

# **a low hum, a strong gale**

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## Abstract

For the past eleven years, despite countless attempts to find a cause, I have lived with undiagnosed chronic pain. This paper functions in support of my thesis exhibition: delving into my lived experience with chronic pain and illness as it relates to disability justice and crip theory. The intent of this body of work is to reconstruct my own practice in order to best accommodate my own access needs. Through *a low hum, a strong gale* I am calling into question what it means to create a body of work that outwardly rejects the idea that to make valuable art, I must ‘suffer for it’. The process of creating the exhibition included working interdependently with others to help materialize my ideas, as well as building upon tasks—primarily breathing—that I can perform from bed when I’m unwell. This paper wrestles with my embodied experience of invisible illness and internalized ableism. My material explorations aim to make visible the invisible—documenting the physical limitations that are a result of my pain, rather than searching for evidence of its existence.



## Acknowledgements

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Thanks Mum for everything. I am so grateful to have you. You have cared for me relentlessly. I know it must be incredibly difficult to have a child who lives with chronic pain. I know you feel like you can't make it better, but you do, all the time. Thank you for laughing with me in waiting rooms, for advocating for me when I don't know how. I appreciate you endlessly. And thanks for reading my writing even when I'm writing about BDSM.



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00.

I tried to search for 'crip time' in York University's library database. I hit enter, and it hit me back with "*Did you intend to search for: 'chip thyme'?*" My phone always underlines 'crip' with a dotted red line. Every time this happens, it feels like the moment when you're thinking about something—and you're sure you've never spoken of it aloud—and then an ad for that exact thing pops up on your social media feed. It's as if the database and my phone both understand how much I've struggled with identifying as crip. It feels like they know that crip feels like a bad word—the wrong word—to use when I'm referring to myself.



Fig. 1. 07.03.2020, 16 minutes, ink on paper, 2020.



For the last eleven years, despite countless attempts to find a cause, I have been living with undiagnosed chronic pain. Throughout this paper, I continue to refer to my pain and illness as ‘undiagnosed’. I feel it’s important to clarify that some of the pain I experience has been diagnosed, with a clear cause—but the majority of my symptoms and pain have remained mysterious since they began over a decade ago. My jaw is crooked and arthritic and the discs slip out when I open my mouth too wide. No one can tell me why sometimes my knuckles get stiff, or my eyes blur, or what those constant spots in my vision are, or why I’m dizzy, and so on. When I say ‘undiagnosed’—I don’t mean that I have no explanation for any of it at all. What I mean is that the answers or explanations I have don’t add up, don’t explain all of it, or completely contradict other answers I thought I had. There is a lack of clarity. It is messy and there are loose ends.

This paper is in support of my MFA thesis exhibition entitled *a low hum, a strong gale* at Gales Gallery at York University.





Fig. 2. 09.09.2020, 32 minutes, ink on paper, 2020.



Upon entering the gallery, the walls straight ahead and to the left each display a curated selection of drawings from ongoing series I have been working on for the past year and a half. The drawings are in black ink on large (25" x 37"), thin, off-white paper, hung using sewing pins in the top two corners. They sit slightly off the wall, swaying gently as you walk past them. The drawn area occupies only a small portion of the paper, in the bottom third of the page. The marks are gestural and scratch-like: reminiscent of sinusoidal lines created by an EKG machine, a polygraph or a seismograph. The lines are broken and scattered, the path of the marker jumbled and unclear. The images refuse the clean linearity of the sinusoidal curves—representative of data sets—that they bring to mind. They hang low on the wall, the drawn area aligned to about belly-height (that is: the height of my belly, as someone who is five foot five). The top of each page is five feet and five inches off of the ground. The drawings hang in groups of one, three, two and five, with gaps between them large enough to accomodate one—sometimes two—additional drawings.



Fig. 3. Image of drawings from installation in Gales Gallery, 2021.



Two handmade gowns hang from the lighting tracks on the ceiling. They are hung using surgical tubing and silver wire hangers. The tubing that ties the hangers to the tracks is made of natural latex that is a muted ochre, the colour of beeswax. The gowns use the pattern of a typical hospital gown, but are made in a variety of sheer off-white fabrics: chiffon, satin, lace. In the corner of the room, to the far right when you enter the space, another gown made from a gauzy fabric hangs from an I.V. pole.



Fig. 4. Installation at Gales Gallery, 2021

In the corner opposite the I.V. pole, a harness made of brass rings, brass wire and latex tubing is mounted to the wall with brass nails. In the front section of the harness a brass ring connects three segments of latex. Above it, brass wire coiled around itself holds a marker that is covered in a latex and paper casing.





Fig. 5. Image of harness from installation at Gales Gallery, 2021

Between the I.V. pole and the harness, a video work projected onto the wall plays on loop. The video is a screen recording of my computer desktop. A voiceover plays into a pair of headphones mounted to the wall beside the projection. I read a short piece of text I have written throughout the process of creating the drawings. The video shows the cursor toggling through different windows on the computer screen. The visuals are videos of the drawing process, and other support materials referenced in the text; including images of pain scales from visits to my



specialists' office, Wikipedia entries about Wonder Woman's lasso of truth, diagrams of pneumographs and the Beaufort Scale.

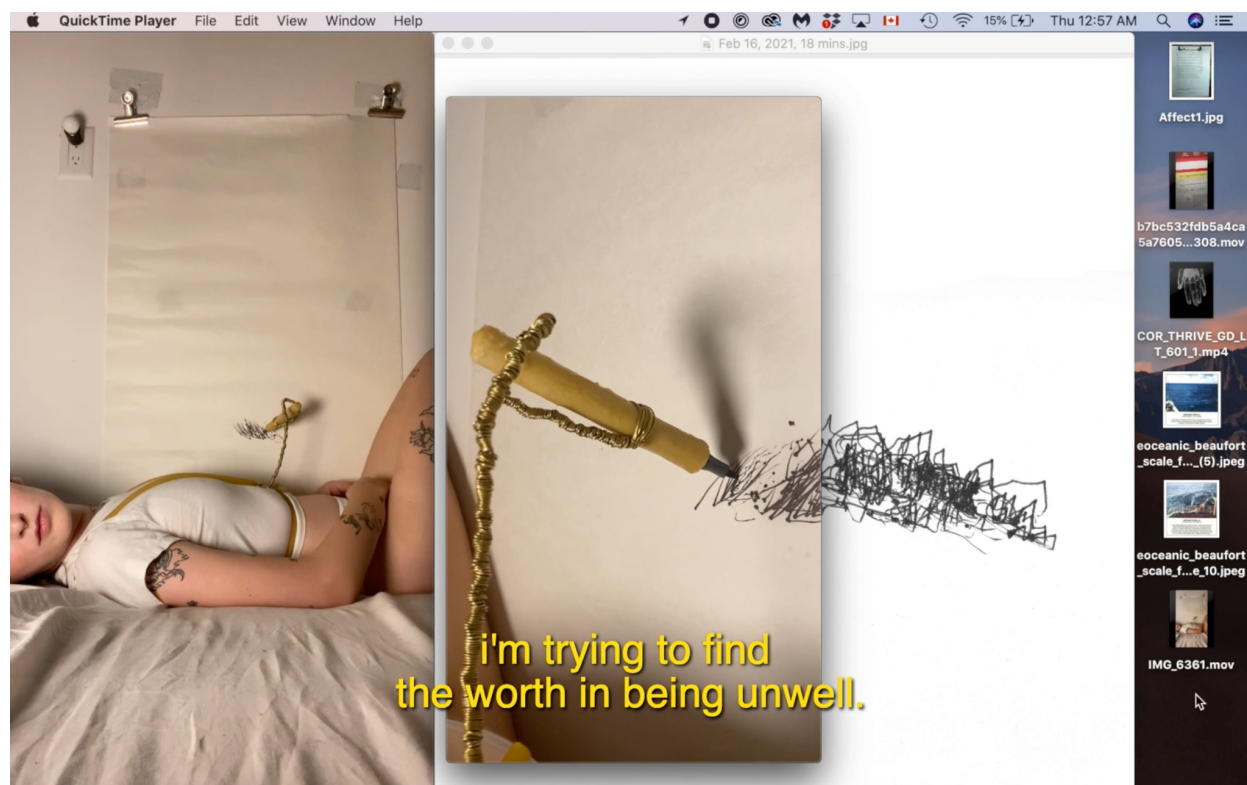


Fig. 6. Still from video work (desktop screen recording) with captions, 2021.

All of the works in the exhibition grapple with my experience of chronic pain, employing adaptive processes. The intent of this body of work is to reconstruct my own practice to accommodate my own access needs. Through *a low hum, a strong gale* I am calling into question what it means to create a body of work that outwardly rejects the idea that as an artist, I must 'suffer for it'. The process of creating the exhibition included working interdependently with others to help materialize my ideas, as well as building upon tasks (primarily breathing) that I can perform from bed when I'm unwell. The series is ongoing and slow. I make new work when I have the capacity to do so.

I have repeatedly been subject to interrogation in medical contexts, making me feel as though I must continually search for evidence of the reality of my pain. Through this work, my aim is to make visible the invisible: documenting the physical limitations that are a result of my pain,



rather than searching for evidence of its existence. My repetitive and performative methodology has allowed me to reclaim the seemingly senseless experience of my pain, while also speaking to the endurance and lack of resolution associated with my chronic condition. In creating adaptive tools, my intent has been to foster a sense of belonging: within my environment and within my own skin.

But maybe it's just an assertion of my aliveness, my presence. Maybe all I'm saying through the work is 'i'm still here, i'm still alive, i'm still valuable' even if my breath is all I have to show for it.



There is no such thing as repetition. Only insistence.

– *Gertrude Stein*



## 01.

In *Plaintext*, Nancy Mairs writes “People—crippled or not—wince at the word ‘cripple,’ as they do not at ‘handicapped’ or ‘disabled.’ Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely” (9). Maybe this is a small part of my hesitation: I wince, too. This is just one of many ways my internalized ableism manifests. I acknowledge and try to push back against the wince.

I think the main reason I take issue with the word, however, is that I do not feel that I am *cripp enough*. The fates/gods/viruses/whatever have not been kind to me, but they have not been unkind either. My identity since the pain began has never been something I can face squarely. It has always felt slippery, liminal, hard to pin down. And though I know my body is crippled, it feels like in claiming a *crip* identity, I'm taking something away from those who somehow ‘deserve’ it more than I do. No one can know the ways in which my body is deviant just by looking at me. And I do not have a name for the ways in which it deviates. The only one who knows the extent of my pain and limitations is me, and these limits have taken years to fully accept. It's as though in my mind, the privileges I experience in living with invisible illness somehow negate me from being able to claim *crip* at all. I can pass as able-bodied when I choose to, I can often choose when and how I disclose my limitations. I do not experience ableism in the same outwardly harmful way those with visible disabilities do. That refusal of identity, because I am not sick enough, allows me to step further, towards: *I am never enough*.

I'd like to add a small side note here about the term ‘bodymind’ which I use throughout this text. In the introduction to *Brilliant Imperfection: Grappling with Cure* Eli Clare describes his intention in using the term:

I followed the lead of many communities and spiritual traditions that recognize body and mind not as two entities but one, resisting the dualism built into white Western culture. Some use *bodymind* or *mindbody*...I settled on *body-mind* in order to recognize both the inextricable relationships between our bodies and our minds and the ways in which the



ideology of cure operates as if the two are distinct—the mind superior to the body, the mind defining personhood (xvi)

I have chosen to adopt ‘bodymind’ to reflect the deep entanglement of mind and body within both crip theory and my personal experience.

