas and kangaroos in Australia, the bears and birds on Turtle Island, boreal and other forests and sea dwelling manatees and whales hurt and killed by our watercraft? My physical suffering is linked to these creatures as I yearn to manifest life in this toxic world. Like the canary that was once cruelly used in coal mines to indicate the presence of poisonous air, I join these creatures in my own survival struggle. I protest the climate change that will consume us, restricting our breathing and forcing us to asphyxiate. All life forms are affected, beyond the prophetic Black Lives Matter protest rallying cry: I can't breathe! I join in from my supine bed position, I want to live, let me breathe.

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. Our illness can worsen when we attempt to meet our needs alone. Some of us have partners to help, while many others languish. Public home care is often inaccessible. These needs are profoundly hard to accommodate in a society that externalizes the costs

of care, rendering many destitute and struggling. 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, and empowerment.

Care collectives arose in the Victorian era to provide care to those who suffered. Schaffer (2021) emphasizes that acknowledgement of suffering and the practice of creating care communities was common throughout the 1850s, although Schaffer's descriptions reveal that it was mainly those women who were privileged and idle and did not engage in daily toil who were able to form these care structures. "Victorian subjects regarded suffering as widespread, natural, and inevitable, and they assumed that other people should be trying to alleviate and distract patients…. Through midcentury, people were expected to provide amateur caregiving in social collectives". Medical hegemony had not yet taken over, and it was believed that all bodies would face debilitating illness, intermittent attacks, and all the injury and aging and disease included in the long span of a life.
(Schaffer, P. 292)

This earlier society appears more accepting of the reality of disability and chronic illness, and may have thus produced less stigma for people with this lived experience. However there are contradictions at this time since this is also the era which saw a rise in eugenics, when it was considered acceptable to strive for familial and national purity. (Waller, 2001) This era was not as dominated by capitalist cure and pharmacology, which increasingly promotes the illusion of the perfect bodymind.

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. Needing care has meant for centuries that Black and brown people could be locked up in carceral settings. The famous former Black enslaved person and activist Harriet Tubman, disabled from a brain injury acquired as an adolescent when a brick thrown by a slave overseer hit her in the head, 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. Yet we must resist romanticizing these collective care experiences.

My own experience with care collectives is sparse, but I do observe some of this behaviour with people and their animals and in my own connection to the healing power of nature. I now rely only on my partner for help. I once prided myself on being able to look after myself until long covid. I dwelled in activist spaces where pushing oneself was worthy of praise, the opposite of what I must now do. This self reliance behaviour and mindset are rooted in capitalist individualism and are harmful to all who cannot maintain this illusion. We can build on earlier Western practices of collective caregiving and reciprocity in Indigenous, Black and Victorian societies. These models encourage me, as it becomes possible to imagine a generative and healing space for people disabled by long covid. Disability futures can wrestle with the need to center those most absent in our fragile community creations. They demand that we rethink community building and

activism, around all those marginalized and facing societal abandonment. This is a politics that embraces vulnerability, and calls for all those who cannot attend a protest whether it be due to poverty, immigration status and/or disability, to be included. Our speculative futures must embrace the imperfection of our sick selves and call for an intertwining of assemblages. Piepzna-Samarasinha (2018) insists that our organizing must develop revolutionary approaches. We must not insist on everyone showing up, when this can mean collapse for those of us with long covid. Slowing down, embracing crip ways of organizing can be revolutionary, says Piepzna-Samarasinha.

As part of collective care, Erickson (2016) advocates that we transform sites of shame inhabited by many disabled people through acts of resistance. These "Cultures of undesirability involve the narrowing of dominant western cultural imaginary so that marginalized others come to be so often understood and constructed as both "'less than"' and "'too much,"' if we are understood as persons at all." (Erickson 2016, P. 11) The author's insistence on building "crip solidarity" within sites of shame shows possibilities for disability futures. Their adamance that everyone be included in movement organizing centering interdependence speaks to the power of care collective work for social change (Erickson, 2019):

> "Interdependence, as an example, a way of being and caring with and for each other that operates from the belief that we all have needs, we all need each other and we can all provide care, centers and celebrates difference and needs in a way that interrupts the individualism, isolation, and normalization so key to the operation of oppressive logics." (Erickson, 2019, P. 181)

This optimism about interdependent disability futures must show up more widely if we are to disrupt the dominant oppressive culture and create the mutual interdependent connection we desperately need.