I have this feeling of permanently existing in liminal space. That feeling early in the morning or late at night when you are not quite asleep and somehow not awake either: that in-betweenness is where I live. The space between sick and well, asleep and awake, comfort and dis, able and un, life and death.

Once I started reading about crip time, I finally felt I had a name for what it was like to live in this in-betweenness. It provided a way of understanding and knowing that this feeling wasn’t exclusive to me. Crip time gave me a sense of belonging within my crippled-ness. It gave me solidarity. In her text *Feminist, Queer, Crip*, Alison Kafer articulates crip time and the temporalities of disability. Kafer explains crip time, in its simplest form, as the understanding and awareness that disabled people might need more time to accomplish something or to arrive somewhere, whether it’s due to slower speed of movement, or ableist barriers over which one has no control (26).

Crip time goes beyond this, though. It stretches further to bring understanding to the fact that disabled bodyminds often have relationships to time that are entirely unique. Whether it be the result of a need to constantly grapple with and be confronted with our own fragility, vulnerability and mortality—or, the need to barter time carefully, according to what our deviant minds and bodies will allow. There is the ever-present knowledge that you are running out of time and that you must carefully select how you use each moment. The knowledge that while time is limited, pleasure and productivity must be too—should you wish to leave the house in the days that follow.

This theorization of disability, and its shaping of one’s relationship to time, is significant to my own embodiment. My limitations are fluid, and do not necessarily align with our typical understanding of a disabled bodymind. Kafer notes that, with some exceptions, disability studies



have placed primary focus on visible physical impairments and sensory impairments (12). This is where my body deviates from understandings of disability. I have all my senses: there is no visible marker of my limitations: not on my body, not on the scans or films. I can see, hear, speak, stand, walk. I deviate from the normative body and I deviate from normative understandings of disabled bodies. This is why for so long, I have felt that I inhabit the cracks between the two. What marks my difference is the way my body relates to time.

I am not limited in a specific and easily defined way. There is no single box I can check that translates my disability. Rather, I am living in what Kafer calls ‘anticipatory time’. I am constantly bartering time, carefully selecting which moments to choose to be active, and for how long these moments of activity will render me inactive, unable to lift myself out of bed. There are few things I physically cannot do, but there are many things I really, definitely, shouldn’t do if I hope to get out of bed in the days (or weeks) that follow. My life revolves around pacing myself, in order to minimize the possibility of incapacitation as a result of physical pain. It is not always predictable. As Kafer puts it: “For those who live with chronic fatigue or pain, the present moment must often be measured against the moment to come” (39). This anticipation expands beyond measuring moments up against each other. It also encapsulates what it means to live without diagnosis.

I fluctuate between the expectation of explanation and answers, and the acceptance of what Kafer defines as ‘undiagnosis’. In either state, I am on standby. I am waiting for an answer, I am waiting for the pain to subside so I can catch my breath, I am waiting for the pain to catch up to me and knock me off my feet. Kafer equates this with ‘prognosis time’, where both prognosis and undiagnosis are “liminal temporalities, a casting out of time; rather than a stable, steady progression through the stages of life” where “time is arrested, stopped” (36). There is no resolution or linearity in living without a diagnosis.

Time is arrested in anticipation of moments to come, because my body forces me to be attentive in the present at all times. If I am not mindful of all the small sensations of discomfort, there are material risks. I hate it when people suggest meditation or mindfulness as a potential solution to



my chronic pain. I hate it because in illness and in wellness, I am forced to be mindful, whether I want to or not.





Fig.7. 11.20.2020, 24 minutes, ink on paper, 2020.

Love me, the sick person in the prime of their life says, trying to look as if they will grow strong again, for what I have done before, and also what I might do, and also love me for the present in which I am eternally trapped, uncertain of my exact attachment to time.

– Anne Boyer



My practice has always revolved around careful pacing, but previously in a way that involved sporadic bursts of intense labour followed by long and necessary periods of rest. My own access needs were always an afterthought. I learned—through my traditional arts education, and the omission of bodies like mine in the art historical canon—that the value in the work I was making was inseparable from the labour and effort required to make it. I had an underlying belief that the more pain I was in, the better my work would be. A belief that if I were to accommodate myself I would be taking the easy way out.

I began questioning my own approach to making, wondering what it would look like to shape my method of production around my body's needs. I wanted to confront my own ideas of what it meant to be productive and make work that I considered successful, while accommodating my embodiment in the process.

I had Johanna Hedva echoing through my head for weeks. “How can you throw a brick through the window of a bank without getting out of bed?” And I started to ask myself how I could unlearn that my body is apolitical or irrelevant when I can't get out of bed. And I sarcastically asked my friend “How can I make good art when I can't get out of bed?” Then, I couldn't stop trying to answer that question.

I am often forced to retreat to my bedroom when I am unwell, or as a preventative measure to keep me from becoming unwell. This, to me, has always felt like failing; admitting defeat.

I am trying to fight this thought pattern that has become so deeply ingrained in me. Thoughts like: *a life lived in bed is no life at all.*



**02.**

I am failing to meet the standards of productivity I have learned (and learned again) from the relentless voice of a life lived in neo-liberal capitalist space. I am also failing to meet the criteria of disability I have internalized from the limited representation of crip bodyminds that prevails in the mainstream. I know that beating myself up over my failure to meet diagnostic criteria, to work full time, to earn a living, to cook and clean and exercise is not fair. I would never be this critical of anyone else. I know these 'failures' are not just my own, and no fault of my own.

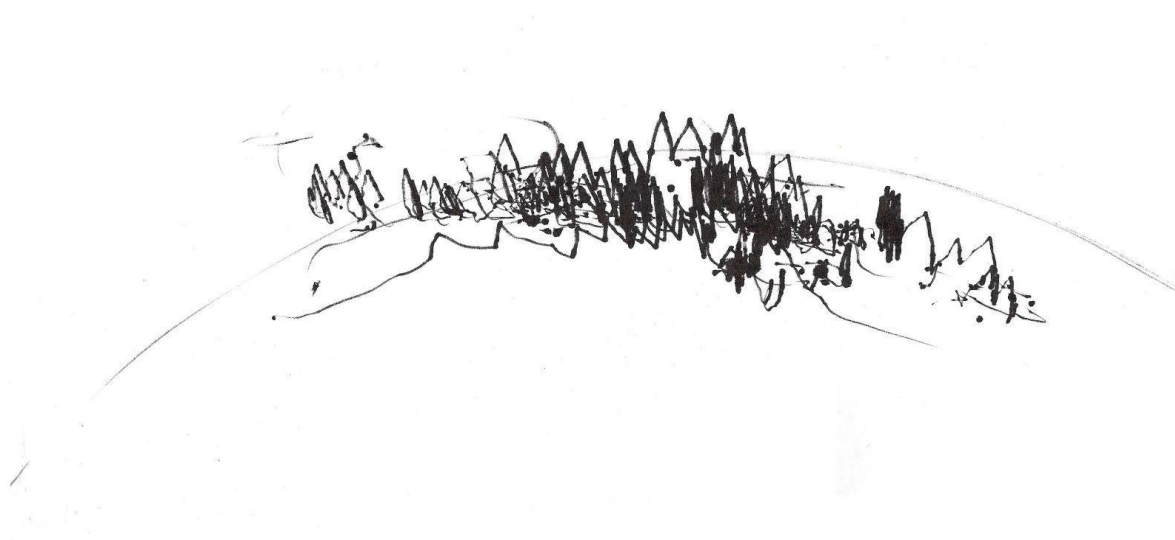


Fig. 8. 07.02.2020, 22 minutes, ink on paper, 2020.



I began to make a shift towards emphasizing my moments of perceived failure, continuing what Leah Lakshmi Piepzna-Samarasinha refers to as the ‘time-honoured crip creative practice’ (17) of working-from-bed. My aim was to find a way of ‘throwing bricks’ without ever having to leave bed: whether it was because of necessity in the moment, or anticipation of moments to come. I wanted to find a way of rejecting the normative narratives and ideals that have used productivity, independence and financial stability as the criteria that define us as valuable; to use my embodiment and temporality as central to my method of making work. I wanted to begin to unlearn the values I have upheld in my own practice: to begin moving past an emphasis on time-consuming, tedious, laborious work that only makes me feel shittier than I already do.

I was listening to an episode of *Crip Times* where chronically ill artist Cindy Baker discusses her piece *Crash Pad*, and says, “The piece is an opportunity for me to let the public see an artist who is working hard at resisting the impulse to work hard.” I paused it for a moment. I simultaneously felt seen, and jealous that I had never thought to put it that way. *An artist who is working hard at resisting the impulse to work hard.*

*Crash Pad* is an installation and durational performance piece in which Baker rests in the gallery space, on a sculptural object that simultaneously resembles a bed and a pill in a blister pack. The mattress is white in the shape of a round tablet sitting on a thin silver platform. The crumpled blanket looks like foil being pulled back to access the medication.





Fig. 9. Cindy Baker, *Crash Pad*, dc3 Art Projects, Edmonton, AB, 2018, dc3 Art Projects, “Cindy Baker: Crash Pad”.

In an interview about the exhibition, Baker discusses an older performance work in which she encased herself in a heavy plexiglass box, rolling it with her as she walked through the city. She says “it was so bad for me in so many ways and yet I felt like a productive and *good* artist.” (dc3). Baker’s thought process throughout her practice mirrors my own in this way.





Fig. 10. Cindy Baker, *Plexiglass Box*, Dunlop Gallery, Regina, SK, 2003, dc3 Art Projects, “A Conversation with Cindy Baker”.

I have a background in printmaking. Throughout my undergraduate studies, I always felt as though the best work I was making was the work that required the most effort, and thereby inflicted the most damage on my body. This included making several incredibly detailed hand-carved 2' x 4' woodcuts, hand-pulling hundreds of sheets of paper only to tear them apart and piece them back together, and countless other undertakings that left me bedridden for days after their completion.

Baker talks about this trope, especially predominant in performative work, that viewers and artists continue to uphold. That is: the damage you are willing to risk or inflict on your own body



is equal to the dedication you have to your art form, and with that dedication the artwork becomes more powerful, valuable and successful. See: Chris Burden, Marina Abramovic, Yoko Ono, Carlos Martiel, Petr Pavlensky, Stelarc, Gina Pane—just to name a few. I battle with the influence works like theirs have. These artists' representations of pain range from capitalization on shock value, to carefully considered risks that function politically and meaningfully. The emphasis on works that employ pain in this way—that situate performative and wilful pain as noble and radical—is something that I struggle with as it relates to crip theory. When I think about how this intersects with notions of the ‘supercrip’—this idea so perpetuated in our culture, that to be a *good* disabled person, you must *buck up* and *overcome* the barriers you face—I want to throw something.

Alison Kafer continues to expand on her definition of anticipatory time in *Feminist, Queer, Crip*, stating that: “This idea of conserving energy, of anticipating, can be read as queer in that it bucks American ideals of productivity at all costs, of sacrificing one’s body for work. In other words, how might we begin to read these practices of self-care not as preserving one’s body for productive work but as refusing such regimes in order to make room for pleasure” (39). How might we learn to view these practices as necessary rather than superfluous? What does making room for pleasure make room for? What does it mean to wilfully reject suffering in the name of valuable output and productivity?



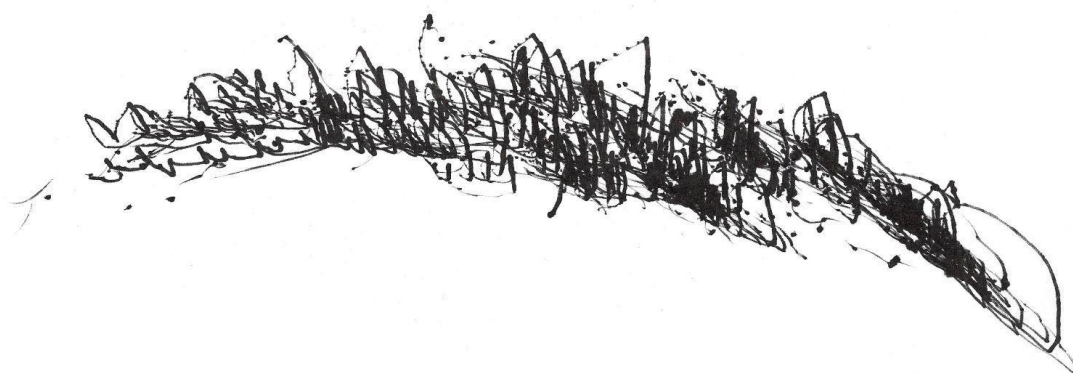


Fig. 05.16.2020, 22 minutes, ink on paper, 2020.



Disability theorist Rosemarie Garland-Thomson's concept of the 'misfit' resists the notion of a generic disabled body, focusing instead on the individuality of differing embodiments. She views the disabled bodymind as one that defies the expectations of physical environments, revealing a dynamic encounter between flesh and world (592). With this concept, Garland-Thomson aims to shift dominant discourses surrounding disability towards understanding our bodies in relation to the material world, as opposed to understanding them in relation to each other.

It is not only the encounter between 'flesh and world' that is relevant within the context of my work. Time is inseparable from the way my particular flesh encounters the world. Time shapes the way my flesh exists in the world, and my flesh shapes the time I spend in the world. I am perpetually anticipating, on standby or pause.

This past year, I began creating a series of 'drawings' as I lay in bed. I formed wire appendages that wrap around my belly and have an extended arm that holds a marker parallel to the floor. The arm reaches a piece of paper mounted on the adjacent wall. The marker then transcribes the natural motion of my body with each breath I take, resulting in scratch-like and gestural drawings. In this process the wire forms become prostheses that 'ease the material divergences' between my body and its working environment (Garland-Thomson 601). I am altering my method and materials to 'fit' my embodiment. I am subverting perceptions of sick and disabled bodies, in my rejection of the idea that I am in need of fixing or a cure. Instead, fixing my practice to better suit me and what I am capable of. I am pushing back against the idea that my embodiment is something I need to overcome, allowing it instead to dictate my approach to working.

I circled back to the Cindy Baker episode of *Crip Times*. Later in the episode, Baker continues on to say "I just want to start really quietly and say 'This is me resisting, you're witnessing me resisting and it's valuable'." I hit pause again because it is annoyingly resonant. I, too, am resisting. Even if it is only a whisper.



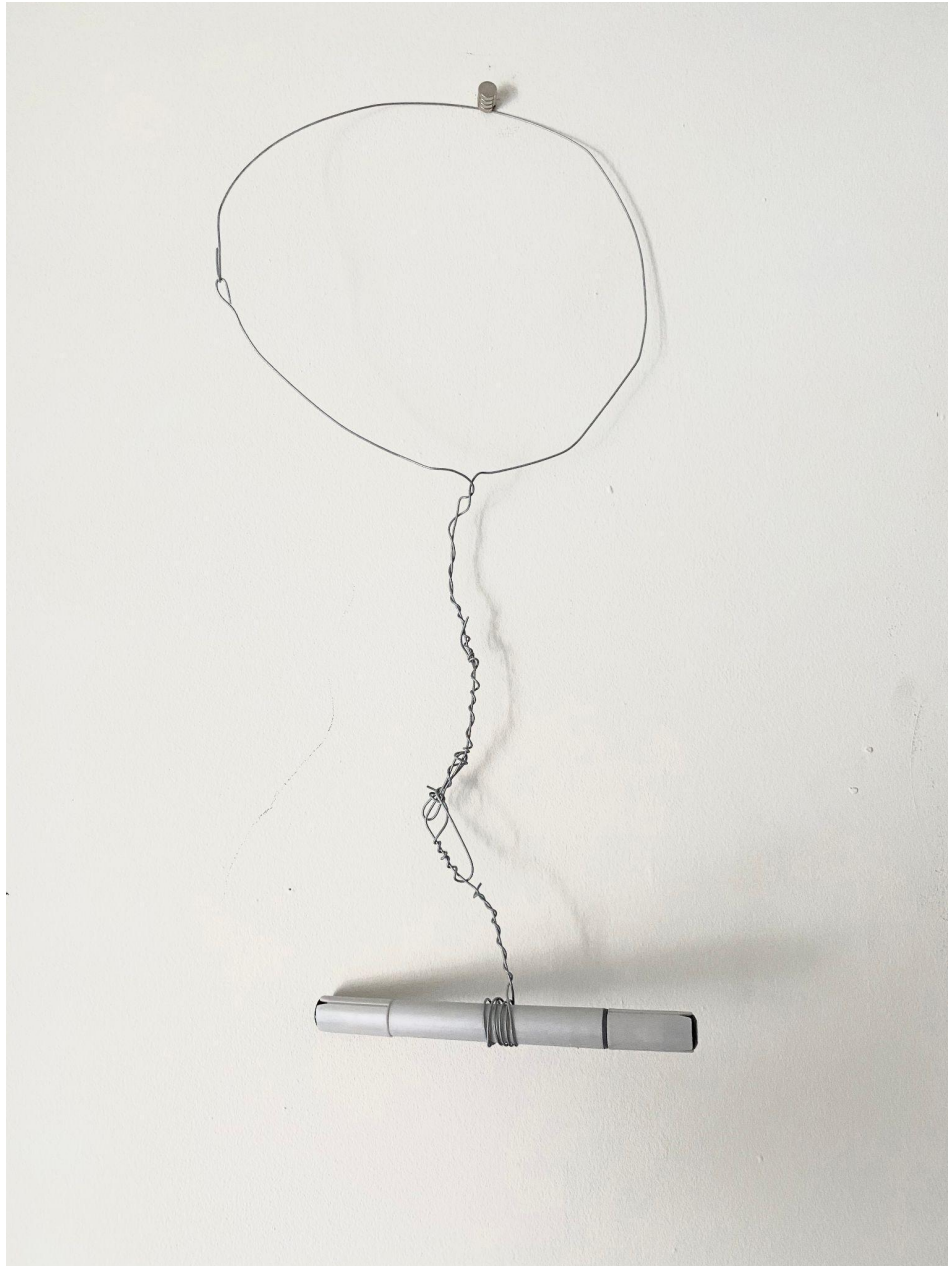


Fig. 12. Photograph of drawing tool prototype, 2020.

A physiotherapist once told me that my breathing is ‘all wrong’. She said that my chronic pain had altered the way I inhale and exhale and that I needed to learn to breathe all over again. Her name was Flo, which feels like a fitting and significant detail. In this body of work, I am actively choosing to use this ‘wrong’-ness—the misfitting—my pain has created. It has altered me down to my most basic human ability. But, I can breathe, even if sometimes that’s all I can do.





Fig. 13. 09.18.2020, 22 minutes, ink on paper, 2020.



“Disability is defined as lack of productivity. We are all to be smoothly running engines, and disability renders us defective products.” (Kafer 54). Often I stall, rendered defective. When I do, and all I’m left with is my breath and my thoughts, it becomes immediately clear how deeply capitalist notions of productivity and value have shaped my self-view. The internalized ableism feels inescapable. It has seeped its way into almost every aspect of my day-to-day. I don’t know if my work or my life will ever be completely void of it; it feels unlikely. But I will continue to try. A soft whisper as I work feels like a good place to start.

I am no longer looking for moments of wellness and sucking them dry for all that they're worth. I am trying to find the worth in being unwell. But at what point does searching for meaning in something so complex, abstract and unknowable cross over into meaninglessness?

Once again I find myself in a space of in-betweenness. I am circling five out of ten on the pain scale again because the middle is where I feel most at home. Messiness and all.



03.

We look like what most movements have been taught to think of as failure

– *Leah Lakshmi Piepzna-Samarasinha*



Fig. 14. 04.26.2020, 42 minutes, ink on paper, 2020.



In scholar Lauren Fournier's recently released book, *Autotheory as Feminist Practice in Art, Writing, and Criticism*, she writes: "Autotheory is theory and performance, autobiography and philosophy, research and creation, knowledge that emerges from lived experience and material-conceptual experiments" (29). Autotheory is an emergent term that feels relevant to the work that I've been making—the thinking and making and writing and reading and lying-in-bed-not-doing-much-of-anything feel inseparable. I don't think I'm formulating a new *theory* of anything. My hope is that the inclusion of the personal and embodied alongside the theoretical research can make my work accessible and relatable in a way that theory on its own can rarely achieve.

In another text, "Sick Women, Sad Girls, and Selfie Theory", Fournier describes the work of several sick and disabled writers and artists. She identifies their work as building upon lived experience to generate theory that is inclusive of "a practice of 'failing' to be as active as one would like to be—as a feminist activist, as a scholar, and so on." (648). An autotheoretical approach to working, in the context of disability and illness in particular, can offer new modes of processing what it means to experience 'failure' on a bodily, molecular level. The embodied experience of 'failure' is so often overlooked and underrepresented. It is a mode of being, working and living that I inhabit, and have for over a decade.

Reading, viewing, and bearing witness to 'failure' in this way holds power. Chronic pain and illness are so often framed as an individualistic failing. When I am in pain I am wracked with guilt. I fail to meet deadlines, fulfil responsibilities or be reliable in my showing-up (for people, for events, for duty). And when I express my needs/failures/inabilities on any given day, I am so often hit back with suggestions on how to make myself feel better, as if I haven't used all the tools in my eleven-years-of-this box. As if I simply haven't tried hard enough: to get better, to push through. The solidarity in narratives of working-from-bed—working only when and how your bodymind allows—makes space for theories that are resistant and resonant.

Working-from-bed narratives construct a space where rest is not only okay, but necessary.



In their book *Care Work: Dreaming Disability Justice*, Leah Lakshmi Piepzna-Samarasinha discusses their autotheoretical approach to writing (without naming it as such, though I would argue it absolutely is):

Serious cultural work isn't supposed to include lists of fragrance-free curly hair products or instructions about how to tour while sick and hurt less, right? But—*fuck that*. The making of disability justice lives in the realm of thinking and talking and knowledge making, in art and sky. But it also lives in how to rent an accessible porta potty for an accessible-except-the-bathroom event space, how to mix coconut oil and aloe to make a fragrance-free hair lotion that works for curly and kinky BIPOC hair, how to learn to care for each other when everyone is sick, tired, crazy, and brilliant. And neither is possible without the other. (24)

Piepzna-Samarasinha calls into question where 'serious cultural work' ends and personal and embodied knowledge begins.