The complex relationships of care grounded in acts of friendship and kinship can help build collective power for disabled people and offer a glimpse of what could expand through mycelial networks in this hyper capitalist society. These collective acts provide a compelling alternative to normativity which reproduces stigma through objectification and shunning of disabled people. This "social relationality and action instead of individual psychology" (Schaffer, 2021, P. 2) is currently manifest by disability activists who create care collectives and mutual aid circles. Popular writers including Mingus (2011) and Piepzna-Samarasinha (2018, 2022) situate this generative work in the realm of disability justice, insisting on centering leadership by those most impacted and a commitment to leave no one behind. Sins Invalid (2015) shared their ten principles of disability justice to promote interdependence, wholeness and the inherent worth of all people in our collective spaces, outside of commodity relations. This ethical framework can help foster resilient, diverse community. However, we must be careful not to romanticize care collectives, as their internal dynamics can reproduce systems of oppression with queer disabled people of colour often taking on more exhausting care work than their white disabled peers. (Piepzna-Samarasinha, 2018) This problematic reality must be tackled if care collectives are to become a sustainable source of power building to disrupt dominant systems of inequity and control.

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, which are readily accessible and often generously offered to settlers. We can find healing within the thinking of Indigenism, which also may heal our communities and lands. (Amadhahy, Lawrence, 2009) Hillier (2022) asserts that healing must prioritize Indigenous land and water based knowledges.

(Lecture, 2022, York Univeresity) This work is pre-colonial and based on holistic approaches to the environment; it is continual, celebrating and honouring plants and animals and occurs despite settler colonialism. The emphasis on holistic value systems and balance extends to certain Indigenous understandings of disability, which I crave while dwelling under a binary approach to disability under normative capitalism. In my studies with Professor Sean Hillier and through absorbing multiple readings especially those by Leanne Betasamosake Simpson, I have noticed that it appears more common for some Indigenous people with disabilities to prioritize their community kinship ties rather than focus on 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, DaSilva, Riffel & Sellers, 2009, P. 7), 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. An increasing number of Indigenous women take part in Mother Earth Water Walks. Water is here seen as a sentient being which much like Indigenous Peoples has faced historical trauma and needs healing. The women's actions are based on the natural Anishinaabek law of Zaagidowin (Love). They embody environmental justice in practice in a holistic way centring the Anishinaabek concepts of "love, kindness and generosity". (McGregor, 2015, P. 71). I felt generosity and kindness emanating from the women I walked with and their kin ten years ago. The five to 15 Indigenous walkers were helping heal and preserve the headwaters of five major rivers which provide drinking water for many downstream. The water walkers blessed the waterways with tobacco in rituals at crossings, reminding us that water is sacred and life giving and must not be polluted. Healing for Indigenous peoples often feels generous; it can extend to settlers with disabilities and is holistic. I recall my time with these water walkers, imagining them by my side as I struggle with my illness.

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). Indigenous Peoples' shared experience of the impact of colonization and their emergent culture can help ease the experience of disability. (King, Brough & Knox, 2014) This sense of kinship and community supersedes the need to self-identify as "disabled". (King et al) This is an alternative to the social model of disability, the latter which prioritizes rights but does not question the racist colonial state. (Hollinsworth, 2013) Indigenous worldviews which do

not fixate on impairment are more generative and relational, offering opportunities to connect many diverse peoples in futuristic healing practices, especially those that tie us back to the lifeforce breath of the Earth.

Forces of colonization continue to erase Indigenous Peoples whose knowledge about preserving ecosystems based on land and water stewardship is crucial at this time in history. (Simpson, DaSilva, Riffel & Sellers, 2009) This knowledge is urgently needed by those of us who struggle with environmentally induced disabilities. 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," (Wall Kimmerer, 2013, P. 27). Indigenous Peoples with the strong leadership of women across Turtle Island continue to provide hope to me that we can tie into existing communities who are already embodying the futuristic timespace of the Chthulucene. Perhaps my long covid reality can blend into this mix, and be a force for growth and connection.