When Fournier's text is read alongside Piepzna-Samarasinha, it is blatantly obvious how the notion of autotheory is interwoven in *Care Work*. Fournier notes: "Autotheory is also the site of engagement with the materials of the writer's or artist's life: embodied experience can become another text, framework, or catalyst through which to think through aesthetic, social, cultural, moral, and political issues." (35) Piepzna-Samarasinha continually reinforces this idea in their writing through the entanglement of personal narratives, dreams, and theories for the future of the disability justice movement. They wrote it 'mostly in the majestic disabled revolutionary space of writing from bed in old sleep pants' (9).

In *a low hum, a strong gale* I am using the intricacies of my embodiment alongside material exploration in my work/sickbed to think and write through the difficulties of larger societal structures. Structures that have taught me this act of being attentive to my sick body, in-and-of itself, is a failure. And I am using this process to push back against, and to remind myself that these structures are not ones I want to be a part of: they are not structures that leave room for disability justice.



The knowledge the chronically ill, chronically pained, and disabled community have is valuable. The embodied experience of living in a way that is deviant—frowned-upon, even—can construct meaning and build the foundation for new ways of being. Ways that uphold interdependence, care and empathy—resisting the championing of independence and productivity that so often wreak havoc on our bodyminds, disabled and abled alike.

This is a conversation I have seen arising more and more since the beginning of COVID-19. Stories of workplaces suddenly granting accommodations to non-disabled folks—ones that disabled employees have been asking for, for years. Stories of able-bodied friends turning to disabled ones to seek advice on how to live in the confines of their homes. Non-disabled people who were suddenly out-of-work received government benefits far greater than ODSP (Ontario Disability Support Program) payments—and completely inaccessible to disabled people. The pandemic forced circumstances that were previously exclusive to disabled/chronically ill bodyminds onto the non-disabled, and accommodations developed and were implemented at what seemed like lightning speed.

All I can do is hope that this can be a lesson in the value of disability narratives. No one is immune to the circumstances disabled people live with, and maybe that's why it's so hard for non-disabled people to talk about and hear about realities of crip embodiment. It's scary and uncomfortable to grapple with the idea that one day you might lose the ability to walk, or might live in constant pain. That one day, you may not be able to work anymore because of illness or injury, and if that happens, you may not be able to pay your rent.

It's easier to look at someone with chronic pain or illness or disability and let yourself fall into the assumption that *they just aren't trying hard enough*, that it's *just an attitude problem*, that *this is something that can be fixed, overcome*. It's easier to have those thoughts than to fully engage with the fact that our bodies and minds are universally vulnerable. Easier than the acknowledgement that someone whose body does not fit into a normative understanding of 'health'—with a body that causes pain, or a bodymind that struggles to navigate a world designed for able-bodies—can have a desirable future and does not need to be *fixed* or *cured*. It's easier to view all of this as individualistic failings of crip individuals than to take a step back



and look at how we continue to enforce the idea that a deviant bodymind cannot be a *good* one, or does not need or deserve care and support. Disability justice shows us that crip futures can be desirable—and more than that, that we all have a lot to learn from actively listening to what disabled communities have been shouting for decades.

Leah Lakshmi Piepzna-Samarasinha continues in their book to discuss applying anti-ableist practices within activist organizations. Rejecting the notion of self-care, the author advocates for collective care: a practice which facilitates a culture within organizations where “people feel fine if they get sick, cry, have needs, start late because the bus broke down, move slower, work from home—and these aren’t things we apologize for.” (108). In applying these practices to our organizations and lifting the burden of individualized guilt, we can construct spaces “where we actually care for each other and don’t leave each other behind.” (108). These shifts benefit everyone, but can’t—won’t—happen without working-from-bed narratives. Centering crip voices can remind us, over and over, that it is not an individual failing to have individual needs.

Yashma Maya Padamsee writes in her article “Communities of Care, Organizations for Liberation”, “Too often self-care in our organizational cultures gets translated to our individual responsibility to leave work early, go home—alone—and go take a bath, go to the gym, eat some food and go to sleep. So we do all of that ‘self-care’ to return to organizational cultures where we reproduce the systems we are trying to break.” We cannot break the systems without breaking down the ableism within them. Activist organizations cannot be sustained without collective care. Disability communities have the embodied knowledge and personal experience to show us resilience in the face of grief, what activism-from-bed looks like, how interdependence can create sustainable collective action.



## 04.

In her essay, “6 Ways of Looking at Crip Time”, Ellen Samuels writes “*Crip time is time travel*. Disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings.” Samuels goes on to explain that for many disabled people, the experience of time shifts. Younger bodies can be impaired in ways that most commonly affect older bodies. Many disabled folks will be treated like children no matter their age.

There’s another type of time travel I experience, caused by very specific sensations of pain and malaise. I don’t know how else to describe it other than that it’s like when you hear a song, and instantly you’re overwhelmed with memories of that one specific period of time when you couldn’t stop listening to it on repeat. It’s like that, but much more intense. The time and place that I visit most frequently and vividly is high school. This is a time I don’t want to remember but is firmly imprinted in my memory regardless. I’m not sure why this stage in my life is the most easily defined by one specific feeling. If I had to guess, I would say it was because this is when my pain really began to impact my life in a significant way. It was still novel and I still had an idea of what a zero on the pain scale (meaning ‘no pain’) felt like. Each day that I was in pain felt more significant than it does now. It hadn’t yet become a permanent fixture in my life. These flashbacks are unwelcome. I always know where I am, and who I’m with, and that over a decade has passed. But it’s as if my body is trying to convince me otherwise. When I close my eyes, I have to open them again; just to ground myself in the present, far away from the house I grew up in: the house that is haunted with the ghost of the body I used to have.

How do you rate *that* kind of discomfort on a scale from zero to ten?

Samuels continues: ‘*Crip time is grief time*.’ Maybe the memories of the beginning of my chronic pain are more difficult because I had so much more to lose then, than I do now. I was watching my perfectly able, young, active body deteriorate rapidly. There was a huge mourning period and learning curve associated with the new pain I was experiencing. I had to get to know



my new body and what I was capable of, all while leaning on the idea that I would soon find an answer and a cure, returning to *normal*. I was making adjustments and adapting so constantly and quickly, holding onto the idea that it was all only temporary.

It's not to say that I don't experience grief now, but it feels different than it used to. This *is* my normal now.



Fig. 15. 02.16.2021, 18 minutes, ink on paper, 2021.



I feel a constant push and pull between a desire to feel—but mostly just to *be*—better; and loving my body and the person it has allowed me to become. My pain has shaped my entire adult life and influenced every part of my existence. The complexities of wanting to be a ‘better’ person—and knowing that being rid of pain would help me perform better, work harder, do more and meet expectations, are deeply entangled with desires to continue to push back against structures that have taught me what makes a person valuable. I want to be in less pain, and in pain less often, but I don’t want to change who I am. A lot of the time my pain and my identity feel inseparable. My pain is not some tragedy that has destroyed my life. There are moments of terrible grief associated with my chronic pain but, there is also pride and joy associated with what my particular embodiment has made—and continues to make—possible.

In her book *Pain Studies*, Lisa Olstein analyzes several episodes of the TV series *House MD*. At the time I read her book, I hadn’t thought about the series in years. I used to watch it semi-frequently before pain became a fixture in my own life. There was some allure and satisfaction I found in watching the cranky Dr. Gregory House (who is addicted to Vicodin as a result of chronic leg pain) solving seemingly unsolvable medical mysteries. In one episode, Olstein explains, House is suddenly not so cranky anymore. He has started taking methadone to replace his Vicodin—and even though it is dangerous, his pain is finally gone. He is cheerful and nice and pain-free, but he misses a diagnosis for one of his patients—and stops taking the methadone. The patient ends up fine despite the initial misdiagnosis—that is not the problem. Olstein writes: “The problem is that without the irritation of his pain, that toil, without its friction, its urgency, something—it’s hard to say exactly what—he isn’t himself” (97). House, the doctor so fixated on diagnosis and cure, refuses a solution to his own pain in favour of hanging on to the version of himself with which he is most comfortable. Like House, I find the idea of cure alluring. I also wrestle with the idea of what I would lose if I were to be cured. I grieve for my able-body and conversely, I fear what it would mean to lose my disabled one.

In *Brilliant Imperfection: Grappling With Cure*, Eli Clare articulates the complexities of desiring cure:



Cure is such a compelling response to body-mind loss precisely because it promises us our imagined time travel. Back to a time pre-pain, pre-exhaustion. But this promise can also de-value our present-day selves. It can lead us to dismiss the lessons we've learned, knowledge gained, scars acquired. It can bind us to the past and glorify the future. It can fuel hope grounded in nothing but the shadows of *natural* and *normal*. And when this time travel doesn't work or simply isn't possible, we need a thousand ways to process grief prompted by body-mind loss. Certainly our losses are real, but so is our adaptability.

(57)

And again, I am stuck in the middle. Between the idealized past and the hopeful future. Between learning to love what this body has taught me and allowing myself to grieve what has been stolen.





Fig. 16. 10.19.2020, 19 minutes, ink on paper, 2020.



## 05.

*The Body in Pain: The Making and Unmaking of the World* by Elaine Scarry was published in 1985. It was one of the first—and remains one of the most pertinent—theoretical texts to discuss pain in great depth. Scarry's text revolves around the idea that physical pain defies language and is entirely inexpressible. In the introduction to the text, Scarry asserts:

For the person in pain, so incontestably and unnegotiably present is it that 'having pain' may come to be thought of as the most vibrant example of what it is to 'have certainty,' while for the other person it is so elusive that 'hearing about pain' may exist as the primary model of what it is 'to have doubt.'(4)

My failures to express my own pain are something I think about often. I have tried countless times to describe my pain—to general practitioners, rheumatologists, neurologists, so many other specialists, friends, family, lovers, partners. Because of my failures to accurately convey my experiences, I often feel responsible for the mysteriousness of my own ills. I feel as though my inability to communicate my own pain clearly and concisely has contributed to (created, even) the lack of resolution or understanding of my chronic condition. The lack of understanding then, returns to the problematic narrative: that my pain and its mysteries are a direct result of my own individual failures. My inability to express my pain means that the pain cannot be diagnosed, and therefore cannot be legitimized and treated.

In Anne Boyer's autotheoretical text, *The Undying*, in which she reflects on her experience with breast cancer, she directly contests Scarry's notion, pushing back against the general acceptance that pain destroys language. Boyer argues instead that pain alters it: asserting that just because our language lacks the adequate vocabulary to describe suffering and pain, doesn't mean it always will. She writes: "Suppose for a moment that claims about pain's ineffability are historically specific and ideological, that pain is widely declared inarticulate for the reason that we are not supposed to share a language for how we really feel" (213). This becomes more complex in encounters with doctors and specialists: in situations where describing your pain is necessary for the steps towards treatment and management. The most common way I am asked



to describe my pain is with the pain scale: the zero (or one, depending on which doctor's office you are at) to ten scale where zero (or one) is no pain, and ten is the worst pain imaginable.