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. This question has haunted me. When the pace of activism becomes unsustainable for disabled bodies, we are left behind, even in movements supposedly grounded in justice. Mingus (2011) insists that we prioritize access intimacy in our movements, yet this seems a futuristic utopian goal to me. 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. We must untangle the oppressive forces of medical systems from our bodyminds which are linked and not separate. Medical systems often dismiss our suffering when it does not fit their narrative**.** 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 spoisonous toxins. Yet canaries can take flight when they somehow escape the toxic confines, sharing their 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 she was, 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…” (Unitarian Universalist Association, 2005, # 1009).

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. I am here and present in the world, engaging in a form of quiet activism that many of us with chronic energy limiting illnesses can embrace as we dwell in our homes, severed from the busy capitalist world. We can reject erasure and devaluation. Through these solitary 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 auto theory process has helped me enter a new space of healing and to manifest a stronger identity as a person living with long covid. Through this work I hope for our illness to be more accepted into the canon of Critical Disability Studies, as our discipline opens doors to emerging Disability Futures.

Bibliography

- Adewunmi, B. April 9, 2023. The Guardian. https://www.theguardian.com/artanddesign/2013/apr/09/liz-crow-bed-disabled-rights

- Stacey Alexander; Marla Beauchamp; Jaymie Firkus; Doug Gross; Glen Stewart Hazlewood; Thao Huynh; Tania Janaudis-Ferreira; Grace Lam; Louise Lemay; Grigorios Leontiadis (co-chair); Lara Maxwell; Hiten Naik; Kelly O'Brien; Carla Pra. (n.d.). (2025) Canadian Guidelines for Post COVID-19 Condition. Can. https://can-pcc.recmap.org/recommendation/8d2e1653-e860-4c96-9162-66837f6f5fdb. P. 8.

- Au, L., Capotescu, C., Eyal, G., & Finestone, G. (2022). Long covid and medical gaslighting: Dismissal, delayed diagnosis, and deferred treatment. SSM-Qualitative Research in Health, 2, 100167.

- Amadahy, Z., & Lawrence, B. (2009). Indigenous peoples and Black people in Canada: Settlers or allies?. In *Breaching the colonial contract: Anti-colonialism in the US and Canada* (pp. 105-136). Dordrecht: Springer Netherlands.

- Ayers, K., & Reed, K. (2022). Inspiration porn and desperation porn. *Redefining disability*, 90-101.

- Bacchi, C. (2010). Foucault, policy and rule: Challenging the problem-solving paradigm

- Baldwin, J. (2025, March 30). DJD with Jay In-Bed Activism and Desiring Liberation- Being Chronically ill, severely disabled and ALWAYS Exha. *DJNO*. https://www.djno.ca/post/djd-with-jay-in-bed-activism-and-desiring-liberation-being-chronically-ill-severely-disabled-and-a

- Barad, K. (2007). *Meeting the universe halfway: Quantum physics and the entanglement of matter and meaning*. Durham, NC: Duke University Press.

- Bell, C. M. (2011). Introduction: Doing reaal detective work. *Blackness and disability: Critical examinations and cultural interventions*, 1-7.

- Belser, J. W. (2020). Disability, Climate Change, and Environmental Violence: The Politics of Invisibility and the Horizon of Hope. *Disability Studies Quarterly*, *40*(4).

- Bergmans, R. S., Chambers-Peeple, K., Yu, C., Xiao, L. Z., Wegryn-Jones, R., Martin, A., ... & DeJonckheere, M. (2024). 'I'm still here, I'm alive and breathing': The experience of Black Americans with long COVID. *Journal of Clinical Nursing*, *33*(1), 162-177.

- Berne, P., & Raditz, V. (2019). To survive climate catastrophe, look to queer and disabled folks. *Yes! Magazine*.

- Butler, J. (2016). Rethinking vulnerability and resistance. *Vulnerability in resistance*, 12-27.

- Canada, P. H. A. of. (2024, October 22). *Government of Canada*. Post-COVID-19 condition (long COVID) - Canada.ca. https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/symptoms/post-covid-19-condition.html

- Canadian Guidelines for Post COVID-19 Condition. (n.d.). Research Recommendation Pharmacological and non-pharmacological clinical interventions for post-COVID-19 condition. https://can-pcc.recmap.org/

- Chen, M. Y. (2014). Brain fog: The race for cripistemology. *Journal of Literary & Cultural Disability Studies*, *8*(2), 171-184.

- Churchill Polar Bears. (No Date) https://churchillpolarbears.org/polar-bear-tours/arctic-summer-trips/

- Clare, E. (2017). *Brilliant Imperfection: Grappling with Cure*. Duke University Press.

- Davis, N. (2024, January 6). Long Covid causes changes in body that make exercise debilitating – study.

- Deacon, G. (2025, February 5). *This is how I recovered from long Covid It's not a magic pill* . https://aloveaffairwiththeunknown.substack.com/p/this-is-how-i-recovered-from-long?utm_campaign=post&utm_medium=web.

- Dew, C. (2022). Book Review: "Women For Peace: Banners From Greenham Common", by Charlotte Dew https://stitchedvoices.wordpress.com/2022/05/09/book-review-women-for-peace-banners-from-greenham-common/

- Dillon, Grace L. and Marques, Pedro Neves, "Taking the Fiction Out of Science Fiction: A Conversation

- Duckworth, Z. (2022, August 3). *Why are women more susceptible to long COVID? <Gender & Public Health Emergencies*. Gender & Public Health Emergencies. https://genderandcovid-19.org/editorial/why-are-women-more-susceptible-to-long-covid/

- Egner, J. (2023). "My existence is resistance!" Visible survival as crip resistance. In *Disability in dialogue* (pp. 170-198). John Benjamins Publishing Company.

- Ehrenreich, B., & English, D. (2005). *For her own good: Two centuries of the experts advice to women*. Anchor.

- Ehrenreich, Barbara. *Bright-Sided : How the Relentless Promotion of Positive Thinking Has Undermined America*. 1st ed. New York: Metropolitan Books, 2009.

- Erickson, L. cited in Withers, A.J., Ben-Mohw. L, Brown. L.X., Erickson, L., da Silav Gorman, R, Lewis, T.A., … & Mingus M. (2019) Radical disability politics. In *Routledge handbook of radical politics*. (pp. 178 – 193). Routledge.

- Erickson, L. (2016). Transforming Cultures of (Un) Desirability: Creating Cultures of Resistance. *Graduate Journal of Social Science*, *12*(1).

- Foucault, M. 1980 [1976] 'Two Lectures', in C. Gordon (ed.) Power/Knowledge: Selected. Interviews and Other Writings 1972-77/Michel Foucault. Trans. C. Gordon and others. Sussex: Harvester Press.

- Foucault, M. (1979 For an ethic of discomfort. *The politics of truth*, *122*. (1997)

- Garland-Thomson, R. (2011). Misfits: A feminist materialist disability concept. *Hypatia*, *26*(3), 591-609.

- Goggin, G. (2021). Disability & Inclusive Digital Futures: Pandemic Reflections. *LKAS Symposium, University of Glasgow*.

- Gorman, R. (2013). Mad nation? Thinking through race, class, and mad identity politics. *Mad matters: A critical reader in Canadian mad studies*, 269-280

- Guardian News and Media. (2013, April 9). *Artist-activist Liz Crow's "bed-out" for disabled rights*. The Guardian. https://www.theguardian.com/artanddesign/2013/apr/09/liz-crow-bed-disabled-

rights

- Gumbs, A. P. (2020). Undrowned: Black feminist lessons from marine mammals. Soundings, *78*(78), 20-37.