I often think about Eula Biss' essay "The Pain Scale", in which she analyzes each number in the pain scale—inserting personal narrative, historical reference and science throughout. In the essay, she recounts a conversation with her father, a physician: "'One of the functions of the pain scale,' my father explains, 'is to protect doctors—to spare them some emotional pain. Hearing someone describe their pain as a ten is much easier than hearing them describe it as a hot poker driven through their eyeball into their brain.'"(24). In this case, the descriptors being void of language is purposeful—an intentional choice to prevent the transfer of suffering.

This scale frustrates me endlessly. I never know what to circle. I try to remember what I circled all the times before. I struggle to find any meaning at all in zero, and in ten. I'm not sure I've felt no pain at all—at least not in recent memory—and I definitely can't imagine the worst pain imaginable. I don't know what either end of the scale feels like.



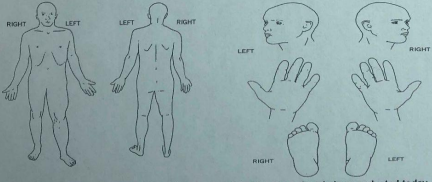
Pain Care Clinic

HANNAN, J. L. DULOCK  
MAR-31 F TEL: 905-599-8707  
12 NOAKS DR.  
MISSISSAUGA, ON L5J 3A1  
HIN: 7963818393 GV  
REF: Dr. L. Deppisch BILL# 089888

Patient Name: \_\_\_\_\_ Date Seen: \_\_\_\_\_

**Progress Sheet – Patient portion**

- Please rate your pain by circling the number that best describes your pain at its **worst** in the past week?  
No Pain 1 2 3 4 5 6 7 8 9 10 Worst Pain
- Please rate your pain by circling the number that best describes your pain at its **least** in the past week?  
No Pain 1 2 3 4 5 6 7 8 9 10 Worst Pain
- Please rate your pain by circling the number that best describes your pain on **average** in the past week?  
No Pain 1 2 3 4 5 6 7 8 9 10 Worst Pain
- Please rate your pain by circling the number that best describes how much pain you have **right now**?  
No Pain 1 2 3 4 5 6 7 8 9 10 Worst Pain
- During the last week, how much **relief** you have received from your pain medication? ☐ N/A  
No Relief 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% Complete Relief
- How much **relief** did you experience after your last pain injection(s)? ☐ N/A  
No Relief 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% Complete Relief
- How long did the **relief** from your pain injection last? ☐ N/A ☐ Hours ☐ Days ☐ Weeks  
No Relief 1 2 3 4 5-6 7-8 9-12 13-16 17-20 21-24
- Is the treatment you are receiving at PCC helping improve your pain? ☐ Yes ☐ No
- Has there been any changes to your health since your last appointment? ☐ Yes ☐ No
- Has there been any changes to your medications since your last appointment? ☐ Yes ☐ No
- If possible, on the diagram below, please shade the areas where your pain is bothering you.



By signing below I reaffirm prior written consent for the procedure being conducted today. I also agree to remain in the clinic 30 minutes after my procedure.

Patient Signature: \_\_\_\_\_ Physician/Nurse Signature: \_\_\_\_\_

Fig. 17. Research image. Photograph of a form at my pain specialist's office.

*Please rate your pain by circling the number that best describes your pain at its **worst** in the past week?*

*Please rate your pain by circling the number that best describes your pain at its **least** in the past week?*

*Please rate your pain by circling the number that best describes your pain at its **average** in the past week?*

*Please rate your pain by circling the number that best describes the pain you have **right now**?*



The numbers frustrate me, and so do the inappropriately placed question marks that have been there for years. So does the fact that they felt the need to name it a ‘progress’ sheet.

I am circling five on the scale of Scarry to Boyer: the scale of ‘pain destroys language’ to ‘we just don’t have the right language’. I am certain that *I* don’t have the language, although I am optimistic that one day I could. I am also certain that pain baffles the numbers zero through ten more than it does any word.

For the most part, I think, our bodyminds forget the pain-past in an act of self-preservation. If I wasn’t caught off guard every time my pain bordered on the unbearable, it would be hard to imagine finding a way forward. And yet, every ten weeks (every time I visit my pain specialist) I am asked to reflect on my pain by circling a number between one and ten. There is a forced ‘presentness’ that comes with pain, and there is the self-preserving dissociation that follows. When my pain is severe, the pain is the only reality that exists. When the pain passes or subsides, I detach myself from it—wilfully or not—and lose all perspective. Opposing moments of pain (no matter how frequent or severe or long) refuse a relationship with one another. Lisa Olstein reflects on this in *Pain Studies* “Fundamentally a creature of the present, physical pain remembered is by definition pain divorced. The difference between recalling the flu and having it—between expecting a child and having one—is like the difference between hearing a description of waves and drowning.” (11).

All I’m trying to say is that chronic pain is its own specific brand of ‘*chip thyme*’.





Fig. 18. 11.03.2020, 28 minutes, ink on paper, 2020.



I am stuck in the middle again. I am failing again. To compare the present pain to the pain past, or to the pain to come. It feels entirely arbitrary. In the middle, at five, I am not being dramatic, and I am not trying to hide anything.

Under the number five in her essay, Eula Biss writes: “Overwhelmingly, patients tend to rate their pain as a five, unless they are in excruciating pain. At best, this renders the scale far less sensitive to gradations in pain. At worst, it renders the scale useless.” (15).

My pain has been flaring for the past several months, and I feel helpless, as though I have exhausted all my options. The injections that have been managing my pain when nothing else could are no longer working like they used to. My pain specialist doesn’t seem to hear me when I say I’ve been deteriorating. I set up a phone call with my general practitioner (who is relatively new to the mysteries of my particular flesh) to discuss what options I had in trying to manage things better. She told me that it sounded like I’d tried everything, before asking ‘*So what exactly did you want me to do for you?*’. I sift through my old medical records, wondering if I should go through the motions of sending them to new doctors and reading through them as if I would be able to find something they could have missed. A letter from my rheumatologist to my other doctors, from when I was eighteen, shows my assessment of my pain: a seven. Next to that it shows her assessment: a two.

What was her assessment based on? How could she rate my sensations, when I could barely do so myself? I was eighteen at the time she wrote that, and yes, I was desperate for someone to listen, to take me seriously. Perhaps my numbers were an exaggeration. Nevertheless, to assess me at a two when it was her word against mine seems unfair. Why would she even rate my pain at all? All she had to go on was the look on my eighteen-year-old face that was already well rehearsed in concealing what was going on beneath my skin. All she had were the answers to her questions, as I hopelessly tried to recall the sensations I’d been experiencing and practicing blocking out.

Eula Biss compares the pain scale to The Beaufort Scale, a zero to twelve scale used to quantify forces of wind (10). I find the short descriptions used in the Beaufort scale much more effective



in quantifying my pain than the pain scale. For example, at number five it says ‘moderate waves, taking longer form’ or at ten, ‘seldom experienced’, and ‘considerable structural damage occurs.’ Maybe it’s helpful because it references time. Everything I do takes longer at a five, and yes, ten seldom occurs, but when it does it feels like it will go on for eternity, stopping time in its tracks.

The Beaufort scale goes beyond ten. Eleven and twelve are labelled with descriptors: ‘very widespread damage’ and ‘devastation occurs’. This scale feels useful because it does not provide the flawed boundaries of ‘no wind’ and ‘the strongest wind imaginable’. Instead of attempting to describe the wind itself, it assigns language to its impacts. I read ‘very widespread damage’ and I think about weeks where pain put my life entirely on hold, when time stood still. When the pain resulted in ‘widespread damage,’ impacting my functioning to the point where I could barely leave my bed, eat, or sleep.

I don’t know what ‘devastation’ looks or feels like, but it could just be that my tolerance for devastation has been steadily increasing.



## 06.

Often my health and most basic bodily functions feel beyond my control. In the process of creating my drawings there is often a strong urge to manipulate my breathing patterns in order to alter the marks being made—echoing my desire to take charge of my illness. Pain is an invisible, unexplained and constant background noise in my day-to-day life, and is as much a part of me as my breath. Although in some ways my methodology has granted me authority—in that I am actively choosing how I am representing my body and the effects of my pain—the result of each drawing cannot be planned or predicted. And there's only so much you can do to control your breath. In this way, the work relies on tensions between 'what is' and 'what is desired': the lack of control, and the desire to gain agency over my body and my narrative.

*When Pain Strikes* is a collection of written and visual work which addresses different practices in managing pain. In the introduction to the book, editors Kim Sawchuk, Cathy Busby, and Bill Burns state: "Asserting that one is in pain is not a declaration of victimhood or self-pity, or 'the new narcissism,' but an acknowledgment that we are not independent agents in absolute control. We inhabit pain-filled environments" (xxii).

In previous work, I have manipulated my own inconclusive MRI scans in an attempt to assert agency over the images of my body. I reached a point with the work I was doing where I no longer felt the MRIs were providing what I was chasing after. The clinical images were inaccessible to me, coded in a way I could not interpret. While the scans were being made I was completely passive and still, having no authority over how my body was represented. I especially struggled with the fact that the scans were inconclusive—making it feel as though they were contending with the existence and impacts of my illness. The scans became like the pain scale: a reduction of the realities of my embodiment to a set of data.

After I began this series of drawings, I started to think of them in direct opposition to the images of the scans. In this process, my body is no longer the object—instead it shapes the process, becoming the material and the tool with which the drawings are made. The experience of witnessing my bodily functions being transferred into a two-dimensional image is entirely



different than viewing an MRI of my body. I can control all aesthetic aspects of the process; getting to dictate how my experience is translated to image, how long I draw for, when the drawing is finished, what tools I use to help me complete them, where the page is hung, and therefore, where the ink lands on the surface of the paper. I am documenting the limitations and impact of my pain, rather than interrogating my body in search of evidence the pain exists at all. The tools being used are incredibly low-tech in comparison to the MRI machines, but are also the difference between prosthesis—a tool that becomes an extension of my body and aids me in the process of making work—and interrogation and analysis.

I realized a while into this practice of drawing that the apparatus I made is a simplified version of a pneumograph. In the early 1900's pneumography was purported to be a method of lie detection, recording breathing patterns during interrogation. It was invented by William Moulton Marston, who bizarrely, was the same man who created Wonder Woman and her lasso of truth. His is a complex story. He was a deviant, a polyamorist, a creative self promoter and a suffragist. But, in his creation of the pneumograph, he also kick-started the complicated legacy of the polygraph (Lepore).

To this day there is very little evidence suggesting that polygraphs can accurately detect when someone is being truthful—there is no evidence to indicate there is a standard physical manifestation of lying (Fienberg 32). Despite the lack of proof supporting its validity, the primary utility of the lie detector relies on the public belief that they do, in fact, work. The more entrenched the idea that the lie detector as a valid scientific method for determining truth, the more likely an individual is to confess in the face of a polygraph, or exhibit nervousness and contradict previous testimonies (Fienberg 51).

I see the polygraph parallel to the pain scale. An attempt to uncover a truth and translate it to data; but one that inevitably fails to represent the embodied experience at which it so desperately grasps. Much like pain, the truth is elusive and impossible to quantify in this way. Instead, it becomes a reduction of the human to numbers and graphs. Corrupt data assigned more meaning than it deserves.



Maybe I subconsciously knew this was what I was making—a pneumograph, I mean. Still interrogating my own body, still trying to detect the reality and evidence of my illness. Or maybe it's my own lasso of truth: revealing the broken lines the data never could, the irregularities of my breathing unrelated to innocence or guilt, the realities of my embodiment the evaluators never asked for.