- Jure, D. (January 31, no year). Mycelium: The Wood Wide Web. https://www.kauaiseascapesnursery.com/blogindex/yilory2ns07nbdf4fn3pwde1gv8ubo

- Hamraie, A., & Fritsch, K. (2019). Crip technoscience manifesto. *Catalyst: Feminism, Theory, Technoscience*, 5(1), 1–33. https://doi.org/10.28968/cftt.v5i1.29607

- Haraway, D. (2015). Anthropocene, capitalocene, plantationocene, chthulucene: Making kin. *Environmental humanities*, *6*(1), 159-165.

- Hedva, J. (2016). Sick woman theory. *Mask Magazine*, *24*, 1-15.

- Hemendinger, K. S. a. E. (2024, August 12). Fitspiration, Pseudo-Healthcare Professions, and the First Amendment. *Skeptical Inquirer*. http://skepticalinquirer.org/2024/02/fitspiration-pseudo-healthcare-professions-and-the-first-amendment/

- Hernández-Garduño, E., Pérez-Neria, J., Paccagnella, A. M., Piña-García, M. A., Munguía-Castro, M., Catalán-Vázquez, M., & Rojas-Ramos, M. (1997). Air pollution and respiratory health in Mexico City. *Journal of occupational and environmental medicine*, *39*(4), 299-307.Kafai, S. (2021). *Crip kinship: The disability justice and art activism of Sins Invalid*. Arsenal Pulp Press.

- Hersey, T. (2022). Rest is resistance: A manifesto. Little, Brown Spark

- https://stitchedvoices.wordpress.com/2022/05/09/book-review-women-for-peace-banners-from-greenham-common/ Greenham Common quilt photo

- https://www.who.int/news-room/fact-sheets/detail/post-covid-19-condition-(long-covid). World Health Organizing, 2025, February.

- Hillier, S. Racism and Health and Indigenous Resilience lecture, Indigeneity and Disability class, York University, June 8, 2022.

- Hillier, S., & Vorstermans, J. (2024). Disability and Disablement in Settler Colonial States: Indigenous Perspectives of Disability Since Time in Memorial.

In *Handbook of disability: Critical thought and social change in a globalizing world* (pp. 525-541). Singapore: Springer Nature Singapore.

- Hollinsworth, D. (2013). Decolonizing indigenous disability in Australia. *Disability & Society*, *28*(5), 601-615.

- Hutcheon, E. J., & Lashewicz, B. (2020). Tracing and troubling continuities between ableism and colonialism in Canada. *Disability & Society*, *35*(5), 695-714

- Kafer, A. (2013). *Feminist, queer, crip*. Indiana University Press.

- Khanmalek, T., & Rhodes, H. A. R. (2020). A decolonial feminist epistemology of the bed: A compendium incomplete of sick and disabled queer brown femme bodies of knowledge. *Frontiers: A Journal of Women Studies*, *41*(1), 35-58.

- Kimmerer, R. W. (2013). *Braiding sweetgrass: Indigenous wisdom, scientific knowledge and the teachings of plants*. Milkweed editions.

- King, J. A., Brough, M., & Knox, M. (2014). Negotiating disability and colonisation: The lived experience of Indigenous Australians with a disability. *Disability & Society*, *29*(5), 738-750.

- Kola, I. (2019). *" I Can't Breathe": The Rise of Asthma in Black Urban America*. Columbia University.

- John Lennon and Yoko Ono laying in bed during their Bed-Ins for Peace in Amsterdam. (No Date) https://commons.wikimedia.org/wiki/File:John_Lennon_en_zijn_echtgenote_Yoko_Ono_op_huwelijksreis_in_Amsterdam._John_Lenn,_Bestanddeelnr_922-2302.jpg

- Lewis, S. L., & Maslin, M. A. (2015). Defining the anthropocene. *Nature*, *519*(7542), 171-180.

- *Liz Crow* - https://www.theguardian.com/artanddesign/2013/apr/09/liz-crow-bed-disabled-rights

- Lorde, Audre. (1980*). The cancer journals.* San Francisco :Aunt Lute Books.

- Lorde, A. (1988). *A burst of light: Essays***.** Firebrand Books**.**

- Macé, M., & Stanley, A. A. (2021). Respire, Con-spire. *SubStance*, 50(3), 178–188

- Pfeiffer, D. (2001). The conceptualization of disability. In G. Albrecht, K. Seelman, & M. Bury (Eds.), *Handbook of Disability Studies* (pp. 29–52). Sage.

- Mbembe, A., & Shread, C. (2021). The universal right to breathe. *Critical Inquiry*, *47*(S2), S58-S62.

- McGregor, D. (2015). Indigenous women, water justice and zaagidowin (love). *Canadian Woman Studies/les cahiers de la femme*.

- McGurk, M. (No date). 365 Days of Art: April 13 – Ordered on Bed Rest, Frida Attends Her Solo Exhibition in Four Poster Bed https://mauramcgurk.com/blog/ordered-bed-rest-frida-attends-solo-exhibition-poster-bed/

- McNamara, R. (2021). A Deep, Feminist Dive Into Autotheory. *Hyperallergic.* Available online: https://hyperallergic. com/647014/autotheory-as-feminist-practice-lauren-fournier-mit (accessed on 20 June 2021).

- Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability & Society*, *26*(6), 667-682.

- Mingus, Mia. (2011). https://leavingevidence.wordpress.com/2011/02/12/changing-theframework-disability-justice.

- Mollow, A. (2004). Identity politics and disability studies: A critique of recent theory. *Michigan Quarterly Review*, *43*(2).

- Muñoz, J. E. (2009). *Cruising Utopia: The Then and There of Queer Futurity*. NYU Press.

- Museum Wales. Greenham common banner image. Permission Amgueddfa Cymru

- Nishida, A. (2022). *Just care: Messy entanglements of disability, dependency, and desire*. Temple University Press.

- Nixon, R. (2011). *Slow Violence and the Environmentalism of the Poor*. Harvard University Press.

- Pfeiffer, D. (2001). The conceptualization of disability. In G. Albrecht, K. Seelman, & M. Bury (Eds.), *Handbook of Disability Studies* (pp. 29–52). Sage.

- Phillips, A. (2009). *Darwin's worms: On life stories and death stories*. Basic Books.

- Piepzna-Samarasinha, L. L. (2018). *Care Work: Dreaming Disability Justice*. Arsenal Pulp Press.

- Piepzna-Samarasinha, L. L. (2022). *The Future Is Disabled: Prophecies, Love Notes and Mourning Songs*. arsenal pulp press.Schalk, S. (2018). *Bodyminds Reimagined: (Dis)ability, Race, and Gender in Black Women's Speculative Fiction*. Duke University Press

- Puar, J. K. (2017). *The right to maim: Debility, capacity, disability*. Duke University Press.

- Public Health Agency of Canada. (2023) *COVID-19 longer-term symptoms among Canadian adults*. Public Health Agency of Canada - Canada.ca. https://health-infobase.canada.ca/covid-19/post-covid-condition/

- Raveendran, A. V., Jayadevan, R., & Sashidharan, S. (2021). Long COVID: An overview. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews*, *15*(3), 869–875.

- Ray, S. J. (2017). Risking Bodies in the Wild. *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory*, 29.

- Rönnberg, D. (2020). The Right to Breathe: An Examination of How Human Rights Can Be Applied to Guarantee Access to Clean Air.

- Samuels, Ellen. "19. Twenty-Seven Ways of Looking at Crip Autotheory". Crip Authorship: Disability as Method, edited by Mara Mills and Rebecca Sanchez, New York, USA: New York University Press, 2023, pp. 203-209.