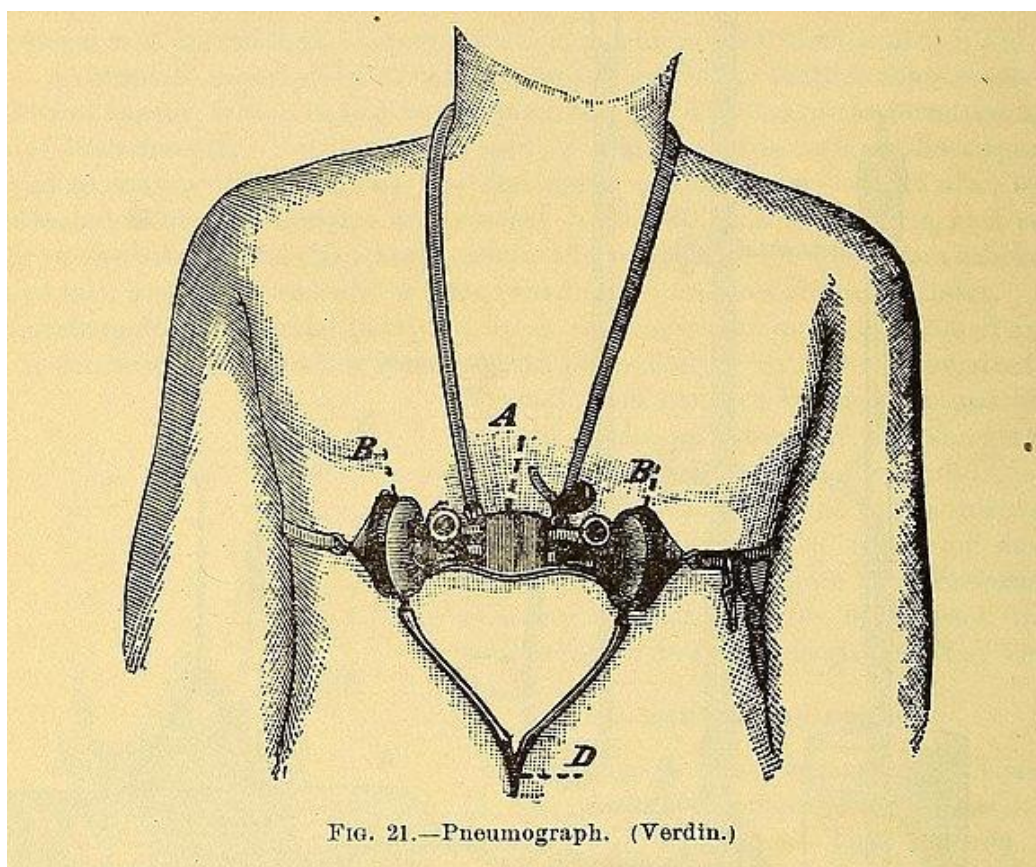


Fig. 20. From Jerome J. Freundlich; James C. Erickson, "Electrical Impedance Pneumography for Simple Nonrestrictive Continuous Monitoring of Respiratory Rate, Rhythm and Tidal Volume for Surgical Patients", 1974.

In my early experimentation of creating the drawing tool/prosthetic/device/whatever, it was very unrefined. Part of me loved this about the prototype. I bounced back and forth between a desire to aestheticize the tool and an appreciation for the fact that it cost me less than five dollars and ten minutes to make. I wanted the tool to stay true to the work: to remain something I could construct without risking more pain. I finally broke down and altered it when I got sick of getting poked in the side by the sharp ends of the wire each time I strapped in to make a new drawing.



I started brainstorming different ways to make the prosthetic comfortable, beautiful, and to appear more bodily in its form. I landed on latex and brass, in the form of a harness, rather than just the ‘belt’ I had been using initially. The harness is more comfortable and practical. It also references BDSM (practices of bondage/discipline, dominance/submission, sadism/masochism). This reference was something I was initially hesitant about—for a lot of different reasons—including that my mom is definitely going to be reading this (*sorry mum*). The more I thought about it though, the connections between kink and the work I’ve been doing started to feel unavoidable, significant.



Fig. 21. Detail shot of drawing tool/harness from installation at Gales Gallery, 2021.

So much of my life has been actively concealing my pain. There are many reasons for it—and it’s extremely common in chronic pain sufferers (Sheppard). There is the need to feel you are in control of your pain, there is the need to feel you are in control of how you present yourself. There is the fear that expressing your pain will make people uncomfortable, or just annoyed and bored because it’s the same shit you tell them every time you see them. There is pressure to perform able-bodiedness—we must behave appropriately; we must be in control of our bodyminds.



Kink, then—and more specifically enacting the role of the submissive who receives pain—can operate as a counterpoint to the experience of chronic, non-consensual pain. It functions as a space where pain can be expressed without judgement, dismissal and abjection, and instead is welcomed and pleasurable (Sheppard). There is someone there witnessing you endure and react to pain and enjoying bearing witness. And that isn't a thing that just *happens* when you live with chronic pain or illness. People don't enjoy witnessing your constant suffering—in fact they very much would like to make it stop—and that makes sense, because you know, you're not necessarily enjoying it or *asking for it* either. In *The Undying*, Anne Boyer considers the way bystanders typically respond to the person in pain:

The drive to stop the pain of others because pain is so loud, so vividly expressed, often takes the form of wanting to do anything at all to end the pain of another precisely because of the way that this pain inflicts the experience of an impossible-to-bear sympathetic discomfort—sometimes in the form of annoyance, sometimes in the form of anxiety, sometimes in the form of pity—upon one's self. (214)

So when your pain becomes a constant, you learn to quiet it down.





Fig. 22, 04.28.2020, 27 minutes, ink on paper, 2020.



I am not alone in this feeling and appreciation for the space of BDSM alongside chronic pain. An article in *Disability Studies Quarterly* by Emma Sheppard titled “Chronic Pain as Fluid, BDSM as Control”, draws upon the experiences of chronically-pained kink-engaged participants, who share a positive relationship with BDSM. Their stories and connections to BDSM reflect this idea of kink as a safe space in which to experience pain, and an escape from the chronic.

As a submissive who consensually receives pain you are actively choosing, surrendering to, and expressing the sensations—knowing that you are able to control the intensity, the type, and the duration of the pain. Here, no one pities you or disbelieves you, or is made uncomfortable by you. You set the boundaries. You don’t have to hide anything. You are in pain and you are desirable. Alongside the pain, not just in spite of it.

The same applies to bondage and restraint. In disability your bodily limitations are unchosen and beyond your control. In BDSM, they are shaped to adhere to your desires and boundaries. BDSM not only operates as an empowering way to express and control the experience of pain and physical limitations, but can temporarily reconstruct an individual’s relationship and experience of their own embodiment.

Kink can initiate this ‘stuck-in-the-presentness’ in a way that makes you hyper-aware of not only the pain you are experiencing, but the pleasure too. It disrupts the practice of actively working to suppress any and all sensations. After years of pain, you learn the skill of completely dissociating from your pain when it’s at its usual low hum. I remember asking my mom to stop asking: ‘how’s your head?’. It was because every time she did, I thought about it and remembered I was in fact, in pain. I had just been able to ignore it until then. (*Mum, if you’ve made it this far, am I remembering this correctly?*) I think this transfers over to other sensations too. When you learn to dissociate in this way, it can take a lot of work to get back to just *being* in your body. And *no*, meditation will not help me.

The work I’m making is relevant to this idea of bearing witness and holding space for pain, and the bodily deviance I experience. I may not be visibly or directly vocalizing my pain, but expressing the limitations it sets—asking the viewer to *look*.



There is no safe word for chronic pain. It can't be managed through communication (this in fact, usually heightens feelings of isolation) (Sheppard). There is no level of planning ahead that can prevent it from becoming unbearable, too much, debilitating, destructive. There is only the attempt at management and survival.



## 07.

The work of Carolee Schneemann—specifically her piece *Up to and Including Her Limits*—keeps coming up in conversation about my work. In this piece Schneemann suspended herself from the ceiling, using  $\frac{3}{4}$ " rope and a leather harness—akin to one an arborist would use at the time. In the performance she holds a crayon, and as her body swings she makes marks on large sheets of paper that cover the floor and surrounding walls. Schneemann identifies this work as involving a submission to the “floating sensation” the suspension allows (MoMA). She uses her whole body to create gestural strokes. She documents the process on tape. The installation includes the video, the tool, and the resulting drawings.

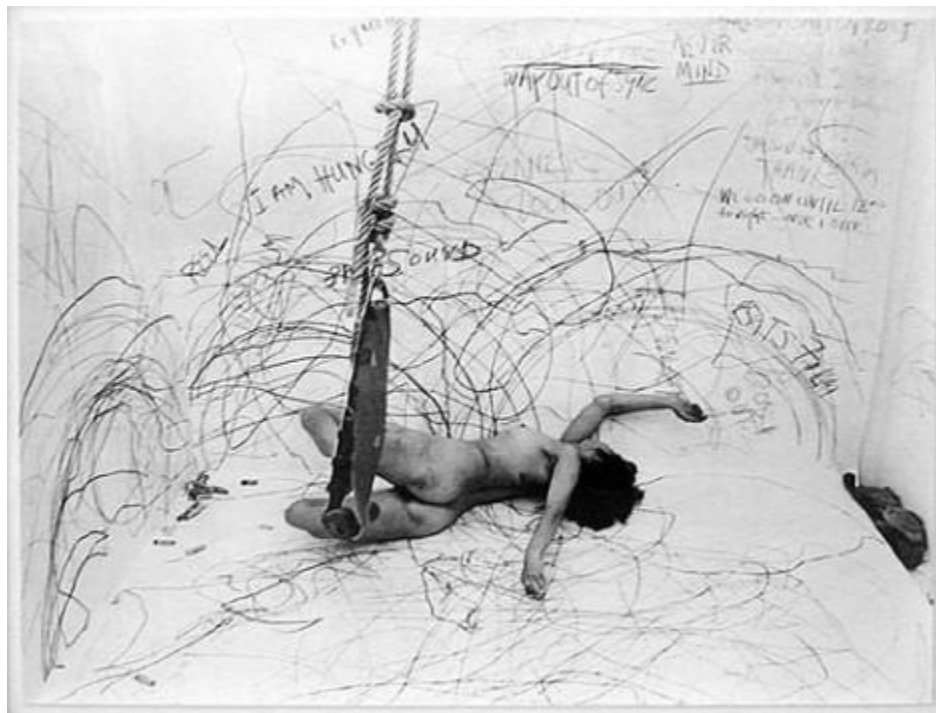


Fig. 23. Carolee Schneemann, *Up to and Including Her Limits*, 1973-76, <https://www.moma.org/collection/works/156834>.

There is a similarity in the appearance and approach of our work, and I think that her alternative and performative drawing practice is likely the reason people keep mentioning her to me. No one yet has mentioned how her title fits in. I am including my limits, but in a way that is in direct opposition to her approach. Where Schneeman's body becomes an extension of her tools, my



tools become an extension of my body. And, unlike Schneemann, I am definitely not pushing my limits. Instead, I am finding the smallest, most limit-respecting task that I can do: either when it's too late and I have already hit my absolute limit, or in an effort to avoid hitting it again. There is a sort of submission involved—but not to my tools and my process—to my own limits. I am looking for the moment where I am free of limitations, for the space where they dissipate and make something new possible.

I'm done asking myself how far I can push. Instead, I'm asking: how can I use my inability to push to my advantage? How does my stagnancy construct meaning? What does the existence of my particular limits make possible, that otherwise wouldn't be?

I, Hannah Bullock, hereby refuse to make art that prompts the question “*holy shit, how long did that take you?*” or “*didn't that hurt?*”.

In an interview about *Up to and Including Her Limits*, Carolee Schneemann says, “it really had nothing to do with self confession, or self exposure, or personal narrative.”(MoMA) For me, self exposure and personal narrative are just the beginning.





Fig. 24. 11.03.2020, 10 minutes, ink on paper, 2020.

What begins as loss or pure suffering frequently becomes ordinary and familiar over time.

– *Eli Clare*



In her book, *Waist-High in the World: A Life Among the Nondisabled*, Nancy Mairs reflects on her experience with multiple sclerosis and her ever-shifting embodied limitations:

Everybody, well or ill, disabled or not, imagines a boundary of suffering beyond which, she or he is certain, life will no longer be worth living. I know that I do. I also know that my line, far from being scored in stone, has inched across the sands of my life: at various times, I could not possibly do without long walks on the beach...; use a cane, a brace, a wheelchair; stop teaching; give up driving; let someone else put on and take off my underwear. One at a time...I have taken each of these (highly figurative) steps...I go on being, now more than ever, the woman I once thought I could never bear to be. (121)

My lines bounce up and down and jumble together, much like the marks I put on paper. The unpredictability is an inevitability. I am refusing to knowingly push myself to the edges of these lines.

In another text, *Carnal Acts*, Mairs articulates the forced mindfulness chronic illness imposes: “I must now *attend* my body—both in the sense of ‘fix the mind upon’ and ‘watch over the working of’ it—in ways that I never dreamed of.” (5). Instead of resisting the limits my bodymind imposes, I am now watching them closely. I watch them fluctuate, and consider them carefully—where I used to pretend they did not exist.

I am accepting the loss of practices and processes I have loved, in favour of self-preservation. And I’m okay with it. More than I ever thought I could be.





Fig. 25. 11.18.2020, 14 minutes, ink on paper, 2020.



## 08.

Interdependence within crip theory is grounded in the rejection of what Mia Mingus refers to as the myth of independence. In her essay, “Access Intimacy, Interdependence and Disability Justice”, she writes:

Interdependence moves us away from the myth of independence, and towards relationships where we are all valued and have things to offer. It moves us away from knowing disability only through “dependence,” which paints disabled bodies as being a burden to others, at the mercy of able-bodied people’s benevolence. We become charity cases, a way for able-bodied people to feel better about themselves and we in turn, internalize our sense of being a burden, sad, and tragic. All of this sets up a dynamic where disabled people feel like we have to be “liked” in order to receive basic daily access to live and where able-bodied people feel entitled to receive praise and recognition for providing access.

I think about interdependence a lot, especially as it relates to different practices of care. I think about how, in encounters with doctors, this notion of care is an exchange that does not feel mutually beneficial at all. I don’t feel I am valued in these situations. I feel dismissed and burdensome and like a nuisance. Perhaps because of their inability to ‘solve’ me. The ‘care’ I’ve received from doctors, for the most part, hasn’t felt like care at all.

My grandmother is a retired physician. She loves to quilt and sew. She has made quilts for each one of her grandchildren. She made costumes for me to dress up in when I was small. I have always seen her sewing as an act of great care. A means of expressing her love. It is care in the traditional and feminine way we understand it. I see resilience in her pursuit of a career in medicine. Her colleagues never let her forget she was one of three women in a program of fifty-six. When I asked her to confirm this detail for me, this is the text message I received:



I was one of 3 women in a class of 56.  
And the only reason we got in is that a woman donated a lot of money to build a new biochemistry building and she insisted that each medical class had to have at least 10% women! How times have changed!

Fig. 26. Screenshot of a text from my grandmother.

One of her overtly sexist professors used to call her ‘missus nurse doctor’. Suffice to say I’m glad *that guy* isn’t my doctor. Against all odds she was determined and committed to her profession—to *care* in every sense of the word.

I asked my grandmother to take apart a hospital gown I stole at a recent MRI appointment. I asked her to replicate it in fabrics suited for a ‘true’ gown. So that I can play dress-up again. So that I can disguise and reinvent my identity as a patient. She may not be able to care for me in the way she was taught to in school, but there is tenderness in her hands, performing a labour of love. Here, her resilience and mine can coexist.

When she gave me the gowns she had made, I asked for the deconstructed original back, just in case I decided to use it somehow. She didn’t keep all of the material, but left this note for me:





Fig. 27. Flatbed scan of the note my grandmother pinned to fabric scraps left over from her sewing, 2021.

I love that she used it to make a mask for someone else. I love that the thing I stole from the hospital continued the proliferation of care in this way. In a way that is so often invisible and overlooked. I think a lot about this kind of care, and how it functions beyond *treatment*. And what it means to feel you are being cared for; devoid of the feeling that you are *broken*, trying to be *fixed*.



In *The Care Manifesto: The Politics of Interdependence*, written by The Care Collective in the wake of COVID-19, they discuss the undermining of care work within dominant neoliberal models of government: “Care has long been devalued due, in large part, to its association with women, the feminine and what have been seen as the ‘unproductive’ caring professions.” (3). This ‘unproductive’ caring has done more for me than any professional, transactional care ever has. Instead of asking “*How can we fix you, so that you can return to independence and productivity?*” it asks, “*How can we carry the weight of this together?*”.

Hospital gowns function to conceal the body, as a uniform identifier of the patient who is passive. The gowns my grandmother made work in opposition to this. Together, we collaborated to decide how they should look. The fabrics are a distinct contrast to the utility of a hospital garment. In their sheerness, they make visible the invisible: my experience of pain, and her ‘invisible’ acts of care.



## 09.

In *Disfigured: On Fairy Tales, Disability and Making Space*, Amanda Leduc explores the disabled body within classic fairy tales and prolific mainstream narratives, revealing archetypes upholding ableism. She writes:

To understand how the medical and social models of disability function in the world of our everyday, and how these models and ways of thinking shape the words that guide countries on a social, political and structural level, we must also understand how the stories we've told in the past have worked to entrench the idea of the disabled other as—at best—an object of pity, and at worst an invisible someone, barely there at all. (47)

I think back to playing dress-up when I was little: my love for Disney princesses and the extremely limited representation they offered. When you yearn to be like a princess in fairy tales you are also yearning for a thin, healthy, able-body and to be saved from anything that may get in the way of that. These stories teach us over and over that if you are not able-bodied, you are not good. You are only sick or disabled if you *deserve to be*. Leduc continues on in her book to say that the disabled body is only ever viewed within fairy tales as broken, and only worthy of a happy ending once the disability has been eradicated or ‘overcome’(68). Disability and illness in these narratives become symbolic of evil; a marker of some inner or moral ill that must be resolved in order for the character to become good, and therefore worthy of happiness and love. I love the gowns my grandmother made me because they contradict these stories we uphold, resisting the problematic archetypes. Their form (the shape of a patient’s gown) and colours (white and off-white, often associated with purity and innocence), work to challenge the idea that a sick person cannot be a good person. Her careful sewing tells me I am worthy of love and support, chronic illness and all.





Fig. 28. 11.14.2020, 32 minutes, ink on paper, 2020.



My narrative resists the idyllic future fairy tales teach us to aim for. In her text, *When the Sick Rule the World*, Dodie Bellamy asserts “The vulnerable body subverts the narrative arc, the fantasy of progress, resolution.” (51). My body and illness subvert resolution, by resisting to fit into any clear diagnosis or cure.

I am no longer buying into the idea that I have to make progress, be productive, find resolve. In the early stages of creating the drawings, I told myself I would make one a day. This way they could become—like my illness—something I was ‘living with’. I failed to follow the routine I was setting for myself. I thought about falsifying my record keeping to make up for days I missed. But the parameters I originally set began to feel contradictory to the intent behind the work. If I falsified my records, they would not be true to the realities of my embodiment—they would have been a fantasy. Now, I only draw when I feel able, I only document the facts of when they were made and how long they took. I can always breathe, but sometimes the task of mounting the paper to the wall feels insurmountable. Sometimes I’m having a good day and would rather be walking my dog or enjoying the sun or spending time with people I love. This is all a part of it: the stops and starts, the rest and the endurance.

The drawings are a document of time passing. Each one records ten to fifty minutes of my breathing. Despite this, they do not document linear time. They document crip time. There is not a drawing for every day of the year. The lines are disjointed and broken. The drawings themselves vary, but there is no identifier of progress being made: in my health, or otherwise. They are an exercise in both taking control and letting go.



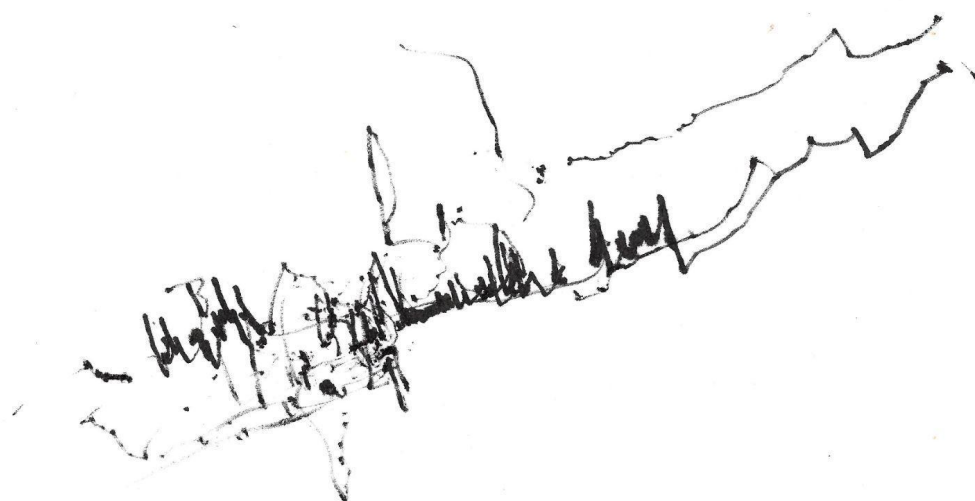


Fig. 29. 11.19.2020, 28 minutes, ink on paper, 2020.



## 10.

When I read Ellen Samuels' "6 Ways of Looking at Crip Time" it was my first introduction to this term. It continues to be the text I circle back to most frequently. Samuels writes about crip time in a way that seems to fit in seamlessly with my work:

*Crip time is broken time.* It requires us to break in our bodies and minds to new rhythms, new patterns of thinking and feeling and moving through the world. It forces us to take breaks, even when we don't want to, even when we want to keep going, to move ahead. It insists that we listen to our bodyminds *so* closely, *so* attentively, in a culture that tells us to divide the two and push the body away from us while also pushing it beyond its limits. Crip time means listening to the broken languages of our bodies, translating them, honoring their words.