- Saskatchewan Health Authority. *Long COVID Self-Management - Breathing Techniques*. (2021). https://www.saskhealthauthority.ca/your-health/conditions-illnesses-services-wellness/all-z/long-covid-post-covid-19-condition-self-management-resource/managing-shortness-breath/long-covid-self-management-breathing-techniques

- Schaffer, T. (2021). *Communities of Care: The Social Ethics of Victorian Fiction*. Princeton University Press.
- Schalk, S. (2022). *Black disability politics* (p. 219). Duke University Press.
- Schulman, S. (2021). *Let the record show: A political history of ACT UP New York, 1987-1993*. Farrar, Straus and Giroux.
- Scott, C. (September 9, 2022) Frida Kahlo medical history explored in exhibition. www.seegreatart.art
- Sharpe, C. (2016). *In the wake: On blackness and being*. Duke University Press.
- Simpson, L., DaSilva, J., Riffel, B., & Sellers, P. (2009). The responsibilities of women: Confronting environmental contamination in the traditional territories of Asubpeechoseewagong Netum Anishinabek (Grassy Narrows) and Wabauskang First Nation. *International journal of Indigenous health*, *4*(2), 6-13.
- Singh, M. (July 9, 2020) George Floyd told officers 'I can't breathe' more than 20 times, transcripts show https://www.theguardian.com/us-news/2020/jul/08/george-floyd-police-killing-transcript-i-cant-breathe
- *Singing the Living Tradition. A supplement to Singing the Living Tradition*. (2005). Unitarian Universalist Association of Congregations. Beacon Street Press.
- Sins Invalid, 2015. www.sinsinvalid.org/blog/10-principles-of-disability-justice
- Solnit, R. (2020). *Hope in the dark: Untold histories, wild possibilities*. Haymarket Books.
- Sontag, S. (1978). *Illness as metaphor* Farrar, Penguin Books.
- Taylor, S. (2004) “The Right Not to Work: Power and Disability.” *Monthly Review* 55:10.
- United Nations Department of Economic and Social Affairs, April 23, 2021 https://www.un.org/development/desa/dspd/2021/04/indigenous-peoples-sustainability/
- van der Velden, C. T. (2019). *Crafting Protest Craftivism as Soft Feminist Activism* (Master's thesis).

- Vázquez, Angela Meriquez. “Still on the Margins: Long Covid Patients of Color.” *Disability Visibility Project*, 25 Dec. 2023, disabilityvisibilityproject.com/2023/12/02/still-on-the-margins-long-covid-patients-of-color/.

- Waller, J. C. (2001). Ideas of heredity, reproduction and eugenics in Britain, 1800–1875. *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*, *32*(3), 457-489.

- Ware, S. M. (2025). Going through the portal: Permeable walls and immersive community engagements rooted in disability justice. In *The Museum Accessibility Spectrum* (pp. 119-130). Routledge.

- Wendell, S. (2001). Unhealthy disabled: Treating chronic illnesses as disabilities. *Hypatia*, 16(4), 17–33. https://doi.org/10.1111/j.1527-2001.2001.tb00751.x

- Wendell, S. (1996) The rejected body: Feminist philosophical reflections on disability. New York: Routledge.

- Whyte, K. (2017). Indigenous climate change studies: Indigenizing futures, decolonizing the Anthropocene. *English language notes*, *55*(1), 153-162.

- Wiener, J. (1998). Pop and avant-garde: the case of John and Yoko. *Popular Music & Society*, *22*(1), 1-16.

- Wilkerson, A. (2002). *Disability, sex radicalism, and political agency*. Hypatia, 17(3), 123–156. https://doi.org/10.1111/j.1527-2001.2002.tb00913.x

- “Post Covid-19 Condition (Long Covid).” *World Health Organization*, World Health Organization, www.who.int/news-room/fact-sheets/detail/post-covid-19-condition-(long-covid). Accessed 25 Oct. 2025.

- Yong, E. (2022). *The pandemic after the pandemic*. *The Atlantic*. https://www.theatlantic.com/health/archive/2022/08/long-covid-chronic-illness-disability/671146/

- York, R. (2024, May 19). *https://medium.com/the-random-nerdiness-collective/the-toxic-side-of-health-coaches-8daa08c0573f*. The Toxic Side of Health Coaches A shady, unregulated industry of well-intentioned but unqualified people. https://medium.com/the-random-nerdiness-collective/the-toxic-side-of-health-coaches-8daa08c0573f

- Young, S. (2014). I’m not your inspiration, thank you very much. TED: Ideas Worth Spreading. https://www. ted. com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much.