I kept having to postpone the submission of this paper because my pain kept trapping me in my body, making me unable to focus my attention on anything beyond the limits of the moment. My mum kept offering to make edits, I kept telling her I had nothing new to show her. She sent me a message that said: *It's like a snake eating its tail. You can't write your paper about not being able to leave your bed because you can't leave your bed.*

I am endlessly chasing my tail. I am stuck in the moment and in a perpetual in-betweenness. From calm to storm, inhaling and exhaling. I am circling back to crip time, circling five on the pain scale.



## Works Cited

- Baker, Cindy. "Plexiglass Box." *Cindy Baker*, 31 Jan. 2009, [www.populust.ca/cinde/wp/2009/01/plexiglass-box/](http://www.populust.ca/cinde/wp/2009/01/plexiglass-box/).
- Bellamy, Dodie. *When the Sick Rule the World*. Semiotext(e), 2015.
- Biss, Eula. "The Pain Scale." *Creative Nonfiction*, no. 32, 2007, pp. 65–84. *JSTOR*, [www.jstor.org/stable/44363570](http://www.jstor.org/stable/44363570).
- Boyer, Anne. *The Undying*. New York: Penguin, 2020. Print.
- Burns, Bill, et al. "When Pain Strikes." *When Pain Strikes*, University of Minnesota Press, 2007, pp. Xi-xxv.
- The Care Manifesto: The Politics of Interdependence*. The Care Collective, London: Verso Books, 2020.
- "Cindy Baker: Crash Pad." *dc3 Art Projects*, 27 Apr. 2018, [www.dc3artprojects.com/cindy-baker-crash-pad/](http://www.dc3artprojects.com/cindy-baker-crash-pad/).
- Clare, Eli. *Brilliant Imperfection: Grappling with Cure*. Duke University Press, 2017.
- Fienberg, Stephen E. *The Polygraph and Lie Detection*. National Academies Press, 2003.
- Fournier, Lauren. *Autotheory as Feminist Practice in Art, Writing, and Criticism*. The MIT Press, 2021.
- Fournier, Lauren. "Sick Women, Sad Girls, and Selfie Theory: Autotheory as Contemporary Feminist Practice." *A/b: Auto/Biography Studies*, vol. 33, no. 3, Sept. 2018, pp. 641–660, doi:10.1080/08989575.2018.1499495.
- Garland-Thomson, Rosemarie. "Misfits: A Feminist Materialist Disability Concept." *Hypatia*, vol. 26, no. 3, 2011, pp. 591–609. *JSTOR*, [www.jstor.org/stable/23016570](http://www.jstor.org/stable/23016570).
- Gillespie, Jessa, and Cindy Baker. "A Conversation with Cindy Baker." *dc3 Art Projects*, 24 May 2018, [www.dc3artprojects.com/a-conversation-with-cindy-baker/](http://www.dc3artprojects.com/a-conversation-with-cindy-baker/).
- Hedva, Johanna. "Sick Woman Theory." *Mask Magazine*, Jan. 2016, <http://www.maskmagazine.com/not-again/struggle/sick-woman-theory>.
- Kadoura, Yousef, et al. "Crip Times Episode 4: The Cindy Baker Episode." *Crip Times*, performance by Cindy Baker, season 1, episode 4, Wheels on The Ground Production, 7 Dec. 2020.



- Leduc, Amanda. *Disfigured: On Fairy Tales, Disability and Making Space*. Coach House Books, Toronto, 2020.
- Lepore, Jill. "Episode 2: The Detection of Deception." *The Last Archive*, season 1, episode 2, Pushkin Industries, May 2020.
- Lorde, Audre. *The Cancer Journals*. Penguin Books, 2020.
- Mairs, Nancy. *Carnal Acts: Essays*. Beacon Press, 1996.
- Mairs, Nancy. *Plaintext: Essays*. University of Arizona Press, 1997.
- Mairs, Nancy. *Waist-High in the World: A Life Among the Nondisabled*. Beacon Press, 2001.
- Mingus, Mia. "Access Intimacy, Interdependence, and Disability Justice." Longmore Lecture in Disability Studies . Longmore Lecture in Disability Studies , 10 Feb. 2020, San Francisco , San Francisco State University,  
[www.youtube.com/watch?time\\_continue=4&v=ONpqOHGIbZM&feature=emb\\_title](http://www.youtube.com/watch?time_continue=4&v=ONpqOHGIbZM&feature=emb_title).
- Olstein, Lisa. *Pain Studies*. New York: Bellevue Literary, 2020. Print.
- Padamsee, Yashna Maya. "Communities of Care, Organizations for Liberation." *Naya Maya*, 15 Sept. 2014,  
[nayamaya.wordpress.com/2011/06/19/communities-of-care-organizations-for-liberation/](http://nayamaya.wordpress.com/2011/06/19/communities-of-care-organizations-for-liberation/).
- Piepzna-Samarasinha, Leah Lakshmi. *Care Work: Dreaming Disability Justice*. Arsenal Pulp Press, 2019.
- Samuels, Ellen. "Six Ways of Looking at Crip Time." *Disability Studies Quarterly*, vol. 37, no. 3, The Ohio State University Libraries, 2017, doi:10.18061/dsq.v37i3.5824.
- Scarry, Elaine. *The Body in Pain: The Making and Unmaking of the World*. New York, NY: Oxford University Press, 1985.
- Schneemann, Carolee. "Carolee Schneemann, 'Up to and Including Her Limits.'" *Khan Academy*, The Museum of Modern Art, Sept. 2014,  
[www.khanacademy.org/partner-content/moma/the-museum-of-modern-art/moma-artist-interviews/v/schneemann-on-line](http://www.khanacademy.org/partner-content/moma/the-museum-of-modern-art/moma-artist-interviews/v/schneemann-on-line).
- Schneemann, Carolee. "Carolee Schneemann. Up to and Including Her Limits. 1973–76: MoMA." *The Museum of Modern Art*, 2019, [www.moma.org/collection/works/156834](http://www.moma.org/collection/works/156834).
- Sheppard, Emma. "Chronic Pain as Fluid, BDSM as Control." *Disability Studies Quarterly*, vol. 39, no. 2, The Ohio State University Libraries, 2019, doi:10.18061/dsq.v39i2.6353.



## Works Consulted

- Akers, Matthew, director. *Marina Abramovic: The Artist Is Present*. Feltrinelli Real Cinema, 2012.
- Anastasi, William. "William Anastasi. Untitled (Pocket Drawings). 1969: MoMA." *The Museum of Modern Art*, [www.moma.org/collection/works/90658](http://www.moma.org/collection/works/90658).
- Berkowitz, Amy. *Tender Points*. Timeless, Infinite Light, 2015.
- Butler, Judith. "Vulnerability and Resistance." CalArts Aesthetics and Politics Program. Demonstrating Precarity: Vulnerability, Embodiment, and Resistance, 2015, Los Angeles, CalArts REDCAT, [www.youtube.com/watch?v=fbYOzbfGPmo](http://www.youtube.com/watch?v=fbYOzbfGPmo).
- Carlos Martiel*, 2021, [www.carlosmartiel.net/](http://www.carlosmartiel.net/).
- Di Bella, Maria Pia., and James Elkins. *Representations of Pain in Art and Visual Culture*. Routledge, 2013.
- Eberstadt, Fernanda. "The Dangerous Art of Pyotr Pavlensky." *The New York Times*, The New York Times, 11 July 2019, [www.nytimes.com/2019/07/11/magazine/pyotr-pavlensky-art.html](http://www.nytimes.com/2019/07/11/magazine/pyotr-pavlensky-art.html).
- Frank, Arthur W.. *The Wounded Storyteller: Body, Illness, and Ethics*. Second edition. The University of Chicago Press, 2013.
- Haven, Leif. "ON KAWARA IS STILL ALIVE." *ENTROPY*, 12 July 2014, [entropymag.org/on-kawara-is-still-alive/](http://entropymag.org/on-kawara-is-still-alive/).
- Hedva, Johanna. "My Body Is a Prison of Pain so I Want to Leave It Like a Mystic But I Also Love It & Want It to Matter Politically." Vimeo. 2019, Los Angeles, Women's Center for Creative Work, [vimeo.com/144782433](https://vimeo.com/144782433).
- Huber, Sonya. *Pain Woman Takes Your Keys and Other Essays From a Nervous System*. University of Nebraska Press, 2017.
- Kawara, On. "On Kawara. I Am Still Alive. 1973: MoMA." *The Museum of Modern Art*, [www.moma.org/collection/works/96314](http://www.moma.org/collection/works/96314).
- Kutner, Eric, director. *Shot in the Name of Art. Op-Docs*, The New York Times, 22 May 2015, [www.youtube.com/watch?v=drZIW53D11k&ab\\_channel=TheNewYorkTimes](http://www.youtube.com/watch?v=drZIW53D11k&ab_channel=TheNewYorkTimes).



- Miller, Tessa. *What Doesn't Kill You: A Life with Chronic Illness--Lessons From a Body in Revolt*. Henry Holt and Company, 2021.
- Mingus, Mia. "Access Intimacy: The Missing Link." *Leaving Evidence*, 5 May 2011, [leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/](http://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/).
- O'Rourke, Meghan. "What's Wrong With Me?" *The New Yorker*, 19 Aug. 2013, <https://www.newyorker.com/magazine/2013/08/26/whats-wrong-with-me>
- Reilly, Caroline. "For Chronically Ill People, Masking Pain Is a Form of Protection." *Bitch Media*, 12 Feb. 2020, [www.bitchmedia.org/article/privacy-and-disclosure-with-chronic-illnesses?fbclid=IwAR3QB9bap1V4Xa5LX6zTa0ib-v6YgXnM8pYElOYK9y01myY2WUgj6ky4EeA](http://www.bitchmedia.org/article/privacy-and-disclosure-with-chronic-illnesses?fbclid=IwAR3QB9bap1V4Xa5LX6zTa0ib-v6YgXnM8pYElOYK9y01myY2WUgj6ky4EeA).
- Sontag, Susan. *Illness as a Metaphor*. New York, NY: Farrar, Straus and Giroux, 1978.
- Sontag, Susan. *Regarding the Pain of Others*. Picador, 2003.
- Sweeney, Elizabeth. "Premise/Shift." *Akimbo: The Cripsters*, 23 Jan. 2020, [akimbo.ca/akimblog/premise-shift-by-elizabeth-sweeney/](http://akimbo.ca/akimblog/premise-shift-by-elizabeth-sweeney/).
- Fleischmann, T. *Time Is the Thing a Body Moves Through*. Minneapolis: Coffee House, 2019. Print.
- Taylor, Sunny. "The Right Not to Work: Power and Disability." *Monthly Review*, 1 Mar. 2004, [monthlyreview.org/2004/03/01/the-right-not-to-work-power-and-disability/](http://monthlyreview.org/2004/03/01/the-right-not-to-work-power-and-disability/).
- Tangled Art Disability. "THREE WINDOWS: FLOURISHING." *Tangled Art Disability*, 23 Aug. 2018, <https://tangledarts.org/exhibits/three-windows-flourishing/>.
- Thomas, Aislinn. "Three Windows." *Aislinn Thomas*, 22 June 2019, <https://aislinnthomas.ca/index.php/portfolio/three-windows/>.
- Wilder, Darcie. *literally show me a healthy person*. New York, NY: Tyrant Books, 2017.
- Wong, Alice, ed. *Disability Visibility: First-Person Stories from the Twenty-First Century*. New York: Vintage , a Division of Penguin Random House LLC, 2020. Print.